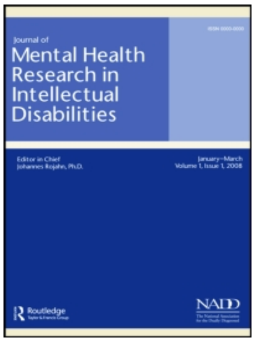

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11th European Congress Mental Health in Intellectual Disability

Luxembourg, September 21–23, 2017

“Better Mental Health for People with Intellectual Disability”

Providing better care using knowledge transfer and bridging together innovative and collaborative networks

Abstract Book

Committee: Germain Weber (Austria), Marco Bertelli (Italy), Filip Morisse (Belgium), Carlo Schuengel (The Netherlands), Roger Banks (United Kingdom), Régine Scelles (France), Tanja Sappok (Germany), Gerard Zribi (France)

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WHERE TO HEAD TO IN THE NEXT TWO DECADES?
EAMHID 11TH CONGRESS: THE FIRST IN THE SECOND SERIES OF TEN.
SHORT RETROSPECT – CHALLENGING OUTLOOK!

An Introduction to the Abstract Volume of the Luxembourg Congress 2017

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"Mental health matters…. also for people with intellectual disabilities!"

This might have been the unexpressed slogan motivating a numerous ambitious researchers, professionals, NGO managers, mainly from the Netherlands and the United Kingdom, to call for a European mental health agenda for people with an intellectual disability in the late 1980s and the early 1990s. The European Association on Mental Health and Mental Retardation now known as European Association on Mental Health in Intellectual Disabilities has its origins in that period with the aim of making use of early evidence to promote a new thinking about the "mental health issue" in people with intellectual disabilities. From the early days of the founders and the association's multi-professional membership, psychiatrists, psychologists, educational scientists, mental health nurses, managers of support services for people with intellectual disability were convinced that staging a biennial European congress presenting and promoting advances in the area of mental health and intellectual disability might be a substantial step towards major change. Indeed, up to this point, mental health issues and problem behaviour in people with intellectual disabilities were commonly referred to as being inherent to the intellectual disability itself, with low intellectual functioning being viewed as a result of a "dysfunctional" or "abnormal" brain situation. In line with this assumption and the fact that there was no cure for the suggested "brain damage", it was common practice to "treat" mental health problems in this population without comprehensive mental health assessment and thus abstaining from treatments based on diagnostic criteria and clinical evidence. Now, 20 years later, with major advancements in basic and applied research, knowledge on mental health issues specific to people with intellectual disabilities has raised substantially. In the past 20 years, the EAMHID organised ten conferences, with the inaugural being held in Amsterdam in 1995 and the 10th being hosted in Florence in 2015. Abstract compilations of these conferences are a good proof that EAMHID is offering a unique platform in Europe for exchanging advances in the field, disseminating evidence-based practices, promoting competences and skills within professional groups and encouraging research. Obviously, much changed during this period, with more and more voices reaching out with convincing evidence, using the network offered by EAMHID.

However, limitations of these achievements become evident when evaluating the success of the knowledge accumulated in this period being transferred into practice and when assessing the impact our knowledge actually has for the mental well-being of individuals with intellectual disabilities.

"Everyone has an equal opportunity to experience mental well-being throughout their lifespan, particularly those who are most vulnerable or at risk" (WHO Europe, 2013).

Indeed, mental health is more than a health issue, covering areas like education, family ties, employment and earnings or healthy life-styles as outlined in the "European Mental Health Action Plan" of WHO Europe 2013. Further, there is a broad agreement that good mental health is essential for all human beings, including people with intellectual disabilities in order to enjoy a good life and especially a good life in the community. In turn, social participation and inclusion are vital ingredients nourishing good mental health. This interplay and reciprocal effect between personal outcomes and social factors as well as the biological factors interacting with behaviour and experience are highlighted in the so-called bio-psycho-social framework, a widely recognised model. Consequently, this paradigm prominently determines WHO Europe's "cycle for mental well-being".

Recently, most of our societies committed themselves to developing equal opportunities for people with disabilities, aiming, among other things, for social inclusion of people with disabilities in all areas of life, including people with intellectual disabilities, presenting a substantial move offering options for new mental health promotion strategies especially for people with intellectual disabilities. The lack of inclusion and violence are known to be major risk factors for mental health, while an accessible and acceptable mental health system is of great importance for effective support and education, and community ties are significant protective factors for good mental health. In addition, recent evidence on adversities in the affective-emotional development of children and young adults with intellectual disabilities as well as new findings with respect to biological factors and gene-to-behaviour relations, often reported with specific syndromes, are now offering us new perspectives for understanding the complex and high vulnerability for mental health problems in people with intellectual disabilities.

Thus, with this conference in 2017, the first of the next series of ten, EAMHID strives towards a next major step for improving mental health for people with ID. In its call for contributions, EAMHID offered traditional formats for presenting genuine research like individual papers or symposia, offering the collaboration of up to four scholars, contributing to one overall topic. In addition, co-productive workshops were offered within the traditional congress tracks. This new format goes far beyond classical formats for presenting research at conferences and aims at bringing stakeholders from different sectors together, including people with intellectual disabilities themselves. We are convinced that a congress offering an inclusive setting and taking advantage of more inclusive strategies will offer a better frame for inspiring experiences. Looking at the big picture opens perspectives for something new, often leading to cross-sectoral collaboration, be it in areas of research or sectors that are commonly not linked or communicating with each other. Thus, EAMHID encourages more unified efforts as kick-off for a next substantial promotion of good mental health for people with ID.

According to this unified approach, those responsible for the scientific program of the congress have brought together some leading experts from selected sectors offering keynote presentations and focused communications to share their knowledge and expertise. The abstract collection of this volume summarizes recent advances in the field of mental health and incorporates early developments in co-productive strategies illustrating the way in which this new kind of collaboration contributes to better mental health for people with ID. Research contributions range from basic research such as gene-behaviour interaction to outcomes in transpersonal interaction analysis, and from recent strategies in assessing traumatic stress to applied behaviour analysis in inclusive educational settings.

This volume is organised into different sections beginning with keynote abstracts, followed by focused communications. The over 200 peer-reviewed abstracts selected for presentation are divided into thematic sectors, including individual abstracts, symposium abstracts and abstracts related to co-productive workshops, having been associated with one of the congress's tracks. In addition, abstract of pre-congress workshops offered in supplement, as models transferring research into applied practice are included. The abstract volume concludes with an alphabetic index of the contributing authors, referring to the page of the respective abstract.

May this volume be part of a new step towards improving the mental health of people with intellectual disabilities, and may this lead to more effective and respectful treatment with person-centred and biographical approaches being more widely used to understand the individual's mental health challenges, thus going beyond explaining it.

Mental health for people with intellectual disability is definitely more than a health issue!

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KEY-NOTE SPEECHES

Critical Factors to Promote Mental Health in ID: Looking for a Coherent and Inclusive Approach Against Fragmentation and Splitting at Different Organisational Level

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Our globalised multicultural society is characterised by changeability, diversity, and uncertainty. Ours is a predominantly neoliberal society (Verhaeghe, 2015) assessing everything and everyone from a business and market paradigm. With their subjacent views on man and society, these developments provide in a certain way and to a certain extent the foundations for a particular way of speaking and thinking, a certain practice vis-à-vis persons with ID. Disability care has undergone a paradigm shift over the last fifty years, from a medical paradigm to a citizenship paradigm. A person with ID no longer belongs in psychiatric care: People with ID are now fully-fledged citizens. Earlier, we strove to normalise and integrate "different" persons; today the guiding principle is inclusion. These societal tendencies coincide with scientific and organisational developments such as Quality of Life, a socio-ecological approach of disability, “bespoke” assistance and need-oriented care. Mental healthcare knows a similar evolution: societalisation, de-institutionalisation, flexibilisation and marketisation become common practice. Both mental healthcare and care for the elderly–especially the demented–show a paradigm shift. Once the medical discourse has reached its limits, many all-important questions remain unanswered for those struggling with complex and lifelong problems. The Quality of Life approach–the Ter Horst orthopedagogic adage of restoration of ordinary life–gains full significance in these factual domains of “disability” in the broad sense of the term. What do these evolutions entail for persons with mental health problems in ID? Our yearlong experience with these people in Belgium and Luxemburg allows us to identify some problematic phenomena–viz. fragmentation and splitting–that impose a(n) (ideology-)critical attitude towards the dominant discourse and its guiding principles. Our experience imposes certain fundamental reflections on language hygiene (Broekman, 1996): However important principles like inclusion and societalisation may be, they are not a self-evidence but a challenge, and they should not be wielded as slogans or dogmas. As guiding ethical principles take form, they need constant reformulation on a human scale.

We distinguish three domains in which the core problem of fragmentation and splitting occurs with all its ensuing iatrogenic effects:

Legal and administrative organisation of health care: a double diagnosis

In our Western societies with all their historic national idiosyncrasies, the differentiation between mental health care and disability care has yielded a separate organisation of the latter. It has developed its own identity, different and separate from mental health care. They each fall under the jurisdiction of different ministries and administrations, and have their separate financing and regulations. They also use expertise and knowledge models from different faculties. They employ more or less numerous, differently trained staff. Both function according to their own (mutually exclusive?) discourse.

The “double diagnosis” in this context is a very meaningful artefact. I do not use the term to refer to a double diagnosis strictu sensu; I am referring to those persons who resort under both domains at the same time. It is not the clinical but the business logic (who foots the bill?) which becomes the final stumbling block through which these people fall between two organisational stools. Double diagnosis turns into an excuse for splitting and exclusion.

Layered realities: colonisation of life factuality

The meso-level is where the interface and transformation must take place, from the objectivating macro-logic to the level of actual service, namely in the life-factual subjective and intersubjective context of the real individuals concerned. Here, the implied expertise, emotional stamina, availability and perseverance throughout every crisis, and reoccurrence of basal problems are of crucial importance. This asks of all concerned, especially professionals, a reflective approach enabling them to catch the specific central psychodynamics and socio-emotional development of a specific person with all subjectivities and details. The continuity of relations proves priceless here.

Restoring ordinary life or the transformation towards the (INTRA-)subjective

What is examined, thought and diagnosed, in short the macro-meso-level, cannot simply be applied on the micro-level; mutual reduction must be avoided. Both levels follow their own logic (Broekman, 1996). An objectivating integrative diagnostic has to be rephrased in a case-related understanding of the particular "psychodynamics" in which the socio-emotional dynamics are active as well (Dosen & De Groef, 2015). A function-oriented diagnostic (Vanheule, 2017) instead of a dysfunction-oriented one, together with an anthropopsychiatrically conceived psychopathology (Feys, 2009), may prove inspiring in this case. Such a rephrasing creates a link between the objectivating diagnostics and meaningful metaphors from stories about the person concerned, and acquires the qualities of a portrait. Surpassing the different jargons of the various disciplines and models has a transdisciplinary effect. It reformulates the case–in a contained manner, promoting dialogue–in everyday, concrete language and strong images that speak for themselves for all those concerned. The institutional middle staff play an eminently crucial role in this contained rephrasing.

All the crucial factors from the different domains can be clustered as follows:

- Contact, continuity and circularity;
- Coherence, consecutive consistency;
- Implied commitment and control;
- Comprehensive containment.

To the extent to which the implementations of these "Cs" misfire or fail, one may expect splitting and fragmentation, with all the pathological consequences for all those concerned.

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From Molecular Studies to Targeted Treatments in Fragile X Syndrome

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Studies of animal models of fragile X syndrome (FXS) and the molecular pathways that are dysregulated in the absence of FMRP have led to new targeted treatments of children and adults with FXS. FMRP controls the translation of hundreds of messages important for other disorders including schizophrenia and autism spectrum disorder (ASD). We know that the mGluR5 pathway is upregulated in FXS and the GABA pathways are downregulated. The initial trials of mGluR5 antagonists did not show efficacy in adolescents and adults with FXS in the behavioural outcome measures that were chosen. However, there is evidence that younger patients may do better and the outcome measures should include cognitive measures in addition to electrophysiological studies, measures of habituation to sensory stimuli, eye tracking studies, and behavioural measures. We have found that the event related potentials (ERPs) particularly habituation paradigms that target brain processing abnormalities with deficient GABA inhibitory input were particularly helpful in our controlled trial of minocycline in young children with FXS. Other new measures include expressive language sampling measures developed by Dr Len Abbeduto and colleagues and the use of the NIH toolbox adapted by Dr David Hessl for children with FXS to assess improvements in cognitive processes and attention. We have also learned that early intervention with targeted treatments can significantly improve developmental testing in young children with FXS as seen by the controlled trial of low dose sertraline in those ages 2–6yo. This controlled trial of 2.5–5.0 mg of sertraline over a 6 month period demonstrated significant improvements in the Visual Perception and Fine Motor subtests and in the overall Composite T score in the Mullen Scales of Early Learning (MSEL) in those on sertraline vs placebo. Those with FXS plus ASD also demonstrated significant improvement in the Expressive Language subtest of the MSEL on sertraline vs placebo. Early intervention is also studied now with the mGluR5 antagonist, AFQ056, combined with intensive language intervention provided by videoconferencing to the family in their home for young children with FXS ages 3–6yo in a multicenter trial funded by NIH. Mouse and Drosophila models of FXS have demonstrated the benefit of metformin as a targeted treatment and encouraging results are seen in open label studies with a controlled trial in process. Other medications that have shown efficacy in FXS include minocycline, arbaclofen and trofinetide and these studies will be reviewed. Since many pathways are dysregulated in FXS it may take more than one treatment to make overall cognitive and behavioural improvements in FXS. The addition to novel learning paradigms for FXS are also expanding and such paradigms can be combined with a targeted treatment. We have shown efficacy in language improvements with a Parent Implemented Language Intervention (PILI) that is guided by a speech and language pathologist combined with a BCBA and the intervention is given through skype twice a week in the home. The PILI intervention has also been combined with a controlled trial of lovastatin, another targeted treatment for FXS in an ongoing trial. The future looks bright for new targeted treatments that will benefit not only FXS but other neurodevelopmental disorders including ASD that have common aspects of molecular dysregulation.

Challenging Behaviour: Individual Difference Matters

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The substantial body of research into the relationship between the aetiology of intellectual disability and emotional, cognitive and behavioural phenotypes has resurrected the importance of individual difference. Identification of dimensions of difference in the research literature has broadened models of the causes of challenging behaviour beyond exclusively operant learning theory accounts that have neglected evidence that demonstrates a more limited role for the environment than previously claimed. Review of the behavioural phenotype literature reveals substantial individual difference on the dimensions of physical health, sensory experience, social motivation and cognition, and cognitive and emotional profile that directly and indirectly influence behaviour when an individual engages with their environment. These dimensions of difference cannot be ignored and should be afforded equal weight to that given to environmental characteristics when designing interventions or personalised services. Meaningful and robust appraisal of these dimensions of difference is the next challenge that will enable the design of environments that can cater for differences of importance.

The Disabled Child: The Desire to Know and Learning With One's Peers

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The child goes through learning processes that, in part, are guided, sustained and organised by adults and, also come from what she jointly constructs with her peers in symmetrical and reciprocal interactions. Every child invests in knowledge for varied reasons. Some are inward looking (desire to control things, to reduce disquieting forms of strangeness and answer to a questioning, etc.), while others are outward looking and focused on the bonds they nurture with those close to them (desire to be recognised, esteemed, have an influence on the other person, to overcome, etc.). All these reasons can be closely intertwined. In this quest for knowledge, brothers and sisters, and peers, can be an extremely valuable resource and adults need to make sure that the disabled child is not deprived of that support. Now, disabled children often experience difficulties in establishing diversified, elective and evolving relationships with their non-disabled or disabled peers. They then remain alone, solitary amid the groups around them, especially in those freer moments when there is no adult intervention to organise interactions. It is frequently noted that disabled children "cling on" to adults and have difficulty in striking up friendships spontaneously and above all in creating lasting bonds with people who are not professionals or members of their family or their generation. This lack of chosen and evolving relations with others has an impact on inclusion processes and the social, family and emotional life of disabled subjects. The reasons behind this situation are complex and the existence of deficiencies is not enough to explain this phenomenon. Based on research work and clinical practice, the conference will open up avenues for investigation: 1) to support the development of skills in the disabled child to interact with her peers and 2) to identify the conditions that will foster the emergence of co-learning between children and seek out what favours or hinders the advancement of relations, when one of those involved has a disability. The main goal is to stimulate co-learning between peers not just in terms of knowing but also knowing how to be among children. These are the essential skills needed to live as best as possible in society and be a true part of one's generation.

FOCUSED COMMUNICATION

Psychotherapy in Supporting People With ID: New Advances From Research and Clinical Practice

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There was a time when many people asserted that models of psychotherapy provided to the general population are not appropriate or plausible for use with people with intellectual disabilities. Looking back, early accounts of psychotherapy with people with intellectual disabilities were few and ambiguous as to the nature or degree of impairment presented by clients, and further confused by a lack of consensus, consistency and clarity in the terminology used to describe people with intellectual disabilities and the nature of their impairments. Early attempts to use a psychoanalytic approach, notably by Pierce Clarke in the 1930s, were with people described as having amentia or being feebleminded. However, it may be like other early reports published which later referred to "mental retardation" that were found to be of clients diagnosed prior to the change in the diagnostic criteria in 1971 from one to two standard deviations below average IQ. Examination of participant details found these to be now classified in the borderline range of intellectual functioning. There is a general consensus that the earliest published account of psychodynamic therapy with someone with an intellectual disability meeting current diagnostic criteria was Neville Symington's paper published in 1981,"The Psychotherapy of a Subnormal Patient", in which he reported his own therapeutic work with a man having an IQ of 59. It is notable that clinical interest in delivering this and other approaches increased around this time as exemplified by an increase in published accounts. Concurrently, applications of cognitive behaviour therapy were being made and published accounts started to appear. Between the end of the 1980s and 2000 several books on the subject were published. Concurrently, our knowledge and understanding of the mental health needs of people with ID has developed. The recently published DMID clearly shows that people who have ID are affected by the same range of mental health concerns as the rest of the population. Further research on prevalence suggests that they have even greater needs. Therefore, it is logical to argue that if the mental health needs of people who have ID are the same, then the range of interventions available to them should be similar. There is now a wider range of psychological therapies available to people who have ID, as exemplified through published work in Europe, the USA and Australia. A range of approaches has now a well-established case study literature and an evidence base is starting to emerge. Cognitive behavioural psychotherapy is more widely available and has a larger corpus of literature. This has been well described and several meta-analyses of its effectiveness are available (e.g. Nicol, Beail, & Saxon, 2013). The literature has also expanded to address specific issues, difficulties, and unique considerations of providing psychotherapy for people who have ID. It has become noticeable at international research congresses, such as those organised by EAMHID, IASSID and NADD, that a wide range of psychological therapies was being made available to people who have ID. This has been confirmed in more recent publications. NADD in the USA have published a book (Fletcher, 2011), and the UK British Psychological Society and the Royal College of Psychiatry of Intellectual Disability have published a report (Beail, 2016) on the current range of psychological therapies available on either side of the Atlantic. In addition to CBT and psychodynamic psychotherapy, these include Dialectical Behavioural Therapy, Cognitive Analytic Therapy, Solution-Focused Therapy, Mindfulness and Acceptance and Commitment Therapy, group approaches, systemic approaches, and arts therapies. This has involved much pioneering work of individuals and teams who have been prepared to explore which reasonable adjustments need to be made to psychotherapeutic approaches in order to enable people with ID to access and make use of them. In this presentation, the development of psychotherapy provision is considered against the translational continuum. The five phases (basic science, early studies, early clinical trials, late clinical trials, and implementation) will be used to evaluate advances from research to clinical practice. Unfortunately, the research available is scarce as intellectual disability has and continues to be an exclusion criterion in psychological therapy research trails. Hence, this evaluation uses data from published accounts of psychotherapy with people who have ID, research studies, reviews, and meta-analyses. These reports and studies are used to populate the five phases of the continuum. What emerges is that some parts of the basic science phase are now clearly populated, but methodological research is still needed (e.g. Vlissides, Beail, Jackson, Williams, & Golding, 2017). There are several early studies (e.g. Lindsay et al., 2015), but early clinical trials are noticeably absent. Attempts at late clinical trials have been made and it would seem that implementation has gone ahead on the basis of what is available along with a pioneering spirit (Beail, 2016). This leads to reflections on the future role of research across the phases and the question who should be doing what in our enterprise to contribute to patient benefit.

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Mental Health and Quality of Life in Neurodevelopmental Disorders

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In the field of neurodevelopmental disorders (NDD), particularly intellectual disability (ID) and autism spectrum disorder (ASD), healing or restoring functional capacities to levels that are similar to those of the majority of people is not a realistic aim in most cases. Thus, outcome measures for therapeutic interventions are heterogeneous, uncertain or restraining (Bertelli & Brown, 2006). In the last decades, alternative outcome measures have been developed, based on the concept of comprehensive well-being and quality of life (QoL), which surpass the criteria of normality and morpho-functional integrity, suggesting care provision aimed at improving a person's satisfaction with their own life. Even though QoL has now become a mainstream theory, its measures are not more reliable than those used for traditional medical approaches.

QoL is still a polysemic expression which defines a multidimensional concept, referring to a wide variety of aspects, involving numerous definitions and applications. Even the criteria for classifying different models have not been agreed upon yet. For the application with persons with ID, consensus has been reached only on the need to assess both qualitative and quantitative components through objective and subjective perspectives (Bertelli & Brown, 2006). Thus, the level of inclusion of areas that have been recognized to be applicable to any person's life and the level of sensitivity to subjective variations within these areas could be a useful basis for benchmarking assessment tools in accordance with current knowledge. In the model I find most useful for planning and carrying out interventions with persons with NDD, the individuals' satisfaction with an aspect of life has to be mediated by the importance they ascribe to it (Becker, Diamond, & Sainfort, 1993). Thus, a comprehensive and productive assessment of QoL must include measures of both individual attribution of importance and individual perception of satisfaction in those areas. The opportunities a person had to attribute importance and to perceive satisfaction in an area are also crucial. A reliable assessment of a person's quality of life is hard to establish. In current practice, it is evaluated by combining information from different proxies, for example family caregivers, family members or health care professionals. Proxy assessment involves several problematic issues. First of all, it may vary depending on factors such as individual character and perception, cultural level or the nature of the relationship with the person with ID or ASD. For example, most researches have shown that parents and relatives in general tend to attribute a lower level of QoL than health care workers do. Another major element is that the proxy can assess the person with NDD as they consider the person would evaluate himself (proxy-person perspective), but it can also occur that the proxy adopts their own point of view in evaluating the person with NDD (proxy-proxy perspective). For individuals with severe ID, proxy-patient assessment is of controversial validity and reliability, and an accurate understanding of their wishes or interests continues to be a very troublesome challenge. Some authors created a system to evaluate importance and satisfaction of this group of persons based on a structured observation of their recurring behavioural repertories. In sociology and more recently in mental health care, QoL assessment aims to identify the hierarchy of areas of current or potential interest in every person's life in order to enhance the general satisfaction in these areas and therefore life in general. From this point of view, QoL consists of the identification of a path or a way of living rather than the achievement of a contingent objective. The QoL assessment includes the number of meaningful experiences people have in life areas they value the most, and the opportunities they receive in order to acquire these experiences, including the possibility to make independent choices. In other words, the assessment of QoL aims to identify the extent in which the different life areas contribute to the achievement of a full and actively lived life. The employment of QoL as an outcome measure is particularly useful for multidisciplinary integrated interventions involving different professionals, family, and life environments which are increasingly recognized as most appropriate for mental health needs of persons with NDD. Similarly, it suits the need for close interaction between various agencies related to social, educational, legal and health sectors for the integration of services to form a holistic management of the individual. Considering the high vulnerability of persons with NDD and the significant prevalence of psychiatric disorders in this group, it is important to adopt an approach that comprehends as many facets as possible in its assessment. Problem behaviours (PBs) may also be an example of usefulness of the participatory paradigm. Generally, PBs in PWID are treated pharmacologically and the search for a therapy which takes into account the individual specific conditions and the improvement of quality of life is disregarded. Actually, clinical practice suggests that an effective intervention on PBs should be characterized by a simultaneous consideration of organic, psychiatric, and socio-functional aspects and their pathogenetic contribution, on the basis of a multimodal analytical approach. This indication is confirmed by recent evidence from scientific literature that supports the effectiveness of therapeutic processes developed on the basis of specific clinical and environmental information related to each patient. Such procedures can also be helpful in providing effective models for the assessment of adaptive skills. An integrative assessment which consists of contributions from various disciplines might also allow the identification of problems in the classification systems strictly linked to clinical practices. It can also be useful in providing genetic models for psychiatric disorders commonly experienced by persons with NDD, with potential benefits for their early identification as well as for the development of increasingly sensitive diagnostic tools. In fact, more than any other mental health condition, ID and ASD provide sufficient opportunities to explore the clinical expression of the body-mind link. Traditionally, mental health care for individuals with NDD has been parsed out to multiple providers and/or agencies along disparate funding lines. Providers of services for physical health, mental health, and behavioural issues have often separate allocations and are managed by different entities. Bringing together those disciplines which have traditionally served individuals with ID, in line with the QoL approach, challenges the status quo and implies a drastic renewal of the current system of service provision in many countries across the world. The QoL approach is also aligned with new conceptualisations of person-centred psychiatry, which highlights the importance of engagement, empathy and partnership in the clinical care process, and sustains the patients' autonomy, responsibility and dignity, while advancing the recovery and promotion of well-being. To assess the domain of a person's experience and values, a person-centred integrated diagnostic process uses descriptive categories, dimensions, and narratives to cultivate patient-family-clinician partnerships for achieving shared diagnostic understanding and commitment to care (Botbol et al., 2016). The implementation of QoL in psychiatry of NDD may also support a shift from the traditional over-reliance on the unitary intelligence (IQ) score in favour of specific cognitive functions. The assessment of cognition should be aimed at identifying strengths and weaknesses that can impact individual skills which contribute to satisfaction with life. After much research focused on the individual QoL, the international scientific community has now dealt with the generic QoL of the families including people with NDD. The most relevant studies on this theme in respect to ID have been conducted with the Beach Center Family Quality of Life Scale and the Family QoL Survey, while the Quality of Life in Autism Questionnaire has resulted in being the most often used tool for parents of children with ASD. As mentioned above, different QoL assessment tools do not include the same life domains. Spirituality represents one of the major differences. In the model and tool for the QoL measurement proposed by the research group of the Centre for Public Health at the University of Toronto (Renwick & Brown, 1996), spirituality represents an emic area with considerable implications for the lives of all people in all cultures. In this instrument, spirituality is evaluated through the following items: value attributed to life, intimacy and introspection spaces, how individuals pray or meditate, participating in religious activities, and feeling useful by helping others. Some wider declinations are also included, such as having personal values, right/wrong and good/bad criteria, things to live for and in which to have faith, and celebrating anniversaries or special events. In the tool of the World Health Organization (WHOQOL-SRPB Group, 2006), aspects considered essential for the impact of spirituality on QoL are represented by attributing a meaning to life, ability to awe, feeling a sense of wholeness, integration, hope and inner peace, being optimistic, calamity and being in harmony with the surrounding. The reference to spirituality is described by the authors in the explanation of the items of the tools: For example, the state of inner peace can be connected to the personal relationship with God rather than the faith in transcendent principles or moral values. Finally, in the QoL Questionnaire by Schalock, Verdugo and collaborators, spirituality consists of a sub-indicator or sub-descriptor of the emotional being, which is one of the several possible ways a person may express a subjective degree of quality in the area of emotionality (Schalock & Verdugo, 2002), depending on the context and the person. Religion is one of the most frequent sub-indicators. Most researchers identify spirituality as a significant predictor of a high level of QoL in the medium and long term, together with optimism, good mood, collaboration in care, and social support. Recently, the strong connection between spirituality and QoL has been operationalised in the concept of Spiritual Well-Being, which expresses the way and the extent to which spirituality affects the individual perception of life as a whole.

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Mental Health and Intellectual Disability: History and Concepts Towards Evidence-Based Practices

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Since the 1960s we have witnessed the closure of long-stay facilities and the resettlement of people with Intellectual Disability (ID) in community support services. Dynamic sociological and ideological views arguably have had greater impact on the care of people with ID than some of the achievements in molecular genetics and neurobiological research. One of the problems with ideologies, however, is that they sometimes conflict with other ideals such as evidence and objectivity, which can be a complex issue. With the increasing closure of facilities, people with ID and mental health problems found themselves moving to less restrictive environments or remaining longer with their families. In such community settings, it became clear that services from both the ID network and the mental health system were required. The provision of the essential mental health services for people with ID and mental health problems became a major issue in the US and UK as community resettlement plans started to be implemented (Bouras, 2017). The process of deinstitutionalisation for people with intellectual and developmental disabilities has progressed well compared to that for those with mental health problems. It evolved more gradually and selectively, and resulted in less recidivism. Perhaps the fact that it is more difficult to deny the presence of actual disability in this group, compared those with mental health problems, has made the crucial difference in this respect. The form of change depends on each country's unique historical perspective and national philosophies about care for people with ID. These include service design and planning, care packages, funding streams, staffing patterns and resources. Historically, people with ID were seen as being incapable of having mental health problems. However, epidemiological studies over the recent years consistently disproved this, showing that people with ID have a higher frequency of mental health problems than the general population. Furthermore, an understanding of a clear increase in the prevalence of behavioural problems in people with ID has emerged. It is evident that when behavioural problems or challenging behaviours are not included, the increased prevalence in mental disorders in people with ID is less marked. One of the most difficult issues has been how behavioural problems are conceptualised and classified, and to what extent mental health and behavioural problems should be considered separately in people with ID (Cooper, 2016). The distinction between mental health problems and behavioural problems has significant clinical and service implications. In clinical practice it is not always possible to neatly separate mental health problems and behavioural problems in people with ID. It is likely that there is a combination of biological, social and environmental factors, which interact with cognitive and adaptive deficits to make persons with ID vulnerable to mental health and behavioural problems. The need for a bio-psychosocial approach, including co-ordinated multidisciplinary input, is of paramount importance. Half a century after the introduction of community care for people with mental health problems including those with ID, the adoption of the concept of "meta-community mental health care" (Bouras, Ikkos, & Craig, in press) is suggested. This concept capitalises on the successes of community care but equally acknowledges the limitations, including the wide range of complexities that have been experienced in the implementation of community care plans. The aim is to provide a conceptual framework in which to reflect on experience and to consider new or revised therapeutic initiatives and service developments. The starting point of meta-community care is the knowledge we already have of the principles of good community care, including the need for effective, accessible, efficient and coordinated systems with meaningful user participation. Ensuring parity of esteem between physical and mental health, and ensuring equitable access to effective treatment methods can be added to the aforementioned principles. There is an encouraging increase in the evidence base on issues relating to people with developmental and intellectual disability including certain associated conditions. The most expended area in recent years is related to autism spectrum disorders where the literature is rapidly growing. Ill health and intellectual disability as well as service systems are also receiving attention. An obvious question at the times of translational research is how the outcomes produced by research have been translated for the benefit of people with ID, their families and their careers. High-quality research to strengthen the evidence base such as recent studies is necessary (Sheehan & Hassiotis, 2016). The transformation of care for people with ID over the last few decades includes the movement towards integration, participation and choice for people with ID as a facet of larger disability, civil and human rights movements on a national and international level. There is now a consensus on the need to respond more adequately to mental health needs in this population. The current trends are geared towards community integration schemes with service users' participation at all levels, including design and implementation with a person-centered approach. In spite of the existence of policies and services for people with developmental and intellectual disability, recognition of and provision for their needs carries low priority. This gap is greater in low and middle income countries, where the burden of disability needs to be recognized in order to plan for and meet the needs of those with developmental and intellectual disability across their lifespan. In 2015, the United Nations General Assembly (Votruba, Thornicroft & FundaMentalSDG Steering Group, 2017) adopted 17 Global Goals: 193 world leaders pledged to take action to end poverty and inequality, and to protect the planet. They agreed on 169 targets to help them achieve those goals within 15 years. Mental health was included in the 2030 Agenda for Sustainable Development (SDG); Goal 3 is "good health and well-being—ensure healthy lives and promote well-being for all at all ages." Target 3.4 is: "By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being." These goals adopted by the international community should facilitate a conceptual re-orientation in thinking about mental health care for people with ID. The number of possible interfaces between services is increasing. Together with existing uneven financing systems, these interfaces are increasingly struggling to manage the providing of personalised care pathways adjusted to the needs of service users, their careers and families. We still have little information about the effectiveness or the cost–effectiveness of many interventions and methods of delivering services to the community, and we are lacking established methodology for evidence-based evaluations.

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Enlarging the Frame: Issues of Inclusion and Mental Health in an Ageing Society

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Introduction

This contribution frames the notions of inclusion and mental health by describing trends in European societies at the social and economic level that will have direct consequences for a participative civil society and social cohesion. Our starting point is the observation that the world faces challenges at the start of the 21st century that are new and unprecedented in its history. The four global forces that break all the trends known so far in human history include urbanisation, accelerating technological development, greater global connections, and population ageing (Dobbs, Manyika, & Woetzel, 2016). We will first describe the scale of population ageing, as ageing populations characterize several developed economies. In a second step, we will highlight some consequences of population ageing for social welfare, and in a third part we will elaborate on the notion of justice and inclusion in rapidly changing societies. The World and Foremost Europe are Ageing: it is a well-known fact that Europe is ageing; UN data from 2012 show that nine of the 10 oldest populations of the world are from Europe: While Japan has the highest proportion of elderly people, Germany and Italy take second and third place—followed by Bulgaria, Finland, Croatia, Greece, Latvia, Slovenia and Malta. However, the demographic trend of an ageing population is also showing in China and will soon reach Latin America as well. Dobbs et al. (2016) state that–for the first time in human history–ageing could mean that the planet's population will reach higher age everywhere. Due to growing life expectancy and at the same time decreasing fertility, societies run the risk of over-ageing with the older part of the population forming the majority and leaving children, adolescents and adults in the minority. This demographic change has severe consequences at all levels of the socio-ecological context ranging from differential experiences of ageing at the personal level, intergenerational relationships to effects at the wider social and macro-economic level (Ferring, 2017). This latter point is elaborated in the following. Social Welfare and Public Expenditure: the sustainability of public expenditure as well as the division and distribution of public resources provides a new challenge and is heatedly debated in most European countries. In the public media, at government level, and in scientific discourse the balance of public investments in work and employment, education and training, social security and health care provision as well as the sustainability of the welfare state model as a whole are widely discussed. The costs of an ageing society are enormous. The longer people live, the more likely it is that they will attract a (chronic) illness and will require care. The cost estimates with respect to the high prevalence of Alzheimer's and neurodegenerative diseases illustrate this point. The estimated global cost of dementia amounts to a total of USD $818 billion estimated 2015 worldwide (Alzheimer's Disease International, 2015). In Europe, the total expected cost of dementia reaches €189 billion per year across the 15 EU countries before the Eastern enlargement (Luengo-Fernandez, Leal, & Gray, 2011). An ageing population will also put social security and pension financing at risk. The active work force is getting smaller in many European countries and a rapid decline of the worker-to-retiree ratio can be observed across Europe. Moreover, people live, on average, longer post retirement and with increasing age, people tend to show a pronounced need for public support. Yet the distribution of public resources depending on the needs of persons appears no longer sustainable and this has led to a reflection and review of the social welfare model in some European countries. This potential reform of the welfare system is sometimes framed in terms of return of investment. The logic behind this is simple: The state invests into education, training as well as employment and work, and expects active participation from its citizens and a return of its investment both in terms of social and financial returns. The open question within such a framework is, however, what will happen to persons who cannot live up to the standards of an achievement-related society and will not be able to provide a specific return of investment—a question of social and economic cohesion. However, not only individuals are affected by this question of cohesion. Within some European societies, players within the economic sector have gained public attention, in particular some banks and investment banks which had run into liquidity problems. These private banks were saved by public money; national households saved these banks because of their so-called system-relevance. It goes without saying that this poses additional strain to national and European households as well as to discourses about the justification of such actions by the public. Linked to this is also the phenomenon that the unequal distribution of wealth in most countries is increasingly being challenged as socio-economic inequalities widen within Europe and beyond (see Ferring & Albert, 2013). These observations set the frame for the discussion of inclusion and mental health in society. The underlying question of is what is just and justified when it comes to the distribution of resources will be deliberated next. Justice and Inclusion: the question at the heart of social policy and academic discourse is: “How will our present decisions and actions at the political level affect the future of the individual and the society?” There are the intended consequences, which also imply at the first level a realization that today’s political decisions will impact future developments in all domains of a civil society including education, economy, health, and social policies. The unintended consequences are of course more difficult to predict. At a second glance, the impacts may not be that clear-cut and easy to detect. However, one problem of the political decision-making process is also that the different parties and interest groups involved have from the outset differing and often conflicting ideas about what to achieve. Some goals are equally desired, but difficult to achieve. Examples include the need to increase or at least to maintain productivity, but not at the risk of environmental pollution, weighing up investment decisions into education and employment against finite resources vis-à-vis the health care needs of an ageing population. These examples illustrate that thinking about the consequences of present decisions and actions for future developments almost always implies an ethical statement about which consequences should be expected for future generations. This leads then to the concept of justice and, more specifically, distributive justice and the underlying notion of the fairness of resource allocation. Justice is a relative term and depends on the criterion used to evaluate justice. There are several principles to be discussed here. Arts and Gelissen (2001) elaborate that some welfare states “have embraced a notion of equality that reflects a redistributive justice of collective solidarity. Others, however, have cherished a conflicting notion of solidarity, i.e. equity, which reflects the rationality of a quid pro quo actuarial principle of distributive justice” (p. 283). Underlying these models are different justice principles such as “neediness” favouring persons in need of help and resources or “achievement” favouring persons who achieve the most with respect to a given criterion. At the individual level, persons may experience existential guilt when having the impression of being advantaged (Schmitt, Behner, Montada, Müller, & Müller-Fohrbrodt, 2000) or people may feel disadvantaged and excluded. It is an open question how societies will develop in the coming decades with respect to distributive justice and the inclusion of all parts of civil society, given all the trends up to this point. It goes without saying that social cohesion and peace will depend on the answers that are found here.

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Challenges of Partnerships Between Patients and Healthcare Professionals

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The issue of the relationship between health and knowledge is made essential through multiple factors. In a period marked by an upheaval of information, communication and health systems, the place of disease as well as physical, psychological, mental and social vulnerabilities in the society have changed. The formerly passive relationship between professionals and patients is today described as an active exchange of knowledge at both the individual and inter-community levels. Many discourses deal with a questioning of the relationship between caregiver and nurse, between knowledge savant and lay knowledge, and models of existing practices. More precisely, when viewing the speeches of experts, politicians or activists (Godrie [in submission], Flora, 2015; Colledani et al., 2017), we propose to characterize the present period as being in a transition between two epochs: The first is that recognition of experiential knowledge of patients (understood in the broadest sense) has become a social fact (Jouet et al., 2009) and a second epoch is about to come, which should be characterized by systematization of reflexive cooperation of all types between patients, users, relatives, and health professionals. Particularly in Europe and Quebec, speeches by experts or politicians about this cooperation between patients and health professionals do not only refer to individual commitments, but also to commitments with collective and even societal dimensions and challenges. Three types of collective engagement would be emerging today (Las Vergnas, Jouet and Renet, in submission): Collective reflective co-operation of type 1 (CRC1): the joint improvement of the health care system through the development of a representative health democracy. This corresponds to the involvement or commitment of patients (or their relatives) in the organization or regulation of the health care system (i.e. effective presence of representatives of users in hospitals or territories, consultation and advice on research protocols). Collective reflexive cooperation of type 2 (CRC2): the integration of patients and relatives in the circuits of transmissions of knowledge on diseases, and the regulation of the experience of the disease. This corresponds to patients' educators or teachers involved in therapeutic patient education, peer mediators and other peer assistants, and patients included in health professional training systems, such as in the medical schools of Bobigny, Montreal, Nice, Lausanne or within the framework of the Lyons program PACTEM "Patients involved in the teaching of medicine". Collective reflexive cooperation of type 3 (CRC3): co-productions of knowledge on health problems, and treatments based on the experience and reflexivity of patients and relatives, corresponding to patient co-investigators. What about the field of disability and mental health? A focus on these evolutions will be placed in the field of disability and mental health in order to support the actors of adjacent fields. In fact, over the past decade, there has been a wind of renewal on psychiatric and mental health care practices. We wish to build on the French framework to propose a modelling of the progress of these different cooperative processes in the field of psychiatry and mental health. Particularly in the French context, a renewal of the practices of care emerges with a double dimension. It is based, on the one hand, on ideologies built around a "citizen subject", engaging in autonomy and participation, empowerment, and social and cultural currents renewing policies privileging sociocracy, the common, and the transversality of powers. On the other hand, it feeds on the existence of a crucible of medical controversies (neurosciences, psychoanalytic currents, institutional psychotherapy, cognitive-behavioural sciences, etc.). We can also add that this renewal of approaches is also qualified as a crisis when one takes into account the economic injunctions of rationalization of expenditure by regrouping it into meta-structures with a balkanized care offer, following a safe ideology. Taking into account the typology of co-operation mentioned above, there are CRC1s in the abundance of user associations and the multiplicity of their actions (Madpride, Fadapride, lobbying the public authorities, representation in the dedicated bodies of health democracy, members of the National Mental Health Council created in 2016, etc.). CRC2s are present in therapeutic education programs, in the curricula of medical students of health professions at medical universities, health peer support programs, "Housing First", in the creation of Recovery College or Repit House (Marseille). The CRC3s are convened in the co-research practices, as the Emilia program, or the actions of user-researchers in committees and research programs, including the different stages of involvement of people in the scientific process. One of the causes of the multiplication of these collective collaborations in mental health is undoubtedly to be sought in the deployment of the approaches centered on the recovery of the people. Indeed, culturally and epistemologically, the mental health recovery paradigm is a powerful lever for these collaborations. Thus, when looking at the question of living with psychiatric disorders, recovery can appear as a process of valorisation and self-validation of the experience of chronic disorders: Through narration of the self, the patient daily transforms bits of (even operational) knowledge fortuitously into knowledge capacity (Fernagu-Oudet, 2012): The patient develops power to act, and builds the means to accept and commit himself in the best way possible to a new life regime, that of life with disorders. Similarly, hope, social support, and joint interlocution appear as factors of conversion of a lived experience because that which we know as a psychiatric disorder, whose nature remains diffuse and uncertain, can be transformed into knowledge in the right environment. Examples include the formal framework of the French GEMs (peer support groups) or, in a different mode, the informal sharing of digital social networks. It can happen that the group that has become a "community of learners" (Wenger and Lave, 1991) within the spatio-temporal magma of the informal becomes a form of deviance and critical posture, making boundaries between medical and bio-political epistemologies porous. However, we must keep in mind the importance of the situations and environments in which experiences happen. The learning evoked is constructed from particular experiences, defined by medical nosography as dysfunctions and symptoms, which are probably not reproducible for other pathologies: Learning is enabled through a capacitive environment. Advocates of this assumption are, among others, the Network of Voice Entenders and in an experimental context the French DingDingDong collective, an association for patients diagnosed with Huntington's disease, but also other associations for autism with neurodiversity (Chamak, 2015).

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Trauma and Traumatic Sequelae in People With Intellectual Disabilities

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There is evidence pointing to a greater risk for people with Intellectual Disability (PWID) of being exposed to traumatic events (TE), especially interpersonal trauma (Wigham & Emerson, 2015). Among the most prominent risk factors, members of this population are often marginalized and vulnerable, they are separated from their parents early in life to live in service facilities. Life events (LE) not defined as traumatic by the DSM-5 might also lead to pathological trauma sequelae in PWID. However, LEs play an important and relevant role in the development of mental illnesses in the population with ID. LEs functioning as risk factors have to be disentangled from specific LEs that cause pathological trauma sequelae. The importance of daily hassles in this population has been highlighted, as PWID may rate them as more impactful compared to their peers without ID. It can be assumed that LEs, e.g. bereavement, transfer to a new service facility, educational measures (e.g. safety room), and developmentally inappropriate experiences might lead to pathological sequelae. No study so far has investigated the variety of LEs and TEs in the population with ID, and the accumulation of multiple adverse events is highly under-researched in this population. **Traumatic Exposure**: Sexual abuse is the TE with the most evidence in PWID (Wigham, Hatton, & Taylor, 2011b). In a qualitative study, PWID perceived and described victimization and the psychological aftermath more or less precisely and with strong emotions. The main response were feelings of being de-evaluated, helpless and hopeless. Most participants perceived sexual abuse as the worst form of abuse. Notably, for TEs other than sexual abuse only very little research exists (Berger, Gelkopf, Versano-Mor, & Shpigelman, 2015). Furthermore, the range of TEs as described in DSM-5 (American Psychiatric Association, 2013) accounting for PTSD might differ from the general population (GP), due to limitations in coping, memory integration, emotional processing, and functional assessment, which are all related to diagnostic overshadowing. Therefore, it is unclear whether TEs as described in DSM-5 (APA, 2013) are a valid concept for PWID. Although the DM-ID 2 was recently published with adapted criteria for PTSD, only limited evidence for the adaption was given

(Blanco, McCarthy, Razza, & Tomasulo, 2016). **Prevalence**: Prevalence of victimization in PWID is elevated compared to the GP. PWID are more prone to interpersonal victimization by multiple perpetrators, especially sexual victimization. In their meta-analysis, Jones et al. (2012) showed that 26.7% of children with ID experienced combined physical and sexual violence, 20.4% were exposed to physical violence, and 13.7% to sexual violence. The odd ratios ranged between 2.8 for sexual violence and 3.68 for combined violence. The existing studies are limited by a lack of sufficient measurements, the quality of study designs, and poor scientific standards in general, such as including a vast heterogeneity of disabilities as well as traumatic events (Jones et al., 2012). Moreover, most existing studies focus on abuse, whereas further TEs have been excluded so far. **Risk Factors**: The risk of developing PTSD is exacerbated by aspects such as lower cognitive abilities and therefore difficulties in memory integration, fewer possibilities for disclosure and therefore limited social support, and a lack of specific treatment. PWID are more vulnerable to social determinants of poor health, such as poor housing and lower income. They often grow up marginalized and in service facilities, receiving no training for mastering negative life events. Moreover, societal stigma and discrimination, negative traditional beliefs, ignorance within communities, and a lack of social support for caregivers are important risk factors in this population for developing PTSD. Moreover, dependency on personal assistance, and reduced physical and emotional defences hamper reporting of violence. Early separation from parents and placement in service facilities may contribute to a loss of protective factors. In Austria, a substantial number of adult individuals with ID live in service facilities, most of them since early childhood, under the perspective of providing and enhancing a safe environment, to stimulate the compensation of the developmental deficits. On the other hand, housing in service facilities brings the inherent risk for PWID to be victimized by caregivers or being exposed to interpersonal trauma caused by external people that caregivers are unable to identify. To date, no scientific evidence for such potential TEs is available. **Institutional abuse**: In several European countries, the US, Australia and Canada, adults (of the GP) claimed financial redress and apologies for violent acts committed by members of institutions. The placement in institution took place for several reasons, such as elite education or foster care. Commissions were established to conduct investigations, along with scientific studies. Institutional abuse (IA) is defined as any kind of physical, emotional or sexual violence and neglect that happen within an institution (Lueger-Schuster et al., 2014). Multiple exposures to traumatic experiences (polyvictimization), a delay in disclosure (Lueger-Schuster et al., 2015), and an elevated psychopathological response in non-PWID survivors of institutional abuse from the GP (Lueger-Schuster et al., 2015, 2014) have been repeatedly reported. Clearly, there is need for studies on the PWID community exploring the prevalence of TEs inside and outside of institutions, and the resulting traumatic sequelae. **Posttraumatic Stress Reactions, Emotional Responses, Expressing of Symptoms**: PTSD core symptoms and expression of symptoms. The core symptoms of PTSD in the GP are defined as re-experiencing, avoidance, negative alterations in cognitions and mood, and hyperarousal. Currently, the DSM-5 (American Psychiatric Association, 2013) lists 20 symptoms in four groups, whereas the proposed ICD-11 includes six symptoms in three groups. However, little is known about the expression of symptoms in PWID. The main difference is a preponderance of behavioral symptoms which are often not recognized as PTSD indicators. For example, challenging and aggressive behaviors are mostly interpreted in the light of the ID diagnosis itself, leading to a phenomenon referred to as diagnostic overshadowing (Mason & Scior, 2004), indicating that diagnostic overshadowing might cause a bias of reported PTSD rates with psychological problems and disorders not being adequately related to TEs, and therefore not being recognized. Challenging behaviors are defined as behaviors that are deemed to be challenging by caregivers or families, including behaviors such as aggression, self-injury, screaming, disturbed sleep patterns, and hyperactivity. They might be seen as an expression of traumatic symptoms, which are defined as an adaptive reaction towards a situation out of the range of normality. However, the question remains whether challenging behavior in PWID is an expression of the traumatic sequelae or a more general behavior occurring with any kind of irritation. **Additional symptoms and diagnostic criteria**: Research in this domain is being further complicated by the current reformulations of stress-related disorders in both classification systems. However, the proposed introduction of Complex PTSD

(CPTSD) in the ICD-11 (Maercker et al., 2013) might increase the chance to identify PWID with a traumatic stress disorder, since the additional symptoms of the CPTSD (three dimensions of disturbances in self-organization [DSO], affect dysregulation, negative self-concept and disturbances in relationships) have to be present together with three symptoms of PTSD (re-experiencing, avoidance, sense of threat) in PWID with traumatic stress disorders. The CPTSD diagnosis is defined as a sibling diagnosis (Maercker et al., 2013). Wigham et al. (2011b) reviewed the literature systematically and they found that the DSO symptoms are also present in PWID as a trauma sequelae. However, the newly proposed classification is based on the idea of clinical utility and helps to avoid comorbidities. The principle of clinical utility might be more adequate for PWID. **Assessment**: Recently developed assessment tools (Hall, Jobson, & Langdon, 2014; Wigham, Hatton, & Taylor, 2011a) give the possibility to learn more about the specific trauma-related symptoms, and provide an assessment tool that enables caretakers, parents and of course the individuals with ID to identify the trauma sequelae, to respond to their trauma-related needs, even though they are limited in their quality. These instruments measure general effects of trauma (Wigham et al., 2011a) and are available only in English language. Instruments existing so far need improvements and an adaption for PWID with severe cognitive problems. **Treatment**: Currently, promising studies for PWID suffering from traumatic sequelae are conducted, using e.g. EMDR. So far, no solely anecdotal evidence is given.

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Autism and Offending: Towards an Evidence-Based Approach

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The purpose of this paper is to explore the evidence for offending behaviour in adults with autism spectrum disorder. Autism spectrum disorder (ASD) affects around 1 % of the adult population, but up to 30% of adults with intellectual disability. The prevalence is higher among men with a male to female ratio of around 3 to 1. ASD is a lifelong condition defined by DSM-5 to have two criteria of deficits in social communication and social interaction along with restricted and repetitive behaviour, interests or activities. Research into the nature and causes of ASD has grown significantly since the beginning of this century, having been first described by Leo Kanner and Hans Asperger in the 1940s. In the current decade, there has been a growing literature on people with ASD presenting to the Criminal Justice System (King & Murphy, 2014; Chaplin, McCarthy, & Underwood, 2013). This has partly been due to cases that have been prominent in the media, such as Gary McKinnon from the UK, who hacked into the U.S. government computers looking for evidence of UFOs. The focus of research to date has been determining the prevalence of ASD among offenders within specific populations such as prisoners and how best to identify people with ASD across the Criminal Justice System (McCarthy et al., 2015). In addition, there is literature investigating types of offences committed by people with ASD and the characteristics of people with ASD who commit offences, including comorbidity. In addition, there has been some work on the vulnerabilities of people with ASD within the Criminal Justice System. Studies on the prevalence of offenders with ASD across the wider forensic population have produced mixed results, but a recent systematic review did not conclude that people with ASD have higher rates of offending (King & Murphy, 2014). Studies on prevalence rates of ASD in offender populations have been mainly conducted in the UK, Sweden, Japan, and more recently the USA. The U.K. studies have included the three high secure psychiatric hospitals which in 1999 found a prevalence rate of 2.4% among patients, but this compares with a study in a Scottish prison in 2012 which found less than 1 % of prisoners with ASD (Robinson et al., 2012). The study in Japan was of juveniles reporting a rate for pervasive developmental disorder to vary from 3% to 18%, with findings based on data generated in Specialist Courts. A Swedish study of young people found 27% to have a pervasive developmental disorder among those referred to a Forensic Psychiatric Service. This may indicate that the adolescence period is a high-risk time for a person with ASD to become involved with the Criminal Justice System. A recent study of a maximum security prison in the USA using the AQ-50 identified 4.4% of prisoners to have autistic traits (Fazio, Pietz, & Denney, 2012). Literature on types of offences that people with ASD may commit has mainly relied on case studies. The limited evidence does indicate that young people with ASD are significantly more likely to commit crimes against people and significantly less likely to commit property offences. However, most studies do not use unbiased samples and thus it is not conclusive that people with ASD tend to commit specific type of offence acts, such as sexual offending or fire-setting behaviour. The risk for people with ASD to commit offences can be argued either way, as due to their reliance on and adherence to rules they may be less likely to commit criminal behaviour, but due to their core difficulties with understanding social clues and impairments of empathy, this may increase their risk to commit offences against others, such as committing sexual offences or becoming aggressive. Any disruption to their routine or a sensory overload may lead a person with ASD to become very agitated, resulting in aggression towards others. Obsessional interests may lead to specific types of offending behaviour, such as fire-setting behaviour, cybercrime or obsessive harassment in the form of stalking. For the wider population of offenders, factors leading to offending are early social disadvantage, conduct problems such as truancy or aggression, substance misuse, and comorbid psychiatric conditions such as psychoses. People with

ASD are not excluded from early social disadvantage or adversity, but there is little research on this in relation to future offending behaviour. Research based on clinic or secure hospital populations indicates that the majority of patients with ASD who have committed offences have a comorbid psychiatric disorder. However, drug and alcohol use is less common compared to patients without ASD in secure hospital populations. These are biased samples and therefore it is not surprising to see high rates of comorbid psychiatric diagnoses. In addition, studies have investigated the vulnerabilities of people with ASD. Many people with ASD are frightened and confused by their experiences at the police station, court or prison. People with ASD are vulnerable to bullying and less able to cope in prison. For many, their contact with the Criminal Justice System may be the first time the diagnosis of ASD is made. Evidence to date indicates that people with ASD are not more suggestible to leading questions but may be more compliant, which may be problem when being interviewed at a police station. It is a national policy in England to divert vulnerable offenders, such as those with mental illness, intellectual disability and autism spectrum disorder, away from the Criminal Justice System to hospital care, if indicated, or to rehabilitate them in the community rather than in custodial options as prisons. However, in order to achieve this, we need to identify individuals with ASD early within the Criminal Justice System, such as police stations or courts, while being able to use a validated suitable screening tool in these settings will undoubtedly be a challenge. The final section of this paper describes a study undertaken in a prison in South London to identify the extent of autistic traits among male prisoners and, secondly, the association between autistic traits and common mental health problems. The full details of the methodology are described in the paper by (McCarthy et al., 2015). In total, 240 male prisoners were screened with an age range of 20 to 72 years with a mean age of 34 years. 45% of the participating prisoners were from a black minority ethnic background. We used the 20-item Autism Spectrum Quotient (AQ-20) to measure the autistic traits. Thirty-nine of the prisoners had significant autistic traits as defined by a score of greater than 10 on the AQ-20. Follow-up diagnostic assessment was carried out using the Autism Diagnostic Observation Schedule (ADOS) and, where possible, the Autism Diagnostic Interview (ADI-R). Those with autistic traits had higher rates of depression of 30% compared to 6% for prisoners with no neurodevelopmental disorder ($p < 0.001$), and current anxiety disorders in 27% of prisoners with autistic traits compared to 11% of prisoners without a neurodevelopment disorder. Prisoners with autistic traits also had higher rates of thoughts about self-harm and self-harm behaviour than prisoners without neurodevelopmental disorders. There are a numerous limitations of this study thus lowering the generalizability, but the strength was the use of standardized assessment tools in face-to-face interviews. The evidence to date indicates that people with ASD exist in the Criminal Justice System and that they are vulnerable in terms of their health and well-being. Therefore, we need to improve our recognition of people with ASD early in the Criminal Justice System, not just through screening but the training of police officers, court staff and prison staff to recognise and support people with ASD. This does require a policy commitment for health services to work more closely with the Criminal Justice System to divert people with ASD away from prison settings. Services need to support interventions in the community that reduce the risk for reoffending in the future through the development of social skills and better mental health care for adults with ASD. The evidence base to date is still limited, partly due to biased samples and the way we undertake comparisons with offenders who do not have ASD. Future evidence must not only focus on adults in populations at risk, such as in hospitals or prisons, but should also focus on how to improve life chances and well-being for young offenders with ASD. In addition, more evidence is needed on how to best support people with ASD with their vulnerabilities at the police station and within the court system.

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Cooperation Models Among the Public Health Sector and School System: Inclusion of Children With Autism Spectrum Disorder

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The Italian law prescribes that all children have the right to education in an inclusive school system, regardless of their impairments or special needs. This means that students without disability and students with difficulties or impairments are being placed in the same classroom. This system is in place since the elimination of special schools in Italy in 1977 (MIUR, 1977). The law contains instructions and definitions where schools must implement specific measures to enhance and promote children's development (MIUR, 1992). The intention is that teachers, parents and professionals create together an individual education plan for every student with special needs, based on the assumption that not all students should follow the same program as it's necessary to consider their different performing levels (MIUR, 2009).

A strong and well-working cooperation of the involved families, teachers and professionals is important to implement the concept of an inclusive school. In addition to regular teachers, integration-teachers (teachers with special qualification in addition to the standard teacher education) can be assigned to the entire class including students with special needs. Furthermore, in some cases, the presence of an integration-assistant for students with autonomy impairments is possible. Other important people in this context can be the headmaster and the integration-coordinator (coordinating the integration-teachers or assistants at that school). Besides that, there are school counselling services in every district.

The public health system and the school system have defined a clear agreement containing cooperation, rules, and procedures to guarantee the success of the inclusion model (Autonome Provinz Bozen, 2013). In addition to the school system, the public health system is strongly involved in the support of these specific cases, for example with making diagnoses, writing necessary documents for the school or providing support and therapy for the child and its family (Autonome Provinz Bozen, 2015).

Through presenting of fundamental conditions and various examples from practice with students with autism spectrum disorder it is shown how a network of families, schools and the public health system can successfully work together in an inclusive education system.

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Mental Health for People With ID – A Challenge Between Human Rights and Scientific Progress

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The WHO defined mental health as a state of well-being in which every individual realizes their own potential, is able to cope with the normal stresses of life, work productively and fruitfully, and make a contribution to their community. This definition makes use of a broad approach to mental health in accordance with the definition of health in general proposed by the WHO. From a more general perspective, the following key barriers need to be overcome: absence of mental health in the public health agenda and lack of implications for funding; current organization of mental health services; lack of integration within primary care; inadequate human resources for mental health care; and lack of public mental health leadership. The topic of mental health in people with ID comprises specific aspects. People with ID bear high risks for behavioural problems, mental disorders, and physical diseases. The individual profile of health-related burdens and risks is often associated with the respective cause of their specific condition. Many of the specific conditions relate to so-called rare diseases or rare disabilities, which are unheeded and underfinanced fields of research and clinical practice. This leads to insufficiencies in healthcare for people with ID. There are many challenges in research, medical services, and care for people with ID in order to promote mental health, and to prevent and fight mental disorders. The Convention on the Rights of Persons with disabilities (CRPD) (WHO, 2006) must be the yardstick for this endeavour.

Exploring Problem Behaviour Exhibited by Children and Young Adults: Prevalence, Risk Markers and Antecedent Events Associated With Its Occurrence

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Problem behaviour is a concern that is addressed in all educational agendas. The presence of these behaviours among children and young adults has an impact on the professionals who attend to the children, and on the quality of life of both the children and their families. Therefore, in order to obtain a better understanding of the nature of problem behaviours and to provide more positive environments for all children, a significant amount of research has been conducted over the last decades. When focusing on children and young adults, it is imperative to know the exact prevalence of problem behaviours, as this knowledge provides information that may be used to define types and numbers of services needed for this population. Moreover, the identification of risk markers as well as antecedent events provides us with information enabling the creation of more preventive and ecological educational settings. The present work is divided into two main parts. The first part examines those studies that have explored the prevalence of problem behaviour exhibited by children with and without disabilities over the last 16 years. Thus, it points out some critical concerns (theoretical and methodological) about how the prevalence of problem behaviour exhibited by children is explored. The second part presents results from two different researches. The first explores risk markers associated with the occurrence of problem behaviour among people with intellectual disabilities and the second focuses on the respective antecedent events (discriminative stimuli and setting events) that are associated with the occurrence of problem behaviour. 1) Exploring the Prevalence of Problem Behaviour: the study of the prevalence of problem behaviours among children has been of particular interest in literature. The prevalence rates of these behaviours among children are highly heterogeneous throughout the different studies (ranging from 2.6% to 62% for children without disabilities and from 7.3% to 100% for children with disabilities). Thus, when conducting this type of study, some theoretical and methodological issues may arise. Theoretically, problem behaviour conceptualization and operationalization may lead to a wide range of prevalence rates (Lowe et al., 2007), as they can be over- or underestimated, depending on the definition of the problem behaviour adopted when assessing it. The identification of problem behaviour may be related to its definition (i.e. form, intensity and frequency) and it also may be subjective depending on respondent's experience with problem behaviour. Methodologically, Koritsas and Iacono (2012) noted in their study on the prevalence of problem behaviours among people (children and adults) with intellectual disabilities that the process studies usually obtain various data across studies. For example, some studies have used validated instruments, others solely a few questions within a questionnaire, etc. Hence, when interpreting the results from these studies, we must consider several aspects such as the type of instruments used, the adopted definition of the behaviour, the specific behaviours assessed, and the procedures implemented to assess problem behaviour prevalence. The sampling methods and procedures that are used to ensure the validity of the respondent's description of problem behaviours in children or adolescents are examples of variables that must be considered for analytic purposes. Therefore, we performed a systematic review (Simó-Pinatella et al., under review) and selected 35 studies for analysis according to their theoretical and methodological characteristics. Results underline the fact that we have to ensure reliable prevalence estimation procedures with the necessity to standardize both sampling and assessment methods (such as assessment criteria, informants, etc.). The reliability of the collected data becomes crucial for leading the decision-making process. Future research must therefore test and delve into contextually tailored procedures to guarantee rigorous assessments of the prevalence rates of problem behaviours. Finally, if the targeted population includes both people with and without disabilities, future research should explore the use of instruments intended for all children and young adults. As a result of the above-mentioned literature review, we present a two-step process that could be used in order to clearly identify problem behaviour in school settings. The instruments used in this research were (a) Challenging Behaviour Prevalence in Educational Settings: School Information which is divided into four parts: (1) demographic school information, (2) demographic student information, (3) contextual setting information related to problem behaviour occurrence, and (4) definitions, examples and counterexamples of the type of behaviours that could be defined as problematic; and (b) the Challenging Behaviour Prevalence in Educational Settings: Individual Information, which explores the following eight categories of problem behaviours: self-injury behaviour, stereotypic behaviour, aggressive/destructive behaviour, disruptive behaviour, withdrawn behaviour, non-collaborative behaviour, sleep problems and eating problems. Moreover, social validity from professionals who took place in this process is presented. 2) Risk Markers and Antecedent Events Associated with the Occurrence of Problem Behaviour: Research has also emphasized that specific factors (for example gender or certain diagnostic conditions such as ASD) are associated with the presence of problem behaviour. However, current studies offer different results regarding the type of variables that may act as risk markers for children with ID. Also, the extent to which a certain variable influences the occurrence of problem behaviour is unclear. It is imperative to keep exploring and analysing the association between personal factors and problem behaviours among people with intellectual disabilities. Consequently, we present results of a study that aims to assess whether certain personal variables, such as type of disability, gender or place of residence, influence the occurrence of certain behaviours as aggression, stereotype, self-injury, disruption, withdrawal, and non-collaboration in educational settings (Simó-Pinatella et al., in press). Results of the study suggest that the type of disability, i.e. visual and motor impairment, autism spectrum disorder, attention deficit and hyperactivity disorder, language and communication disorder as well as place of residence and age were found to predict the presence of CBs among children with intellectual disabilities. Finally, we present preliminary results of a research that aims to identify antecedent events that are especially related to children and young adults with intellectual disabilities attending a special school. **Conclusion**: we need to be precise in the identification of problem behaviour, risk markers and antecedent events. The identification of all these variables will help us to design preventive educational contexts.

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Desinstitution and Inclusion … A Real Misunderstanding?

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In spite of the increasing individualism and of slackening of social links, the collective attitudes, the mentalities and the cultural marks evolved and people with intellectual disability are now able to claim the right for their rights: the common rights and the right to access them, simply the right to live, to be correctly educated and cared off, to work, to dream, to love, to make projects, to travel and even—and it's even better—to sometimes protest against the existence that is proposed to them, also to live with other people.

A genuine public commitment towards people with intellectual disability gradually substituted itself to hospices or asylums till the 50s, thanks to the creation of a strong system of social protection, to the economic development and to the involvement of the stakeholders themselves. In France, this has been also concretized by the huge creation of "traditional" institutions, which means autarkic, uniform and leaving only few expression to the users and their relatives: there was no inclusion at all. In the 80s and 90s, the integration of the structures in their community near environment ("decentred" homes, « jobs outside the walls ») and the exercise by the users of rights of consultation and expression developed in a range of European countries. At this step, it's possible to say it is the social inclusion of structures and their users that is concerned.

From 2000 on, those advances are not only going to legitimize but also to widen the field of inclusion as it was practiced till then: choice of the place of living/residence—with or without support- or personal housing, school inclusion but also partial or shared inclusion between schools and socio-medical structures, encouragement towards a fluidity of the personal project … Today are asked at the same time the claiming of the subjectivity and the equality of rights. Certainly stimulating leads, but also very ambiguous, among others regarding the nature of the link between the person who has specific needs and the answers brought by the community. Inclusion, non-discrimination, equal opportunities became the keywords of the disability policy in France and in Europe. We can only actively subscribe to these orientations, but still it is necessary to get on well with their contents.

- *Does non-discrimination means the renunciation or the erasure of the service provision in institutionalised settings and from specialized services ?* The answer by the affirmative lets foresee a kind of modern reappearance from the village fool which, under the pretext of integration, would be condemned to hang around, to live on its family's back and to survive thanks to the eventual compassion of others. Wouldn't it be a wrong application of the deinstitutionalisation that confuses integration with the lack of institutions? We have unfortunately some illustrations of it on the west coast of the United States, but also in several European regions. Would we let the national obligation of solidarity be substituted by random answers produced just by good feelings? Should we come back, in order to realize eventual budgetary savings, on the controversy from about forty years ago regarding the deinstitutionalisation (mind-opening, rights of the users…) and the "desinstitution" (no specialized structures) which was arbitrated in favour of the first one?
- *Wouldn't a limited approach of normalization be equivalent to a denial of rights?*

If the fundamentally « catch-all » notion of mainstreaming (i.e. the same solutions for all with some arrangements for some) means a society without the positive discrimination conceptualized in particular by John Rawls, and without real specific measures, we could notice without any doubt the inability for some to exercise their common rights and thus a real social abandonment.

The equalization of opportunities, to reach the equality of rights, has undoubtedly to make a space, within diversified and mobile devices and solutions, for structures and specialized services, inevitable elements of the real access to the fundamental rights (education, employment…). The concept of inclusion would find a real content there.

PRE-CONGRESS COURSES

DM-ID-2 Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons With Intellectual Disability

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This preconference is intended to describe the purpose and clinical value of the DM-ID-2, as well as to provide information on four specific diagnostic categories. Dr. Jane McCarthy will address Trauma and Stressor Related Disorders. Dr. Laurie Charlot will discuss Depressive Disorders. Dr. Angela Hassiotis will cover Schizophrenia and Other Related Disorders. Additionally, Dr. Sally-Ann Cooper will discuss the benefits of nosology systems and compare the DM-ID and the ICD.

Reference

Fletcher, R.J., Barnhill, J., & Cooper, S-A. (2016). Diagnostic manual – Intellectual disability (DM-ID-2): A textbook of diagnosis of mental disorders in persons with intellectual disability. Kingston, NY: NADD Press.

Talk 1

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Trauma-and stressor-related disorders include disorders in which exposure to a traumatic or stressful event is listed explicitly as a diagnostic criterion. This is a new chapter within DSM-5. The evidence remains mainly type IV and V evidence with most of the new evidence emerging on Post Traumatic Stress Disorders. The question is will the evidence-based approach of DM-ID 2 for Trauma and Stressor Disorders improve clinical diagnosis.

Reference

Fletcher RJ, Barnhill J, McCarthy J & Styrdom A (2016). From DSM to DM-ID. Journal of Mental Research in Intellectual Disabilities, 9 (3), 189–204. doi:10.1080/19315864.2016.1185324

Talk 2

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Becket Multidisciplinary Consultation Team / Adjunct Professor, East Carolina University

In this presentation, conclusions of the DM-ID 2 depressive disorders chapter group will be summarized and modifications to criteria will be presented. Depression occurs more often in people with ID than individuals without an ID. However, communication challenges, and the need to rely heavily on informant reports render diagnostic assessments of possible depression more difficult in our work with people with ID. Developmental considerations impact the phenomenology of depression in people with ID. Findings of irritable mood, motor restlessness and the co-occurrences of conduct disturbances (externalizing behaviours) reflects a pattern similar to that described in children. The new category of disruptive mood dysregulation disorder (a syndrome that has not yet been studied in individuals with ID) will be reviewed considering how it may be applied to people with IDD.

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Davies, L. E., & Oliver, C. (2014). The purported association between depression, aggression, and self-injury in people with intellectual disability: a critical review of the literature. American journal on intellectual and developmental disabilities, 119(5), 452–471. doi:10.1352/1944-7558-119.5.452

Talk 3

Angela Hassiotis
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Whilst the prevalence of psychosis in people with intellectual disabilities (ID) in 3-5 times higher than in the general population, the diagnosis of psychosis has at times been contentious especially in those with more severe ID and/or other comorbidities such as autism spectrum conditions. The interactive lecture will concentrate on the phenomenology of psychosis in people with ID, the differences when compared with symptoms of other developmental disorders or population groups (e.g. those with borderline intellectual functioning) and the use of DM-ID2 revised criteria in routine care using clinical examples.

Reference

Recognizing Psychosis in Persons with Intellectual Disabilities Who Do Not Use Speech http://www.intellectualdisability.info/diagnosis/articles/recognizing-psychosis-in-persons-with-intellectual-disabilities-who-do-not-use-speech

Talk 4

Sally-Ann Cooper
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Learning Disabilities, Institute of Health and Wellbeing, University of Glasgow, UK

There are many benefits of operationalised classification of mental ill-health in improving and standardising diagnostic practice. This presentation will consider the importance of DM-ID2, its relationship to ICD, will draw upon original research data to inform classification (Melville et al, 2016), and consider the issue of problem behaviours in DM-ID2.

Reference

Melville, C., McConnachie, A., Johnson, P., Purves, D., Smiley, E. Simpson, N., Cooper, S-A. (2016) Problem behaviors and symptom dimensions of psychiatric disorders in adults with intellectual disabilities: an exploratory and confirmatory factor analysis. Research in Developmental Disabilities, 55, 1–13. doi:10.1016/j.ridd.2016.03.007

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The Socio-Emotional Development (SEO) in Diagnosis and Therapy of Adults With Intellectual Disabilities

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Theme: In his SEO model, Anton Došen describes five stages of emotional development in ten domains with a focus on children. This model was adapted to facilitate the provision of individualized support for adults with intellectual disabilities (ID) based on a differentiated profile of their socio-emotional needs. Caregivers who are unaware that socio-emotional development can vary across domains may overlook significant socio-emotional needs and overwhelm clients with demands they are not equipped to handle. This can lead to maladaptive behaviour or serious psychiatric disorders. The workshop aims to enable participants to better identify and meet their clients' individual needs according to differentiated profiles of socio-emotional development drawn up using versions of SEO adapted for adults with ID. **Methods**: The model of emotional development (SEO) originally set out by Anton Došen (1990)1 and expanded on by Leen Claes et al. (2012)2 was further modified and condensed to facilitate the assessment of socio-emotional development in adults with ID in daily practice by Brian F. Barrett et al. (2015) and Barrett and Kolb (2013) 3,4 and Tanja Sappok et al. (2016) 5. Workshop participants will be introduced to these adapted versions of SEO by assessing socio-emotional development of adults with ID based on behaviour demonstrated in video footage. Further on it will be shown how the results of this structured approach can be used to adapt settings to clients' needs and therefore reduce maladaptive behaviour in adults with ID. Finally, participants will be encouraged to discuss the instruments' potential benefits and limitations as well as possible challenges in practical application.

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Claes, L., Declercq, K., De Neve, L., Jonckheere, B., Marrecau, J., Morisse, F., … Vangansbeke, T., (Red.). (2012). *Emotionele ontwikkeling bij mensen met een verstandelijke beperking*. Antwerpen-Appeldoorn: Garant.
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Update on Psychopharmacology for Persons With Intellectual Disability And/Or Low Functioning Autism Spectrum Disorder

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The diagnoses of intellectual disability (ID) and/or autism spectrum disorder (ASD) include a wide range of lifelong neurobiological conditions with different aetiologies, clinical features, and co-occurring mental health problems. This implies a proportionate differentiation of psychotherapeutic treatments. In persons with ID and ASD psychopharmacological treatment exceeds that in the general population. Disability severity, race/ethnicity, marital status, head of household education, urbanicity, and private insurance type seem to be significant predictors of polypharmacy. Psychopharmacotherapy is frequently employed to manage problem behaviours before they have been considered to be symptom equivalents of co-occurring mental health problems. In fact, in most cases prescriptions are not supported by precise and appropriate psychiatric diagnoses. The most commonly prescribed psychoactive drugs are antipsychotics (AP), followed by antidepressants, antiepileptic/mood stabilizers and stimulants. Evidence on efficacy, dosage and safety is scarce and derived mostly from naturalistic studies or case reports, with a main focus on identification of side effects and discontinuation rate. Placebo-controlled or active-controlled studies are limited, with small sample size. After some authoritative researchers found no statistical difference of efficacy on problem behaviours between placebo and most antipsychotics, the convenience of the use of this class of drugs in persons with IDD has always been questioned, even for other purposes. In fact the risk of side effects does not seem to be negligible. Traditional AP have been repeatedly associated with extrapyramidal symptoms, cognitive deterioration, and sedation, while for new generation AP special attention was raised by weight gain, dyslipidaemia, hyperglycaemia, and QTc prolongation. Evidence on very new generation AP is lacking, but clinical experience and preliminary studies indicate good safety and efficacy on some symptomatological dimensions, probably linked to a receptor binding profile which is really suitable with the characteristics of these special populations. Antidepressants may be poorly tolerated, induce counter polar switch, and be ineffective in reducing repetitive/stereotypic behaviours. In recent trials, new agents, such as glutamatergic compounds showed some efficacy on specific symptoms and in specific genetic syndromes. Methylphenidate and α-agonists are increasing being considered for counteracting the additional features of hyperactivity and short attention span. Lithium might be effective in reducing aggression. Evidence is limited to support the use of antiepileptic drugs, anxiolytics, and naltrexone for management of problem behaviours. Results from oxytocin trials on social behaviours are inconclusive albeit promising. Melatonin appears to improve sleep-wake rhythm. Trials of dietary supplements show controversial results. The complex variability of problem behaviours, interpretation and prescription rationale indicates that pharmacotherapy for persons with IDD or ASD should be part of an integrated multidisciplinary intervention. It should be considered for severe challenging behaviour after other non-pharmacological interventions have failed. Drugs should be used at the lowest possible dose and for the minimum duration, in combination with non-medication-based management strategies. Treatment outcome measures are heterogeneous, efficacy (on target symptoms) and safety are the most common, while patient-oriented measures, like quality of life, seem to offer the more comprehensive and useful perspective.

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Psychotherapeutic Approaches to the Support and Care of People With Intellectual Disabilities and Their Families

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"It isn't just about therapy—knowledge of psychotherapeutic models can be applied usefully to all aspects of care, treatment, service delivery and development". Psychotherapeutic work is most frequently viewed as a process that goes on between a therapist and a client. Indeed much of the literature tends to focus on this (Beail, 2016; Fletcher, 2011). However, this can mask the usefulness of the psychotherapeutic models in the wider care system. In this workshop we would like to explore the role of therapeutic models in all aspect of care and support from the individual to the wider system. We invite participants to consider how such thinking applies to them in their day to day work, their interactions with others and their interface with the system in which they work. We will explore how incorporating such thinking may allow new perspectives on the origins of identified problems and their potential solutions and also how helpful it may be to understand the responses and functioning of families, carers and the wider "systems". The workshop will also consider the impact of recent developments in psychotherapeutic work such as trauma informed work, disability psychotherapy (Frankish, 2016), positive behaviour support (Gore et al, 2013) and attachment theory (British Psychological Society, 2017).

The workshop will consist of brief presentations, group discussions and some case based exercises. Participants will be encouraged to bring examples and /or dilemmas from their own practice.

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Dementia in Persons With Intellectual Disability

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Goal: Demographic change poses new challenges for the facilities of integration aid. As people with intellectual disability (ID) are getting older, more are affected by dementia. Early detection and diagnosis of dementia is becoming increasingly important for persons with ID, since they are more likely to develop dementia and are affected earlier than the general population. This is especially true for people with trisomy 21 (Kuske, Gövert, Wolff, & Müller, 2016a). As symptoms of dementia are often hard to detect due to the pre-existing disability, diagnosis of dementia is difficult and time-consuming (Kuske, Gövert, Wolff, & Müller, 2016b). There is professional consensus that dementia diagnosis in persons with ID should consist of a proxy inquiry and a neuropsychological test. It should be designed as a baseline and follow-up assessment (Kuske et al., 2016b). An overview of internationally available diagnostic tools (Zeilinger, Stiehl, & Weber, 2013) is given and some of them, such as the NTG Early Detection Screen for Dementia (NTG-EDSD) (Zeilinger, Gärtner, Janicki, Esralew, & Weber, 2016) and the Wolfenbüttler Dementia Test for Individuals with Intellectual Disabilities (Wolfenbütteler Demenztest für Menschen mit Intelligenzminderung—WDTIM), are introduced in detail. Living facilities for persons with ID must adapt to changes in the daily routine of their elderly inhabitants. Some may have dementia and a growing need for rest, some retire from their work or have changed leisure needs. Living environment and day structure should be adapted to current needs to ensure a high quality of life and independence in old age for as long as possible. Options for designing and changing living space by means of colour or light concepts as well as options for daily routine adaptations are presented. Necessary adjustments of day structure are explained (Watchman, Kerr, & Wilkinson, 2010). Dementia often leads to reduction of personal drive and social withdrawal. Therefore, persons with ID should be supported in maintaining their active participation in community life. One option for cultural participation is represented by our model project "Creative Storytelling". Another best-practice example is "wake-up words", which is about reciting poems (Müller & Focke, 2015). It was developed based on the time slips method by cultural anthropologist Anne Basting. "Creative Storytelling" has been designed for people with dementia without ID. The core element is that a group of persons looks at a picture and develops a story based on free associations. This should encourage the participants to communicate, to think up stories, and have a group experience. Using this method with a group of people with ID is reported as a best-practice example (Müller, Aust, & Engelin, 2017). **Methods**: Frontal input, discussion, small group work, short films.

References

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Assessing Emotional Development & Emotional Needs

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With estimates ranging from 30 to 60%, the prevalence of mental disorders and/or challenging behaviours is high in individuals with intellectual disability (ID). In order to better understand and deal with challenging behaviour, Anton Došen (1990) evolved a model based on normal development in infants and children according to which emotional competencies are acquired in a progressive sequence of qualitative changes incorporating emotional as well as social, sensorimotor and cognitive functions. This "developmental-dynamic approach" focuses on providing insight into the underlying basic emotional needs and motivations as a basis for better understanding and addressing the respective behaviour. The level of development in cognition and emotion may differ in individuals with ID. These differences may result in severe challenging behaviours (Sappok et al., The missing link, 2014). Assessing the level of ED can help caregivers better understand clients' behaviour by providing insight into their inner experience (Došen & De Groef, 2015). Meanwhile, different instruments exist to assess the level of ED, e. g. the *The Scale of Emotional Development—Short* (SED-S; Sappok et al. 2016) and the *Schaal voor Emotionele Ontwikkeling van mensen met een verstandelijke beperking—Revised*^{2} (SED-R^2; Morisse & Došen. 2016). Assessing the level of ED is crucial for a person-focused approach to understanding and dealing with challenging behavior. Adapting the environment and attuning sensitive caregivers to clients' basic emotional needs may reduce challenging behaviour and support clinicians to discontinue psychotropic medication for certain symptoms with questionable and limited effects. In this workshop, first Anton Došen will introduce the ED approach including basic needs and motivations. Next, Tanja Sappok and Filip Morisse will present the SED-S and the SED-R^2 as two complementary assessment instruments. Finally, Leen De Neve will bridge from assessment to support and line out the implications for treatment and support. A case study will be prepared and presented. The participants are invited to practice by applying the SED-S in small groups followed by a discussion of the case in the whole group. In a final step, the small groups develop implications of the level of ED for the treatment and support of the client which will be presented and discussed in the whole group afterwards.

Aims:

(1) Introduction of the emotional developmental approach and the associated emotional needs.
(2) Presentation of assessment instruments (SED-S and SED-R^2) for ED.
(3) Treatment and support based on the ED approach.
(4) From assessment to support: training of participants based on a case study.

Methods:

(1) Short presentations by the speakers to introduce the model and instrument.
(2) Exercises (case study) in small groups.
(3) Round table discussion.

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Coaching for Front-Line Staff Supporting People With ID and Challenging Behaviours

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Theme and aims: Today, research and clinical practice recognize the positive impact of high-quality relationships between staff and people with intellectual disabilities on their well-being (Hermsen, Embregts, Hendriks, & Frielink, 2014). The psychological need of relatedness and its relationship with well-being is considered universal and thus also counts for people with intellectual disabilities and challenging behaviours. Daily interactions between frontline staff and clients form the basis for the quality of this relation. Many different variables, such as client (challenging) behaviour and disorders, and staff knowledge, attitudes, and stress levels appear to impact interactions between frontline staff and people with intellectual disabilities. The perception of staff and people with intellectual disabilities on these interactions may be different and also impact the way in which they conceive and subsequently act on each other. For example, a staff member with insufficient knowledge about the development of challenging behaviours and fear for the occurrence of these behaviours, will keep clients with challenging behaviours ′at a distance′ if he/she feels uncomfortable and might even doubt if building a positive relationship is possible. As such, client and support staff variables might be a barrier in building positive relationships and are, therefore, an important starting point for staff training. In our pre-course we will focus on new ways of staff training by improving staff awareness of their own perspective, the perspective of the client and subsequent action and quality of staff-client relationships.

Methods:

(1) The present pre-course starts with an introduction about the history of staff-training research and the need for finding new elements to improve staff training in the field of intellectual disabilities to build positive relationships. Also we introduce the collaboration from our academic collaborative centre (Tranzo, Tilburg University) with health care and

educational organizations and our methods to implement new ways of staff training in existing programs and daily practices.

(2) In the second part we will demonstrate and exercise with instruments to improve our insight in personal characteristics that might influence interactions and relationships (van Oorsouw, Embregts, Bosman, & Jahoda, 2014; Zijlmans, Embregts, Gerits, Bosman, & Derks, 2015). Most of the instruments we use, are developed at our academic collaborative centre and among others focus on staff emotional reactions and staff psychological resources.

(3) In the third part, we will demonstrate that both frontline staff and client characteristics will influence interactions and relationships. We use interviews and video clips of individuals with intellectual disabilities and challenging behaviours. We practice with recording the behaviour and characteristics of the client and relate these results with our own reactions, attributions and personal styles.

(4) Summary and discussion.

In this pre course we will give the state of the art knowledge regarding coaching of frontline staff supporting people with intellectual disabilities and challenging behaviours. We will extensively demonstrate and exercise with materials from research and clinical practice. Because of the complex nature of the interactions between clients with challenging behaviours and frontline staff we schedule time for discussion and reflection on own experiences.

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Reducing Restraints and Restrictive Behaviour Management Practices

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The theme of this workshop is safe and effective reduction of restraint both for individuals and organizations. This workshop will review the definitions of restraint in everyday life and in treatment settings and will then identify acceptable and unacceptable forms of restraint and ethics of restraint use. The workshop will then review prevalence, risk factors and safety data for restraint. It will then review evidence for the functions of restraint for the person restrained and the person restraining. The workshop will then review evidence for safe restraint reduction for individuals. This will include: (a) functional behavioural assessment and analysis, function based and non-function-based interventions for the challenging behaviour that occasion the use of restraint, (b) restraint-specific interventions, such as use of restraint as a positive reinforcer, restraint fading methods and rapid restraint analysis; and (c) non-behavioural interventions including mindfulness. The workshop will then review data on organization-wide restraint reduction dating back to the nineteenth century and including contemporary community services. Common elements include accurate measurement, goal setting, feedback and staff training. The workshop will conclude with recommendations for practitioners and inappropriate, ineffective and harmful forms of practice. The presentation will primarily be lecture format and case discussion.

Lifestyle and Integration of Vulnerable Groups: The Challenge of Partnership and the Transmission of Knowledge

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Although the previous French laws were referring to their administrations to define handicap, the “Law from February 11th, 2005[1] ” is finally trying to provide a definition for the first time[2]. By distinguishing the notions of “psychic functions”, “mental functions” and “cognitive functions”, it officially recognizes “psychic functions” in disabilities. Thus, it legitimizes the use of the notion of “psychic disability” (disabled by chronic mental health problems), already used by those who are halting the confusion between “psychic disability” and “intellectual disability”. This law also proposes another point of view: to consider the handicap as a consequence of health problems in a given environment. This perspective is based on a social model of the handicap, moving away from a medical and individual model, which perceived the handicap as the consequence of the subject’s deficit or inability, expecting them to adapt. I met Zoesch[3] for the first time in 2015, in the context of my activity as psychologist at CMP[4]. This 20-year-old person suffering from a borderline personality disorder and a long history with IME[5] turns out to be a border case between psychic disability and intellectual disability. The effort made to lead him to recovery and social and professional reintegration allows us to gain insight into several essential aspects of support. We will study the functional impact of the psychiatric disease on the suffering person and the various factors to be taken into account to help reintegration. Far from a linear logic, it will be a question of demonstrating the reversibility existing between disease, deficiencies, disabilities and social disadvantages. Zoesch’s situation, mobilizing about ten institutions and services around him, will allow me to illustrate the work on partnership and network. Partnership, generalized in the social area, but also in the sanitary sector through decentralization laws, is nowadays an indispensable principle of action. Although it is essential in the global consideration of the subject and a potential key to success, as we will observe in the case of Zoesch, its implementation can sometimes be complicated. We will outline the conditions for beneficial work, but also their limitations. Finally, I will talk about my experience within an ESAT[6], being specialized in psychic disability, combining work, accommodation and therapy under one roof. This establishment, very different from the CMP, mainly relies on its own ways and resources to reintegrate people in situations of disability. We will show how a common direction helps the articulation and the necessary coherence for the psychic restoration of the subject, but also the possible disadvantages of such a device.

Notes

1. Law nr. 2005-102 from February 11th, 2005 for the equality of rights and chances, the participation and the citizenship of disabled people.
2. "In the sense of the present law, a handicap is defined as any limitation of activity or restriction of participation in the society life within the environment of a person because of a substantial, long-lasting or definitive alteration of one or several physical, sensorial, mental, cognitive or psychic functions, resulting from a polyhandicap or a invalidating health troubles"—Law nr. 2005-102 from February 11th, 2005 for the equality of rights and chances, the participation and the citizenship of disabled people.
3. Name changed.
4. CMP: Centre Médico Psychologique—Hospital department of adult psychiatry intended for tpatients' ambulatory follow-up suffering from psychiatric troubles.
5. IME: Institut Médico Educatif—French welcome establishments for children and teenagers suffering from mental disability with intellectual deficiency.
6. ESAT: Etablissement et Service d'Aide par le Travail—Medical and social establishment of protected workplaces in France, reserved/only for disabled people and aiming at their social and professional integration or reintegration. Former name: CAT (centre d'aide par le travail).

The Institutional Journey: A Psychoanalytical Point of View with Two Voices

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Talk 1: "Looking for the Lost Institution or: From the Breast to the Care and From the Care to the Breast". From an anthropo-psychoanalytical point of view, we shall see that the first social institution encountered by any human being is the maternal breast. First, we'll tackle the different kinds of breasts (physiological-maternal, erotic-feminine, narcissist, oral, anal, phallic, etc.). Secondly, we'll expose the appearances of transitioning from hordes to society and the basic things that constitute an institution. Finally, we want to show some "traces" of breasts in our specialized services.

Talk 2: "Prediction Wish: Journeys and Surprises in a Medico-Social Centre". We shall follow the journey of babies, from neonatology to a centre for 0 to 6 years old children and, of course, also that of their mothers and fathers, accompanied by a psychoanalyst. Listening to these persons, we'll see how nothing can be planned in the sense of their destiny. Unexpected moments show that the child being called deficient, stupid, defective, retarded, etc. can be different.

ASD and Challenging Behaviours – Causes and Practical Implications

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The prevalence of challenging behaviours (CB) is significantly higher in people with intellectual developmental disability (IDD) and autism spectrum disorder (ASD) compared to those with IDD only (McCarthy et al., 2010). Autism-specific causes as well as causes related to IDD often take effect simultaneously. This multicausality contributes to different forms of challenging behaviour. Severe behavioural problems like aggression and self-injury may lead to hospital admission, insufficient educational and medical strategies as well as limited social involvement and participation. Addressing the special needs of persons on the autism spectrum who present behaviours causing concern requires a good understanding of the underlying causes as well as approaches and ideas for practical use.

This workshop is aimed at different professions in the field and has three objectives:

1) Introduction and definitions in the field of autism spectrum and CB including affect regulation in early emotional development.

2) Discussion of multiple and correlated causes like genetics, sensory issues, systemic causality, and communication problems.

3) Presentation of practical implications demonstrated in the example of sensory-bodily interventions, the TEACCH approach (Mesibov, Shea, & Schopler, 2004), the Autism Competence group training (AutCom; Bergmann, Herberger, Birkner, & Sappok, 2016), and de-escalation strategies based on the low arousal approach (Studio 3; McDonnell, 2011).

Methods will be lectures as well as video-based exercises and group exercises, and we hope for lively and fruitful discussions. Own case material is welcome. Even if no ultimate solution will be found, we hope to inspire the participants in handling CB and to impart a multi-dimensional understanding providing more flexibility.

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AGEING AND LIFE-SPAN

INDIVIDUAL PAPERS

Exploring the Experiences of Dementia in People With an Intellectual Disability

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KEYWORDS Dementia; empowerment; services; support

Aim: In recent years, the life expectancy of people with an intellectual disability (PWID) has sharply risen, leading to an increase in dementia. Dementia has serious consequences for the individuals and those around them. Only a small body of research has explored the experiences of dementia from the perspective of PWID and their carers (Lloyd, Kalsy, & Gatherer, 2007; Watchman, 2014). This presentation introduces this area of research, and discusses a PhD study which explored the experiences of PWID and dementia, as well as their carers. **Method**: Semi-structured interviews were conducted across four participant groups: PWID and dementia, family carers, paid carers, and healthcare professionals. At key stages of designing this research, opportunities were taken to collaborate with PWID with experience of dementia, to make it more inclusive. Data was analysed through Constructivist Grounded Theory. **Results**: The challenges of conducting research with a hardly accessible population will be discussed, alongside results across all four participant groups. The role of loss across the participants' experiences will also be discussed, before highlighting how participants attempt to cope with dementia through a continuum of support. The role of NHS services will be illuminated, with focus on a local NHS dementia care pathway for PWID. **Conclusion**: This study will contribute knowledge to a small field of research, and raise awareness of the benefits and challenges of inclusivity within research, and the methods used to apply this throughout.

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Early Signs of Dementia in Down Syndrome Based on a 15-Year Follow-Up

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KEYWORDS ageing assessment

Background: Alzheimer’s disease is the most common cause of death in advanced adulthood in people who have Down syndrome. This prospective, population-based, 15-year follow-up study aimed to define the onset age of dementia. **Method**: At baseline 98 adults were screened for the first time by using the Present Psychiatric State—Learning Disabilities assessment. Since then, these screenings were repeated twice. **Results**: The dementia indicating signs increased rapidly after the age of 35 and appeared most frequently as reduced self-care skills, loss of energy, forgetfulness, and impaired understanding. **Conclusion**: Regular follow-up of people who have Down syndrome from the age of 30 onward enables appropriate interventions to delay the progression of dementia.

Transition to Adulthood Has Negative Consequences for Mental Health in Individuals With Intellectual Disabilities: Results From Qualitative Interviews and Secondary Analyses of Existing Data

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KEYWORDS Challenging behaviour; life events; life span; stress; wellbeing

Aims: Transition to adulthood may be a difficult time for individuals with intellectual disabilities. The literature documents negative outcomes across vocational and social domains in this population, but little is known about mental health in individuals with intellectual disabilities during this period. **Methods**: Semi-structured interviews were conducted with individuals with intellectual disabilities between the ages of 16 and 27 years, and their parents or caregivers. Interviews were transcribed and analysed thematically. In addition, analysis of Scotland’s Census (2011) was conducted. Mental health in the populations with and without intellectual disabilities aged 13–24 years was compared, and mental health in the population with intellectual disabilities aged 13–18 years (pre-transition) and 19–24 years (post-transition) were compared. **Results**: Almost all of the parents interviewed reported their son or daughter with intellectual disabilities experiencing increased mental health difficulties–particularly anxiety–during the transition period. Those with intellectual disabilities, however, were less consistent in their reports of mental health difficulties. Analysis of Scotland's Census (2011) revealed that individuals with intellectual disabilities were more likely to experience mental health conditions than those without intellectual disabilities. Individuals with intellectual disabilities aged 19–24 years were more likely to report the presence of a mental health issue than those aged 13–18 years, suggesting a negative effect of transition from school on mental health. **Conclusions**: Transition to adulthood is a period of particular mental health vulnerability for this population. Improved mental health support during this period is essential.

Ageing in Williams Syndrome: Longitudinal Trajectories of Neuropsychological Functioning in Adults

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KEYWORDS Life span

Background: Research on ageing and trajectories of cognitive functioning in adults with Williams syndrome is limited. In two longitudinal studies described so far in the literature (Howlin, Elison, Udwin, & Stinton, 2010; Fisher, Lense, & Dykens, 2016) the cognitive functioning has been found to remain stable. In both of those studies the participants were relatively young (< 50 years) and follow-up period was relatively short (about 2–12 years) compared to our study where the individuals were followed for 17–20 years with the oldest participant being 86 years old during the last assessment. **Method**: Neuropsychological functioning of 21 individuals (7 males, 13 female) with WS was examined. The mean age of the participants was 33.11 years (SD = 11.88) and 55.35 years (SD = 13.4) in the first and second assessment, respectively. The cognitive and neuropsychological functioning was assessed using the same individually chosen tests (WAIS-R, LIPS, Merrill-Palmer, Nepsy) in both times. **Results and conclusions**: The preliminary results will be presented and discussed in the light of earlier observations.

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The Early Presentation of Dementia in People With Down Syndrome: A Simple Screening Protocol for the Assessment of Dementia in A Sample of the Italian Population

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KEYWORDS Dementia

Aims: Adults with Down syndrome are at a high risk of developing an early onset of Alzheimer's disease. It is important to clinically assess the prodromal symptoms to help early detection of the disease and provide specific treatment (Lautarescu, Holland, & Zaman, 2017). The objective is to propose a specific easy and rapid procedure for the screening of dementia in such population. **Methods**: The Adaptive Behaviour Dementia Questionnaire (ABDQ) (Prasher, Farooq, & Holder, 2004) and the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) (Deb, Hare, Prior, & Bhaumik, 2007) together with the Psychiatric Instrument for the Intellectually Disabled Adult (SPAID) (Bertelli et al., 2012) have been identified because of their realibility and validity. The intraclass correlation for test-retest of the DSQIID in particular is 0.95 with a significance of $P < 0.01$. We also conducted clinical, cognitive and cardiological assessment together with medical reports analysis and neuroimaging assessment when indicated. **Results**: Short memory dysfunction and behavioral symptoms resulted to be the more common indicators associated with the onset of Alzheimer disease, in adults with Down Syndrome. **Conclusions**: Early diagnosis is fundamental in order to display early pharmacological and psychosocial interventions.

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Psychomotor Ageing of People With Intellectual Disability

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KEYWORDS Ageing assessment

Over the past 40 years, the elderly Portuguese population doubled, corresponding to 16.7% of the total population. It is expected that this ratio will increase in near future. Similarly, ageing in individuals with intellectual and developmental disability (IDD) has increased with significant repercussions for facilities, families and caregivers. Services are still not prepared for this “new population group”. Within interventions and support provision for this new population, the lack of targeted and adequate resources is evident together with reduced knowledge of psychomotor competences during the ageing process. It is essential to know the ageing process of people with IDD in order to respond to new needs and emerging challenges arising therefrom. Therefore, this study aims to evaluate and compare the psychomotor profile of 118 participants between the age of 45 and 94 years (67.68 ± 13.09) with typical ageing (n = 39), Alzheimer’s disease (n = 41), and with IDD (n = 38). All participants were evaluated with the Portuguese version of Éxamen Geronto-Psychomoteur. Findings showed, as expected, that both groups with IDD and Alzheimer Dementia showed significant differences at most psychomotor domains when compared to their peers with typical aging. Participants with ID had more positive results in physical domains whereas participants with Alzheimer Dementia presented better performances in cognitive domains. Implications for practice and research are addressed.

The Identity-Building Process of People With Intellectual Disability Throughout the Stages of Life

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KEYWORDS life span

Aims: Throughout the stages of life, in each one, the identity-building process is marked by relationships and building links with others. Through changes in identifications and differentiations, through a complex game of belonging to an assigned or idealized social group, through processes of filiation and affiliation, and processes of social recognition, every one is creating their identity as a son or a daugther, as a brother or a sister, a friend, a spouse, a mother or a father, as a colleague, etc. Because of intellectual disability, several factors take part in the identity-building process. This construction is also influenced by the way the society views and treats the disabled person. **Method**: This presentation suggests some reflections about identity construction of people with intellectual disability throughout the different stages of life. Support and obstacles in this process will be introduced and examined taking into account results of clinical practices, support activities, and research in clinical psychology. Four stages of life will be treated: childhood, teenage years, adulthood and parenthood. **Results**: The self-building as subject with a “disability” is connected to many factors including the view of others. Bonds with siblings and extra-familial links are absolutely necessary for this construction. These relations evolve with the stages of life. **Conclusions**: Conducted research and our clinical practice emphasize the importance to take into account the personal experience of the subject with intellectual disability.

What Indicates and Determines Quality of Life for Elderly People With Intellectual Disabilities?

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KEYWORDS quality of life; support; ageing

Aims: The life expectancy of persons with intellectual disabilities (ID) has significantly increased over the past decades and so has the importance to secure their quality of (later) life. This study aimed to identify indicators of quality of life (QoL) in elderly people with ID as well as influencing factors. **Methods**: Five separate focus groups discussed QoL: one group of elderly people with mild ID, aged 61–88 years (n = 9); two expert groups (n = 17); two groups of family and staff from elderly-, ID- and home care (n = 14). We asked the elderly what indicates good QoL, and the supporters and experts what factors influence QoL outcomes. We thematically analyzed the results. **Results**: The elderly people presented material, physical, relational, emotional and existential issues as QoL indicators. All groups found age, (changes in) abilities, dementia, life events, personality, and having (lost) family to be relevant characteristics. Crucial support factors included a long lasting key worker having time, affordable transport to preferred activities, staff attitude and education, adapted environments, additional support in dealing with losses, and dementia- or end-of-life care. Important macro- and meso-factors include vision development, policy focus, sufficient funding, and co-operation between all sectors involved.

The German Aging and Disability Study (GADS): Setup and 5-Year Follow-Up

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KEYWORDS ageing assessment

Aims: Aging in intellectual disability is a widely unexplored field of research. Due to the fact that no prospective study in this field is available, we created a design for a long-term follow-up study to gain concrete data. **Method**: In a prospective 10-year study, three different types of disabilities are compared, also with a group of non-disabled persons. A total of 464 participants was recruited inn sheltered homes/residences specialized in different types of disability (mental retardation, chronic schizophrenia, addiction), and the control group consisted of 128 persons. The minimum age was 50 years. Besides the recording of extensive socio-demographic data, every participant is rated with four different psychometric tools, namely the Nurses Observation Scale for Geriatric Patients (NOSGER), the Pflegeabhängigkeitsskala (Care Dependencey Scale, PAS), the Nürnberger Altersbeobachtungsbogen (Nuremberg Observation Scale for Elderly People, NAB) and the WHO (Five) Well-Being Scale. These ratings will be

performed twice a year for about 10 years. Also, data regarding health status, such as newly occurred diseases, hospital stays, changes in medication, etc., will be recorded. **Results**: All disability groups showed poorer psychometric performance than the control group, but the scores for the ID-group were even worse; the increase of decline in psychometrics was more pronounced. Also, conditions related to physical health (obesity, heart disease, hypertension, diabetes, etc.) where more prominent. The level of psychosocial functioning was less distinct. Medical care was less intensive. **Conclusion**: Due to poorer performance in health-related subjects and the (at this time of the study) impression of faster aging, more attention has to be paid to physical and psychosocial health-related factors.

POSTERS

Effects of Aquatic Motor Training on Balance, Gait and Fall Risk Among Older Adults With Intellectual Disabilities

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KEYWORDS Intervention; quality of life; rehabilitation; therapies

Aim: The aim of this study was to examine the effects of aquatic motor interventions as compared to on-land motor interventions on balance, gait and fall risk among older adults with intellectual disabilities (ID). **Method**: Forty-one older adults (age 50–66) with mild to moderate ID were randomly allocated to either aquatic motor intervention (Ai Chi) or identical on-land motor intervention (Tai Chi), twice per week for a period of 14 weeks. Balance, gait and fall risk were assessed using the Tinetti Assessment Tool before the intervention, after 7 weeks of intervention and after 14 weeks of intervention. **Results**: After 7 weeks of intervention, the Ai Chi group showed significant improvement in fall risk ($Z = -2.14$, $p < 0.05$). After 14 weeks of intervention, both groups showed significant improvements in fall risk (Ai Chi $Z = -2.68$, $p < 0.01$; Tai Chi $Z = -2.42$, $p < 0.05$) and in gait (Ai Chi $Z = -2.26$, $p < 0.05$; Tai Chi $Z = -2.23$, $p < 0.05$). In addition, the improved gait score was negatively correlated with the gait score before the intervention ($r = -0.62$, $p < 0.01$). **Conclusions**: Tai Chi and particularly Ai Chi can potentially improve gait and reduce fall risk in older adults with ID. The lower the gait ability before the intervention, the greater the degree of improvement assessed after the intervention.

Dementia in Adults With Down Syndrome: Prevalence, Causes and Assessment – A Clinical Approach

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KEYWORDS challenging behaviour; dementia; diagnosis; psychiatric disorders

Aims: The aim of this study was the assessment of prevalence and causes of dementia in a clinical sample of adults with Down syndrome and mental disorder or severe challenging behaviors. **Methods**: Retrospective analysis of diagnoses of dementia and characteristics of patients with Down syndrome (N = 75) treated in a psychiatric hospital from 2005 to 2012. **Results**: In every third patient with Down syndrome, dementia was diagnosed. Patients with dementia were older and more often female, while no association was found with the level of intellectual developmental disorder. Thyroid function and calcium values were often abnormal in both those with and without dementia. Conclusions: In persons with Down syndrome, dementia is a prevalent cause for problem behaviors and admission to psychiatry, especially in older and female individuals. Among others, assessment of thyroid function and calcium is pivotal. Dementia should be routinely considered in assessment of problem behaviors of people with Down syndrome. A best practice approach for the assessment of dementia in patients with DS will be presented.

Stress and Burden of Staff Working With People With an Intellectual Disability and Dementia

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KEYWORDS dementia; staff; stress

Aim: Due to the increasing number of residents in facilities for people with an intellectual disability (ID) suffering from dementia, staff is faced with diverse new challenges during their daily work. Despite the well-known difficulties, very little attention has been paid to the impacts of this situation on staff. The aim of this study is to identify the psychological stress and burden of staff working in living groups for people with ID and dementia. **Methods**: A questionnaire survey was conducted. The study sample consisted of 31 staff members of three residential groups for people with ID with a high proportion of residents with dementia suspicion or an actual diagnosis. The German employee questionnaires–psychological stress and burden for stationary living areas for people with an ID (BGW-miab)–were used to assess the psychological stress and burden of staff. Data were analyzed using statistical analyses. **Results**: Results demonstrated high values for the dimensions of qualitative and quantitative work burden, social working environment, and work organization. The study sample was much more burdened than the setting reference group. **Conclusions**: Facility staff caring for people with an ID and dementia is faced with many new challenges. Staff members of this study experienced high

stress in different dimensions which could pose a health risk in the long term. There is a great need for measures to support staff members as well as further research.

"Creative Storytelling" - Activating Communication Skills of People With an Intellectual Disability and Dementia

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KEYWORDS Dementia; life events

Aims: In Germany, adequate interventions for people with an intellectual disability (ID) and dementia are missing although this group is constantly growing. Creative storytelling is an intervention for activating communication skills of people with dementia. The aim of this project was to improve cultural participation of people with an ID and dementia. For this reason we investigate if storytelling could be a suitable method for people with an ID. **Method**: The intervention was conducted weekly in two groups in two different facilities for people with ID over a period of 6 weeks (group 1: 4 participants; group 2: 12 participants). Participants were 6 residents with a dementia suspicion or diagnosis. Observations and experiences were collected and reflected. **Results**: First experiences showed that creative storytelling was well practicable with people with an ID and dementia. The method was well received by the participants. An increasing confidence as well as an activation of passive participants could be observed. Nevertheless, some adaptions for this special group of people were necessary, especially concerning the questioning technique as well as the group size. Conclusion: Creative storytelling is a suitable kind of leisure activity and method for the activation of people with ID and dementia. We recommend the use of more concrete questions instead of open questions. A group size of maximum 8 participants seems to be adequate. We would like to encourage others to try this approach of cultural participation (Müller & Aust 2017; Müller, Aust, & Engelin, 2017).

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Interventions for Accompanying and Supporting People With Intellectual Disabilities and Dementia – First Results of Expert Interviews

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KEYWORDS Dementia; prevention; quality of life; rehabilitation

Objective: Broad dementia-sensitive interventions were conducted in two residential facilities of the disability aid. The objective was to improve the quality of life of people with an intellectual disability (ID) and dementia. Interventions consisted of dementia-sensitive and environmental configurations, further trainings and assistance for the staff members. The main objective of this project was to evaluate the effects of the interventions. **Methods**: The dementia-sensitive interventions were evaluated using a pre-post design. Ten staff members were interviewed by experts at baseline and after 1 year. The interviews consisted of seven main topics. Analyses were conducted in dependence on the qualitative content analysis by Mayring. **Results**: The results of the expert interviews showed that staff members responded to the residents in a more reflective and individual way, especially regarding a more individual organisation of daily life and support. The communication within the team and their performance improved, which had a positive impact on residents as well as the case conferences of individual residents. The behaviour and daily activities of the residents did not change according to the interviewees. **Conclusion**: People with ID and dementia have a different care demand. Hence, dementia-sensitive configurations of the environment are needed. The results show that the interventions had a positive impact on the daily work of staff members, but no effects were observed in the residents.

ASSESSMENT, DIAGNOSIS, AND CLASSIFICATION

SYMPOSIA

Symposium: Disorders of Intellectual Disabilities and the ICD-11

Name of chair: Sherva Cooray
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KEYWORDS Classification; policy

Background and aim of the symposium: In the WHO's upcoming new ICD edition, ICD-11, the terminology classifying "mental retardation" used in ICD-10 will be renamed to "Disorders of Intellectual Development". In addition, ICD-11 adapts diagnostic criteria which require adaptations in screening methodology. This symposium aims at

(a) comparatively analyzing the criteria and terminology used in DSM (III to V), and ICD (10 & 11) by Michael Seidel;

(b) reporting findings from an international collaborative study addressing the clinical utility of a pragmatic screening tool by Sherva Cooray, Germain Weber & colleagues;
(c) reflecting on the diversity of terminology with respect to people with intellectual disability from a European perspective by Germain Weber

SYMPOSIUM - ABSTRACT 1

Disorders of Intellectual Development as Successors of Mental Retardation and Intellectual Disability: Is the Approach of the ICD-11 (draft) an Improvement?

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Aim: The presentation will focus on issues of the definition of intellectual disability as presented in the category DID (disorder of intellectual development) of the ICD-11 draft version. **Methods**: By means of comparative analysis, commonalities and differences between the categories Mental Retardation (MR), Intellectual Disability (ID), and Disorders of Intellectual Development (DID), as defined in the DSM-III, DSM-IV, DSM-5, ICD-10 and ICD-11 (draft), are highlighted, as all these categories intend to describe the same phenomenon. **Results**: One of the most important shortcomings of the most recent DID category (ICD-11 draft) is its “linear” approach to severity grades (mild, moderate, severe and profound) based on statistical measures without weighting the specific aspects involved. The descriptions for the severity levels disregard the potential variability of competencies and weaknesses in various mental domains—unlike the DSM-5. In this regard, the ICD-11 drops behind the DSM-5. The ICD-11 draft avoids mentioning the potential relationships with the ICF (WHO). In addition, the ICD-11 draft neglects the importance of the emotional developmental levels as a very influential component of individual capacities for coping with daily challenges and stress. **Conclusion**: The description of the features of the four severity levels does not provide a clear definition which can be applied in practice.

SYMPOSIUM - ABSTRACT 2

Utility of the ICD11 in Diagnosing Intellectual Disability (ID) in LAMICs (Lower and Middle Income Countries)- An International Collaborative Study

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Aim and background: The contribution will focus on ways to facilitate accessibility of ICD-11 criteria for intellectual disability (ID) with regard to diagnosis of mental disorders capable of engendering robust evidence based on epidemiological data. The precise clinical diagnosis of ID utilizing the ICD classification is not viable, limiting its clinical utility in LAMICs, (constituting 80% of the world population) due to dearth of resources and competent professionals. This results in inequity of access to treatment and poorer prognosis compounding stigma in this vulnerable population. The Faculty of Psychiatry of ID UK and the University of Vienna collaborated internationally with partners from India, Sudan, Sri Lanka and Pakistan to evaluate a pragmatic and economic screening tool for detection of ID. **Methods**: Based on current shortcomings in ICD classification regarding people with ID (PWID) by contributing effectively to the WHO ICD-11 consultation process we evaluated: (1) The current evidence-base via a systematic literature search using PRISMA guidelines, critically analyzed the evidence-base and explored the feasibility of applying modified diagnostic criteria. (2) The potential clinical utility of a pragmatic screening tool (Glasgow Level of Ability and Development Scale /GLADs) for detection of ID by health workers following minimal training. **Results**: The evidence-base relating to mental disorders in PWID is poor, significantly hampered by difficulties in applicability of diagnostic criteria. The GLADs appears to be a promising screening tool with good clinical utility for detecting ID particularly where resources are scarce. **Conclusions**: Pragmatic modifications to ICD-11 diagnostic criteria and the GLADS tool potentially improves clinical utility, and research based evidence in PWID

SYMPOSIUM - ABSTRACT 3

Disorders of Intellectual Development: On the Ongoing Diversity in European Terminology Cultures With Respect to People With Intellectual Disabilities

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Aims: The presentation will address the various terms, labels and names currently in use as synonyms for intellectual disability in selected European countries and will also analyze cultural concept dynamics with regard to ID. **Methods**: A collection of different labels was carried out through an analysis of literature, taking into account publications in relevant academic and scientific fields, official public documents referring to ID as well as labels used by representative NGOs operating in the field of ID. Further, information was collected on concepts of ID linked to the various labels and will be compared to current concepts of disability as stipulated and promoted by the UNCRPD. **Results**: Findings show a high variability in labels used for ID within and between European countries. In addition, the terminology as defined in the ICD-10 for ID (or its official translation) is often challenged by country-specific cultural traditions and dynamics. **Conclusion**: With regard to ID and terminology agreements as carved out by

international bodies (e.g. WHO), cultural naming traditions show to be a substantial barrier for acceptance of the use of common wording. The findings will be reflected within the frame of social processes linked to label acceptance and power of attribution.

INDIVIDUAL PAPERS

What to do When Interventions Fail?

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KEYWORDS Self determination

Aims: The revised legislation to promote self-determination of intellectually disabled persons puts pressure on clinicians. Apart from misunderstandings related to limited communicative skills, there may be undiagnosed rare syndrome(s) behind atypical symptoms. This may lead to inappropriate control measures of self-determination. **Methods**: We describe two intellectually disabled adults whose treatment-resistant neuropsychiatric symptoms turned out to be treatable after the right diagnosis was made. **Results**: The first individual was a 42-year-old woman with ID of unknown origin, epilepsy and dyskinesia. She was bed-ridden until the identification of Angelman syndrome (AS) and a myoclonic status in non-progressive syndrome (MSNPS)1—the latter has been described to be occasionally associated with AS. The second case relates to a 55-year-old man with cerebral palsy, whose significant health deterioration was found to be due to continuous spike-waves in slow-sleep syndrome (CSWSS)2. **Conclusions**: These examples illustrate the importance of right diagnostics in the successful management of neuropsychiatric symptoms in intellectually disabled people. Without such diagnostics requiring multidisciplinary team work, the new legal requirements may be impossible to fulfill.

What Does Music Reveal About Autism? Validation of the Music-Based Scale for Autism Diagnostics (MUSAD)

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KEYWORDS accessibility; autism spectrum disorder; classification; diagnosis

Aims: Every fourth person with intellectual disability (ID) has a co-occurring autism spectrum disorder (ASD), which often remains undetected until adulthood. The MUSAD was developed to improve the assessment in adults with ID and reduced verbal abilities. This semi-structured approach uses a music-based interactional framework to assess a broad variety of diagnostic-relevant behaviours associated with ASD. The current study aims to assess the reliability and diagnostic validity of the MUSAD to promote its clinical usability. **Methods**: The sample consisted of 129 adults with ID and suspected ASD. Based on ICD criteria, 78 persons were finally diagnosed with ASD in an expert consensus conference. Selection criteria for the MUSAD algorithm items were: low rate of missing data, good discriminant validity (Gamma >.5; r > .3), high inter-rater reliability (ICC >.7), and a wide range of item difficulties. Calculation of inter-rater reliability was based on the scorings of 3 independent experts in 25 consensus cases measured by the intraclass correlation coefficient (ICC). A ROC analysis was run to assess the cut-point for the newly developed algorithm. **Results**: Twenty items were selected referring to ASD symptomatology (14 social interaction, 5 restricted & repetitive behaviors, 1 motor coordination). Item difficulties ranged from .04 to .74. Inter-rater reliability was good (M = .768, range .673—.895). The diagnostic algorithm based on the selected items showed a sensitivity/specificity of 82/77 %, the AUC was .79. **Conclusions**: The MUSAD is a valid and reliable instrument to support clinicians diagnosing ASD in adults with ID.

Development of a German Version of the Adaptive Behavior Assessment System – Third Edition (ABAS-3)

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KEYWORDS social inclusion

Aims: The ABAS-3 (Harrison & Oakland, 2015) provides a comprehensive, norm-referenced assessment of adaptive skills in up to ten skill areas such as communication, self-direction, health and safety, work, etc. It can assist in the diagnosis and classification of developmental, learning and behavioral disabilities or disorders, the identification of strength and weaknesses as well as in developing and monitoring treatment plans and training goals. So far, there is no such instrument available in the German language. The aim of this study is to produce and evaluate standardized German versions of the parent and the teacher rating forms of ABAS-3, suitable for the assessment of children and young adults of ages 5–21. **Methods**: A representative standardization sample is assessed as well as various clinical samples (such as intellectual disability, physical disability, speech impairment, hearing impairment and behavioural disorders). Theoretical aspects of "adaptive behavior" as well as the German evaluation design will be presented. Methodical and practical considerations will be discussed. **Results/Conclusion**: The German ABAS-3 could have an important impact on the assessment of the overall adaptive functioning and individual adaptive skills of children and young adults in Germany and other German-speaking countries.

People With Profound Intellectual and Multiple Disabilities: A Cognitive Skills Profile

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KEYWORDS cognition

Aims: The development of a personalized project for persons with disability is based on the assessment of their cognitive skills. However, as highlighted by international literature, there is a lack of tools adapted to people with profound intellectual and multiple disabilities (PIMD). This study was aimed at creating and validating an appropriate tool which is supposed to identify the basic skills of people with PIMD, describe the challenges they face, while avoid over- or under-estimations of their capabilities. This presentation introduces this tool. **Methods**: This tool sets up a cross-observation between psychologist, practitioners from the service facility, and parents of the person with PIMD. The tool consists of three scales: (1) reactivity, (2) cognitive skills profile, and (3) emotional state; and can be used for two purposes: (1) regular assessments of individuals with PIMD in order to identify their evolution, the effects of their care, etc., and (2) discussion of people close to them about their skills or emotional states. **Results**: Each "partner" (psychologist, practitioners from the facility, parent) has to state the frequency of occurrence of each item (from never to systematic). Results are synthetized in a profile. **Conclusions**: This standardized and adapted tool enables the assessment of difficulties and recovery of cognitive skills of people with PIMD.

Validation of the DiBAS-R and the Impact of Level of Functioning

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KEYWORDS autism spectrum disorder; diagnosis

Aims: The Diagnostic Behavioral Assessment for Autism Spectrum Disorders (ASD)-Revised (DiBAS-R) is a screening measure designed for adults with intellectual disability (ID) suspected of having ASD. In a primary study, the DiBAS-R has proven good sensitivity and specificity. The current study aims a) to replicate the findings in a second independent sample and b) to investigate how the level of ID impacts the diagnostic accuracy. **Method**: The current study analyses data collected in a clinical sample of adults with ID (N = 381). The impact of the level of ID on DiBAS-R scores is assessed using regression analysis. Diagnostic accuracy is determined in the whole sample and in subpopulations of individuals with mild/moderate and severe/profound ID. Results: DiBAS-R scores were higher for individuals with severe/profound ID (8.8 points) compared to individuals with mild/moderate ID (controlled for ASD, age, and gender). In the whole study population, the sensitivity was .82 and the specificity was .67. Sensitivity and specificity were more balanced in individuals with mild/moderate ID (sensitivity: .80, specificity: .84) compared to the severe/profound subpopulation (sensitivity: .83, specificity: .34). **Conclusions**: The DiBAS-R is an adequate screening measure for ASD. The scale has high diagnostic accuracy in individuals with mild/moderate ID. The DiBAS-R has a high sensitivity in severe/profound ID, but is also over-inclusive. This can be explained by a greater symptom overlap between ASD and ID when the level of ID increases. The results suggest that the DiBAS-R can support clinicians, but also that a comprehensive ASD-specific assessment is pivotal for sound diagnostic decisions.

Norming of the Scale of Emotional Development - Short

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KEYWORDS development; diagnosis; mental health promotion

Aims: Intellectual disability (ID) is often accompanied by delays in emotional development (ED). Insight into ED is crucial for appropriate diagnostic assessment in adults with ID, especially in cases of challenging behaviour. The Scale of Emotional Development—short (SED-S) is an empirically based measure providing the prerequisites for a thorough psychometric assessment. The aim of this study is to norm the SED-S in a population of normally developed children as a reference group. **Methods**: The SED-S was applied in a population of children aged 0 to 12 years (n = 150) according to the five levels of ED as assessed by the SED-S (0–6 months; 6–18 months; 1 ½—3 years; 4–7 years; 8–12 years). First, cross tabulation determined the relation of the diagnostic assignment of the overall level of ED as measured by the SED-S vs. the chronological age of the norming group. The level of exact agreement and the relative accuracy assessed using quadratic weighted kappa were determined. **Results**: A pilot analysis of children (n = 103) revealed a high correlation between the children's chronological age and their level of ED assessed using the SED-S. Overall, 77% were classified correctly. Quadratic weighted kappa was κ = .92, 95% (CI: .88; .95). Results of the item analysis will be presented at the EAMHID congress. **Conclusion**: The pilot analysis shows promising results concerning the diagnostic validity of the SED-S. More in-depth data analysis is necessary to ensure the validity and reliability of the SED-S.

An Investigation of the Adapted GAD-7 and PHQ-9 Clinical Measures of Mood for Adults With Intellectual Disabilities

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KEYWORDS accessibility; psychopathology; psychotherapy; research

Aims: Despite some service and policy developments, people with intellectual disabilities (ID) continue to face barriers to accessing psychological support such as Improving Access to Psychological Therapies (IAPT) services in the UK, due a lack of 'reasonable adjustments'. One barrier may be the services' standard clinical questionnaires (IAPT's 'minimum dataset', including measures of anxiety, GAD-7, and depression, PHQ-9), with reports from service users and clinicians that this can be difficult to use in the standard way for many people with ID. The current study aimed to adapt the GAD-7 and PHQ-9 to make them more acceptable to people with ID, and to investigate the initial psychometric properties of the adapted measures. **Method**: The initial stage of the research reviewed the questionnaires through individual Cognitive Interviews with six participants. In the second part of this initial stage, the adapted questionnaires were reviewed as part of a focus group with seven people with ID, enabling participants to make further recommendations. In the final stage of the study, the adapted GAD-7/PHQ-9 were used with up to 30 individuals alongside the established Glasgow Anxiety /Depression Scales, to assess the initial psychometric properties of the adapted measures. **Results & Conclusions**: A number of recommendations for adapting the GAD-7/PHQ-9 were made via the initial cognitive interviewing and focus group stages. The initial psychometric properties of the measures will be presented. Implications for clinical services and future research will be outlined.

Review of Cases Attending a Psychiatry Service in a Large Urban-Based Intellectual Disability Service in Ireland

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KEYWORDS challenging behaviour; diagnosis; psychiatric disorders

Aims: Descriptive studies relating to the mental health of adults and children with intellectual disabilities (ID) are scarce. This study aims to evaluate the mental health diagnoses, indications for medication use and individual characteristics of adults and children with ID referred for psychiatric care in a large Irish, urban, community-based intellectual disability service. **Methods**: A mental health database was used to identify all adults and children under the care of the psychiatry service. Information gathered included severity of ID, psychiatric diagnoses (using DC-LD diagnostic criteria), psychotropic medication prescribed, use of prn medication, co-morbid diagnoses including autism spectrum disorder and epilepsy, presence of challenging behaviours and levels of required mental health support. In May 2015, there were 390 individuals receiving support from the psychiatry service. **Results**: The age range of the individuals in active care was 3–76 years (M = 38.2, Mode = 41, SD = 16.8), with 17% under 18 years. 21.5% were classified as having mild ID, 53.3% with moderate ID and 23.4% in the severe/profound range. Initial analyses suggest that 14.6% had a non-affective psychotic disorder, 39.5% had an affective disorder, 28.7% had a diagnosis of autism, 19.5% had a diagnosis of epilepsy, 3.1% had a diagnosis of dementia. In particular, further detailed analysis will explore individual characteristics of those in receipt of antipsychotic drugs. **Conclusions**: Detailed data on the mental health needs and specific characteristics of adults and children with ID presenting to psychiatry services is essential in order to provide appropriate clinical supports and inform future service planning and health strategies.

“ABC” – Awareness-Body-Charts to Fill in with Colors

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KEYWORDS mental health promotion; sport

Aim: Existing valid questionnaires concerning body awareness are verbal tools which may be susceptible to reading/interpretation/writing problems, especially for people with mental health problems. The Awareness-Body-Chart (ABC), a self-report assessment tool for the evaluation of body awareness by colouring body charts, was conceptualized. The aim of this study was to test the psychometric features of the ABC. **Method**: A sample of 106 idividuals filled in the ABC as well as a verbal body awareness questionnaire („Kurzer Fragebogen zur Eigenwahrnehmung des Körpers”, KEKS) and the Beck Depression Inventory II (BDI-II). Factor structure, internal consistency and retest reliability of the ABC were investigated. Additionally, correlations of the ABC with the KEKS and the BDI-II, and comparisons of subgroups were conducted. **Results**: Fourteen factors with clear assignments to body parts could be categorized: cranium, face, cervical/lumbar region, chest/abdomen, shoulder, upper arm, lower arm/elbow, hand, back, genital area, thigh/hip, knee, lower leg and foot. The 14 body parts and the total score showed acceptable to high Cronbach’s alphas (α = .64-.97). The test-retest reliability showed values between $\rho = .71$ and $\rho = .96$. The correlation of the ABC and KEKS ($r = .66$, $p < .001$) confirmed construct validity. Comparisons of subgroups and correlations with the BDI-II confirmed the ABC’s validity. **Conclusion**: The newly developed ABC is a reliable and valid self-assessment tool for the investigation of body awareness. It is an easy-to-use tool, at low cost and independent of writing skills. It opens new insights into body awareness patterns in different subgroups. Further studies are warranted in persons with intellectual disability.

The Use of Validation in Mental Health Nursing for Adults With Intellectual Disabilities and Mental Illness: A Descriptive Study

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KEYWORDS intervention; research

Background: There are still only few publications on empirical studies concerning mental health nursing for adults with intellectual disabilities. The few studies published, however, underline the need for facilitated nurse-patient communication adjusted to the patients’ cognitive levels and symptoms, instead of targeting behaviour change. Factors found to have a positive impact on patients with mental illness in the general population seem to be relevant also for patients with intellectual disabilities. **Objectives**: The aim of this study was to investigate the use of validation in mental health nursing for patients with intellectual disabilities and additional mental illness in a specialized psychiatric inpatient setting. Methods: Ten nurses/social educators and four individual therapists described the use of validation; each provided three vignettes with clinical examples. The

resulting 42 vignettes were consequently analysed for categories of validation. **Results**: The analysis revealed overall 10 sub-categories under the main categories acceptance and acknowledgement. The clinical examples support the view that interventions developed for patients in the general population are feasible also for patients with intellectual disabilities. **Conclusion**: Clinical implications relate to the use of validation as an important factor in mental health nursing for adults with intellectual disabilities. Skills required include being capable of interpreting behavioural equivalents of mental illness symptoms, responding adequately to unusual utterances, and occasionally communicating in a predominantly non-verbal way.

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Autism Archetype Survey

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KEYWORDS autism spectrum disorder; classification; developmental disorders; personal development plan; person-centred approach

Aims: To create a test which can assist clinicians to determine levels of functionality within the various characteristics that surround an autism diagnosis. This can help clinicians and those who work with individuals in this population better prepare to serve them. **Methods**: I used the Myers-Briggs and the Five Factor Model as a model in the survey development. Like personalities, autism has many traits that go along with the condition. This test is meant to help determine the severity of the various traits of autism in each individual. I created six different dichotomous relationships that focus on twelve specific traits, of autism. I also conducted a literature review and further determined that individuals with autism vary in severity and these are different in varying categories. Other measures used to determine the validity of the test questions was a qualitative analysis as well as a quantitative analysis using Lawshe's (1975) content validity ratio (CVR) model, construct validity using the multitrait-multimethod (MTMM) design, as postulated by Cook & Campbell (1979), and an exploratory factor analysis of SPSS. **Results**: The findings from the first round of feedback and test results confirm that professionals who work with individuals with autism believe this new survey can help facilitate adequate services by accentuating what an individual's strengths and weaknesses are. **Conclusions**: There is a gap in the way mental health professionals and persons who work with this population go about evaluating an individual's strengths. To say an individual has autism, does not give a clear enough picture of that individual's unique needs.

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Mood Disorders in Patients With Intellectual and Developmental Disorders: Preliminary Data on the New Assessment Tool SPAIDD-M

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KEYWORDS psychopathology

Aims: A growing body of literature showed high rates of mood disorders (MD) in persons with intellectual developmental disorders (IDD) and autistic spectrum disorders (ASD). It is possible that comorbidity rates are even higher than reported so far: the lack of diagnostic criteria adapted for neurodevelopmental disorders and the poor use of reliable assessment tools might be responsible for an underestimation or misdiagnoses. The purpose of the present study was to evaluate the psychometric properties of the SPAIDD-M (Systematic Psychopathological Assessment for People with Intellectual and Developmental Disabilities—Mood Disorders Version). **Methods**: Eighty-nine persons with IDD or low-functioning ASD who showed over-threshold score for MD at a screening tool for most psychiatric disorders (SPAIDD-G) (Bertelli et al., 2012) were consecutively assessed through the SPAIDD-M. Study participants were recruited among persons attending residential or clinic-rehabilitative services of the San Sebastiano Foundation, Florence, Italy. Concurrent validity has been checked in 26 participants with the DASH-II (Diagnostic Assessment for the Severely Handicapped). Inter-rater reliability has been assessed during a special session in which psychiatrists, psychologists and nurses completed the assessment procedure on the same patient, blind to each other's assessments. **Results**: SPAIDD-M showed good psychometric properties: high internal consistency

(Cronbach's α = 0.81), inter-rater reliability (Cohen's k = 0.76) and concurrent validity (reliability between SPAIDD-M and DASH-II: 98%). The correlation with clinical diagnoses was also high (rp = .0531 and rs = .0531, p = .000 for both statistical tests). The prevalence of MD was rated at 22.4%. **Conclusions**: The SPAIDD-M showed good psychometric characteristics, which have to be confirmed in wider samples.

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Bertelli, M., Scuticchio, D., Ferrandi, A., Lassi, S., Mango, F., Ciavatta, C., Monchieri, S. (2012). Reliability and validity of the SPAID-G checklist for detecting psychiatric disorders in adults with intellectual disability. *Research in Developmental Disabilities*, *33*(2), 382–390. doi:10.1016/j.ridd.2011.08.020

Behavioural Equivalents of Psychiatric Symptoms in People With Intellectual and Developmental Disabilities

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KEYWORDS psychopathology

Aims: The last decades' considerable advances of psychiatric assessment in people with intellectual and developmental disabilities (IDD) do not include the ability to identify behavioural equivalents (BE) of psychiatric symptoms and their relationship with different psychiatric syndromes. The present study was aimed at evaluating the correlations between BE and DSM-5 syndromes. **Methods**: An observational cross-sectional analysis was performed for a sample of approximately 1000 adults with IDD. The assessment was conducted with the Systematic Psychopathological Assessment for People with Intellectual and Developmental Disabilities—General Version (SPAIDD-G), which is a checklist for the detection of significant behavioural or observational equivalents. The items of the checklist represent BE of the symptoms of the main psychiatric disorders (PD) included in the DSM-5. **Results**: Although not diagnostically specific, some BE seem to be more strongly related to specific PD. The most significant correlations were found for mood disorders, particularly bipolar disorder. Psychomotor agitation, irritability, mood lability, aggression and distractibility were also present in bipolar patients. For depressed patients, changes in appetite and sleep had higher correlations than in other diagnostic groups. **Conclusions**: This line of research seems to be able to satisfy one of the highest needs of current psychopathology for IDD, which is a better definition and clustering of psychiatric symptoms.

Reference

Bertelli, M., Scuticchio, D., Ferrandi, A., et al. (2012). Reliability and validity of the SPAID-G checklist for detecting psychiatric disorders in adults with intellectual disability. *Research in Developmental Disabilities*, *33*(2), 382–390. doi:10.1016/j.ridd.2011.08.020

The SPAIDD-G: New Findings on the Screening Version of the First Psychodiagnostic Tool for Persons With Intellectual and Developmental Disabilities

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KEYWORDS epidemiology; psychiatric disorders; psychopathology

Aims: The SPAIDD (Systematic Psychopathological Assessment for People with Intellectual and Developmental Disabilities) is the first tool to support clinicians and multi-professional teams in making psychiatric diagnoses in persons with neurodevelopmental disorders (NDD). It includes the “G” form, for general diagnostic orientation as well as a specific index for the various syndrome groups included in the DSM-5. The aims of the present paper were 1) to assess the metric and psychodiagnostic properties of the SPAIDD-G; 2) to provide new data on the prevalence rate of mental health issues in a Italian multi-centric sample of people with NDD living in different settings; 3) to stimulate scientific interest in the presentation of psychiatric disorders in persons with NDD. **Methods**: The SPAIDD-G was consecutively used with 852 persons with ID attending clinical and rehabilitation services across Italy. A part of the sample was also assessed through other screening tools (DASH-II and PDD-MRS), and clinical diagnoses were made by experienced psychiatrists in accordance with the DM-ID and DC-LD criteria. **Results**: The internal coherence of the SPAIDD-G, estimated through Cronbach’s and Kuder-Richardson’s formulas, was stated at 0.81 and 0.97; inter-rater reliability, measured through the Cohen K coefficient, was 0.76. Concordance with PDD-MRS scores, DASH scores, and clinical diagnoses were also high at 77.6%, 57.89%, and 77.7% respectively. The most frequent over-the-threshold scores were for autism, impulse control disorder, and personality disorders. **Conclusions**: SPAIDD-G seems to have good psychometric features and appears to be a valid, reliable and easy screening tool which can be employed by different professionals even after a very short training.

Validation of the SPAIDD-ASD: A New Tool to Assess Autism Spectrum Disorder in Persons With Intellectual Disability

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KEYWORDS autism spectrum disorder; diagnosis; psychopathology

Aims: SPAIDD-ASD (Systematic Psychopathological Assessment for People with Intellectual and Developmental Disabilities—Autism Spectrum Disorder Version) is a new tool to support clinicians in diagnosing autism spectrum disorder (ASD) in people with Intellectual Disability (ID). The main purpose of the present paper was to evaluate the psychometric properties of this

tool; a secondary aim was to estimate the prevalence of ASD in people with ID. **Methods**: Eighty-four adults with mild to profound ID, attending the residential or clinical-rehabilitative services of San Sebastiano Foundation, Florence, Italy, underwent an instrumental screening assessment (SPAIDD-G) for the co-occurrence of psychiatric disorders. Those who scored over threshold for ASD were consecutively evaluated with the SPAIDD-ASD. A part of the participants was also assessed with the Italian adaptation of the Diagnostic Assessment for the Severely Handicapped (DASH-II; Matson) and the Pervasive Developmental Disorder—Mental Retardation Scale (PDD-MRS; Kraijer). Inter-rater reliability was assessed in a special session where psychiatrists, psychologists and nurses independently assessed the same patient. **Results**: The mean age of the sample was 34.98 (±14,96) with a M/F ratio of 1.03. In 32% of the participants ASD was diagnosed. The SPAIDD-ASD showed good internal consistency (Cronbach α = 0.81) and inter-rater reliability (Cohen's K = 0.79). Also, the correlations with DASH-II and PDD-MRS scores were quite high. **Conclusions**: SPAIDD-ASD seems to be a useful and reliable instrument for the assessment of ASD in ID. Results have to be confirmed in wider samples.

The Assessment of Pain in Persons With NDD With Severe Limitations

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KEYWORDS Autism spectrum disorder; diagnosis; mental health promotion; neurodevelopmental disorders; practice

Aims: The IASP (International Association for the Study of Pain) stated that the relief of pain should be considered a human right. When applied to persons with neurodevelopmental disorders (NDD) and significant limitations in functioning and communication, it usually represents a great challenge for clinicians (LaChapelle et al.,1998; McGrath et al., 1998). This population often faces severe health issues, like musculo-skeletal disorders, G.I. system disorders, and pain. Chances are that these subjects cannot communicate their pain and discomfort effectively, and subsequently they have lower chances to receive adequate diagnosis and treatment. A few years ago, the Disability Department in Fondazione Sospiro, Italy, created a special interest research group dedicated to the improvement of the assessment of pain conditions for persons with NDD and severe limitations. Its primary scope is to implement clinical research and the application of an adequate procedure, while the secondary aim is to share this expertise with the scientific community. **Methods**: The Pain and Discomfort Scale (PADS; Bodfish et al., 2001) has been selected as central tool, in accordance with the Author, and therefore translated and adapted to our purposes, creating new materials (videos with clinical cases and manual). A first training (8 hour training, including theoretical basis, protocol description and experiential exercises), was provided by the main Author; a small group of professionals were then supervised on clinical applications, and the PADS was clinically administered to people with NDD and severe

limitations in functioning. **Results**: The first result is related to the training procedure. All the nurses working in residential facilities (n = 30) have been trained and supervised in 2015: Due to the excellent concordance of experts (Kendall's W = 0.896 in 2015 and Kendall's W = 0.879 in 2016), means of expert's scores were taken as the gold standard score for each patient. Pearson's correlation between experts' means and trainees' scores was used as an outcome index of the training. Over 70% of nurses in training obtained a correlation of 0.9 or higher. In 2016, the inter-rater reliability was followed-up using assessment videos. Nurses with low scores had received an additional training. The full training procedure will be presented and discussed. The second type of results is related to the assessment data. Four hundred people with NDD have been screened. Those who scored positive in criteria both for limitations in communication and for health conditions have been labelled as being "at risk" (n = 150), and have been consequently fully assessed with the PADS. Data will be presented and discussed. **Conclusions**: We noticed a strong increase in the awareness of the staff members and in the accuracy of daily nursing activities (evaluation and treatment), especially when people with NDD present communication impairments. People in a risk condition received a better treatment plan, from a medical and behavioural perspective.

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Diagnostic Interview for ADHD in Adults With Intellectual Disability (DIVA-5-ID)

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Background: Attention deficit hyperactivity disorder (ADHD) is a common childhood disorder that can persist into adulthood. ADHD is three times more common in individuals with intellectual disability (ID) than in the general population. There is increasing evidence to support the diagnosis of ADHD in adults with intellectual disability but there were no tools specifically developed to aid the diagnosis of ADHD in adults with ID. The recent development of DIVA-5-ID is discussed within this paper. **Methods**: The DIVA (Diagnostic Interview for ADHD in Adults) is a well-established interview for diagnosing ADHD in adults and has been reported in studies involving people with ID. The DIVA-5-ID was developed by a group of researchers who originally developed the DIVA with advice from specialist ID psychiatrists who had expertise in diagnosing ADHD in adults with ID. The approach was a literature review of the evidence base and then each item of the DIVA was reviewed for use with adults with ID. DIVA-5-ID was developed following the current criteria of DSM-5. **Results**: The DIVA-5-ID is now available and the adaptation of each of the 18 symptom criteria from DIVA to DIVA-5-ID will be presented. The adaptation of each symptom criteria focused on using life examples that are more common to the experiences of adults with ID. **Conclusions**: The development of the adapted tool DIVA-5-ID should lead to improved recognition of ADHD in adults with ID. However further evaluation is required on validity for use in clinical settings.

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POSTERS

The Social Communication Questionnaire for Adults With Intellectual Disability

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KEYWORDS autism spectrum disorder; diagnosis

Aims: Autism Spectrum Disorder (ASD) frequently co-occurs with Intellectual Disability (ID) and often remains undiagnosed until adulthood. The Social Communication Questionnaire (SCQ) is a widely used measure to screen for ASD. To improve the utility of the SCQ for adults with ID, the aim of this study was to develop an ID-specific adult-appropriate algorithm for the SCQ using a core set of valid items. **Method**: The current study analyses SCQ data from three study sites (Berlin, Germany; London, UK; and Ohio, USA) that were collected in adults with ID with and without comorbid ASD. Valid and appropriate items were identified in a training sample (N = 226) and further cross-validated in a second, independent sample (N = 225). **Results**: The newly developed algorithm consists of 24 items compared with the 40

items in the original instrument. The reduced item core set yielded similar diagnostic validity as the original algorithm with good sensitivity values (.81—.89) and low specificity values (.62—.72). **Conclusions**: Overall, the reduced algorithm maintained comparable diagnostic validity to the complete item set. These results indicate that the removed items may not carry diagnostically relevant information in adults with ID, resulting in a more efficient and age-appropriate way of collecting diagnostically relevant information in adults. However, the low specificity values suggest that a comprehensive assessment is essential for a final diagnostic assignment.

Development of an Instrument to Measure Stress Conditions in Patients With Intellectual Disabilities and Psychiatric Disorders

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KEYWORDS disabled patients; stress condition; three-step "smiley" scale; quality of life

Aim: Stress conditions in patients with intellectual disabilities and psychiatric disorders are among all factors the most disabling in their quality of life. Due to marginal group of patients, no standardized instruments exist to assess the degree of stress condition and therapy effects in this population. We aim to develop a self-rating and third-person rating instrument verifying the effect of psychiatric and psychotherapeutic treatments in these patients. **Methods**: First, we asked 50 caregivers of residential facility for patients with intellectual disabilities and psychiatric disorders to define 20 words which describe stress conditions most accurately. According to the quantitative occurrence, 10 terms were worked out. Then, we validated these 10 terms in a self-rating using a three-step "smiley" scale. Professionals knowing the patients rated their stress level on the same scale. According to the degree of emotion, a value of −1, 0 or 1 was encoded, according to the summation of the individual, values ranged from −10 (high stress level) to +10 (low stress level). **Results**: We expect to find a high accordance of the self-rating and the third-person-rating. There might be need for adjustment of the wording of some items in order to adapt them to the patients' vocabularies. **Conclusions**: The development of an instrument to measure stress conditions in these patients is important for the improvement of therapies. The integration of such an instrument in the measurement of psychological, social or medical therapy effects allows disentangling efficient strategies improving the patients' quality of life, as the assessment could be quickly made during a hospital intervention.

The Spanish Version of the HoNOS-LD: Preliminary Results on Its Validity and Reliability

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KEYWORDS disruptive behaviors; problem behaviours; psychiatric disorders

Aims: The aim of this study is to validate the Spanish version of the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) (Roy, 2002) for the use among Spanish-speaking adults with intellectual disabilities (ID). The Spanish version of the HoNOS-LD translated by R. Novell (Salvador and Novell, 2002) was used. **Methods**: A total of 122 subjects (73% women, 27% men) were recruited from three centres in Catalonia. All subjects were evaluated independently by two different raters to calculate the inter-rater reliability. Moreover, 73 subjects were re-evaluated by the same scorer at 5 ± 2 days after the first evaluation to calculate the intra-rater reliability. **Results**: The Spanish version of the HoNOS-LD showed good reliability among different evaluators, with an average slightly higher than 0.8 and high values for the majority of items, and a good intra-rater reliability. The three evaluators had a mean value of Kappa weighted higher than 0.7. The internal consistency of the scale was good with a Cronbach's α coefficient of 0.853. **Conclusions**: The Spanish version of the HoNOS-LD is comparable to the original English version. Thus, this tool seems to be a useful instrument to monitor behaviors and functioning of Spanish-speaking adults with ID.

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CASE REPORT OF SERVICE PROVISION SYSTEM

SYMPOSIA

Symposium: "Identify the Key Elements of the Creation of Inclusive, Inclusive Employment and Job Retention for People in High Psychological Vulnerability"

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SYMPOSIUM - ABSTRACT 1

Identify the Key Elements of the Creation of Inclusive, Inclusive Employment and Job Retention for People in High Psychological Vulnerability

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KEYWORDS Deinstitutionalisation; diagnosis; rehabilitation; social inclusion; therapies

Aim: Mathëllef asbl tries to propose concepts and methodologies that are alternative to usual, generally accepted psychiatric care. Possible and feasible methods. **Method**: the author has practical experience of more than 30 years of daily work with people suffering from severe mental disorder. This personal experience and the concept of Mathëlleff asbl are presented. The author tries to present concerted experiences of successful psychiatric rehabilitation. He wants to show that the Mathëllef experience is a model open to copy and go even further. The author presents a subjective history of psychiatry in Luxembourg (1980–2017), giving an overview of the major concepts and methodologies practiced in Luxembourg. **Conclusion**: Different approaches in rehabilitation are possible! Mathëllef asbl shows that alternatives to classical approaches in psychiatry are possible, if not desirable.

SYMPOSIUM - ABSTRACT 2

Supporting Self-Determination for People With Psychiatric Disabilities: Facilitators of Vocational Recovery and Subjective Well-Being, the Case of ATP asbl. - Association d'aide Par Travail Thérapeutique Pour Personnes Psychotiques (Luxembourg)

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Aim: Although concerted efforts have been made in recent years to improve models of employment support, many people with psychiatric disabilities were not be able to adapt to long-term and stay attractive and competitive in the job market. Numerous authors suggest that social services must promote the self-determination and career development during vocational rehabilitation of their clients in order to initiate and maintain employment after institutional stay. In line with this our paper aimed to update current theoretical framework of self-determination theory (SDT) and clarify key concepts related to employability of persons with severe mental disorders. **Method**: In relation to SDT we conducted a literature review including relevant peer-reviewed scientific journals in the area of mental health and those that have looked at the work situation of people with severe mental disorders. **Results**:The findings highlight the importance of intrinsic goals as a higher motivating factor in vocational recovery. Specifically supporting psychological needs for autonomy, competence, and relatedness in the process of their rehabilitation, people with

psychiatric disabilities may internalize values and skills for change and experience more volitional engagement in treatment and maintain outcomes better over time. **Conclusion**: Paper suggests that the future work of mental health services should focus on assisting people with psychiatric disabilities, to increase their self-determination by fostering their psychological needs, emphasizing intrinsic goals as a catalyst for vocational recovery and subjective well-being.

Symposium: How to Enhance Knowledge Sharing and Application Between Academia and Practice?

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KEYWORDS Coproduction; networking; practice; research

The Academic Collaborative Center Living with an intellectual disability (Tilburg, Netherlands) aims to build a bridge between science and practice. In this Academic Collaborative Center, 11 care organizations for people with ID, Tilburg University, and an advocacy organization for people with ID collaborate durably with the aim to contribute to the development of knowledge, and to use and implement this knowledge. The enhancement of knowledge sharing between science and practice is explicitly part of the mission of the Academic Collaborative Center. In this symposium, three presentations will provide insight into ways to enhance knowledge sharing and application between academia and practice.

SYMPOSIUM - ABSTRACT 1

Barriers and Facilitators for the Sharing and Application of Knowledge in Care and Support for People With Intellectual Disabilities: Results of a Systematic Literature Review

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Aims: Sharing and application of evidence-based and practice-based knowledge is a key issue in providing optimal care and support to people with intellectual disabilities (ID). However, knowledge sharing and application prove to be a challenge within organizations providing care and support for people with ID. Therefore, this review aimed to retrieve organizational factors which are enabling and disabling in stimulating the sharing and application of knowledge in care and support for people with intellectual disabilities. **Method**: A systematic literature review was conducted using the databases PubMed, PsycINFO, CINAHL, ProQuest, and Business Source Elite for relevant articles published in English between January 2000 and December 2015. The process of selection, quality assessment and data analysis was conducted independently by two reviewers according to PRISMA guidelines (Liberati et al., 2009). **Results**: Out of the total of 2256 retrieved articles, 19 articles met our inclusion criteria and were considered in the review. The main findings of the thematic analyses will be presented, i.e. barriers and facilitators for sharing and applying knowledge in care and support for people with intellectual disabilities. A bottom-up analysis of all enabling and disabling factors resulted in three groups of factors: 1) characteristics of the intervention (e.g. paperwork), 2) factors related to persons (individuals and teams of professionals), and 3) factors related to the organizational context (material and immaterial). **Conclusion**: The results will be useful in improving sharing and applying knowledge in care and support for people with ID, which will consequently contribute to enhancing their quality of life.

SYMPOSIUM - ABSTRACT 2

First Steps in Making an Intervention Transmissible to Other Care Providers: From Practice-Based Evidence to Evidence-Based Practice

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Aims: Various good practice interventions are used within care organizations for people with intellectual disabilities (ID). To make such interventions transmissible to other care providers, the practice-based evidence needs to be turned into evidence-based practice. This presentation illustrates this development by displaying the first steps in turning perception-oriented care (POC), a practice-based intervention for ageing people with ID in the Netherlands, into an evidence-based intervention. **Methods**: Based on the framework for design and evaluation of complex interventions of the Medical Research Council (MRC) (Campbell et al., 2000) this study consists of three steps. (1) Theory: content analysis of literature about POC was carried out aimed at identifying underlying themes. To include practice-based knowledge, concept mapping and focus groups were subsequently conducted with staff working according to this good practice intervention. In doing so, the identified themes were both checked and further refined from a practice-based perspective, resulting in a definition of POC. (2) Modeling: a systematic literature

review based on the definition of the good practice intervention will be conducted and observational studies of staff-service user interactions will be performed and, (3) exploratory trial: several case studies will be carried out. **Results**: We have successfully completed the first step of the MRC in developing a conceptual framework of the good practice intervention POC including both theory- and practice-based perspectives. **Conclusions**: The applied method provided valuable insights in first steps of developing a practice-based intervention into an evidence-based intervention, and will contribute to making POC transmissible to other care providers.

SYMPOSIUM - ABSTRACT 3

Sharing Knowledge by Building Networks to Connect Science, Education and Practice

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Aims: The Academic Collaborative Center Living with an ID has the mission to enhance knowledge sharing between science and practice. To achieve successful sharing of scientific, professional, experiential and educational knowledge, durable networks connecting evidence-based and practice-based knowledge are built. **Methods**: The Academic Collaborative Center enhances knowledge sharing by 1) translating scientific knowledge resulting from research projects to various educational levels in collaboration with educational institutes; 2) initiating national networks connecting universities, care providers, organizations representing individuals with ID and their relatives to jointly develop and share knowledge on specific themes; 3) using innovative methods such as communities and experience-based co-design. **Results**: The initiatives of the Academic Collaborative Center result in successful sharing of evidence-based and practice-based knowledge built on equal inclusion of the perspectives of scientists, professionals, individuals with ID and their relatives, and educational experts. **Conclusions**: Building durable networks stimulates knowledge sharing between science, education and practice.

Symposium: Learning to Look With a Generous Eye

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KEYWORDS challenging behaviour; intervention; staff; support

Aim of the symposium: To reveal observation as a therapeutic intervention that helps people with ID who experience mental health problems, by enabling those who support them to attune to their experiences and needs more effectively.

SYMPOSIUM - ABSTRACT 1

Enabling Staff to Watch Each Client's Personhood in a Meaningful Way Using Discovery Awareness (DA)

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Aim: For professional staff, the pressures of their 'work' with a client can cloud their 'view' of the client. Only really seeing this person brings back the possibility of connecting. That is the very first step to self-strengthening (Stern) which leads to a reduction of challenging behaviour. **Method**: DA is a unique way of video-analysis that does not teach. Passing through the different parts of a DA session enables you to experience a shift in your point of view towards the client. You will learn that awareness of body language leads to the possibility of watching and listening to the client's personhood in a more meaningful way. **Results**: DA is a unique way of using video with a clinical team to help them develop the way they view a client. The participants' focus is directed to the client's posture and body language. In so doing, participants start to become aware about their own perspective about the client. What might have been thought of as meaningless behaviour becomes seen as representing the client's experience, emotion, involvement, initiative, communication, being-in-touch-with and self-management. As participants engage with this renewed interest they become motivated to get to know the client again: they report becoming reacquainted with someone they have known for a long time that they thought they knew. **Conclusion**: The increase in general sensitivity to the client is the fertiliser of interactions that strengthen the person's self.

SYMPOSIUM - ABSTRACT 2

'Stepping Back' and 'Seeing Differently': Staff Reflections on Patient Behaviour and the Impact of Discovery Awareness

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Background: How staff understand the actions or intentions of a patient with challenging behaviour has implications for how they work with them in practice. Attributions of what a behaviour means may be made in a moment, but have a far more lasting impact. This paper focuses on staff accounts of the extent to which Discovery Awareness (DA), a video-analysis based method, stimulates curiosity and supports an exploratory approach to seeing behaviours in a new way. **Methods**: Thematic analysis was used to analyse the interviews of 13 staff members who used DA as part of everyday practice. Emerging codes were grouped together into themes. **Results**: Participants identified benefits of DA as aiding reflection on the behaviour and personhood of the patient, as well as their own role in interactions with the patient. Staff also reported that focused structured video analysis provided a space to explore their understanding of what the patient's behaviour means and who the patient is. **Conclusions**: Staff perceive DA as enabling them to 'step back' from previous readings of the patient, the meanings attached to their behaviour and from challenging behaviour in the moment. This reflection can stimulate new approaches to working with patients driven by the staff themselves by the process facilitating them to 'see differently'. Focusing on the patient was also presented as a useful counterbalance to common practices in care which focus on negatively perceived aspects of behaviour.

SYMPOSIUM - ABSTRACT 3

Using Video-Analysis to Work Through Counter-Transference of Professional Staff: Looking to Images as Looking in a Mirror

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Aim: To empower professional staff's capacity to observe by seeing images not only from the objectside (client) but also as a mirror of their own countertransference. Problems and possibilities contextualised intersubjectively help staff to find better attunement with clients who have ID and mental health problems. **Method**: Following the different parts of a Discovery Awareness session, we use that material to explore the way words and interpretations are influenced by counter-transferences from professional staff using a psychoanalytical framework. It is a mentalisation-based, working-through process. **Results**: DA is a unique way of using video with a clinical team to help them develop not only their observational capacities of the client, but also to discuss their countertransference by using the images as a mirror and reference for words and interpretations. In this way participants start to become aware of their own perspective and their own 'emotional' blindness to certain aspects of the client. What might have been thought of as meaningless behaviour becomes to be meaningful from both the objectside (the client) and the subjectside (the professional). Empowering staff to encounter mental health problems in ID enlarges care and support possibilities for their clients. **Conclusion**: Increasing the capacity to attune to clients is essential to professional working with clients with ID who experience mental health problems. Becoming more open to emotional truth has healing effects for both staff and clients.

CO-PRODUCTIVE WORKSHOPS

Facing the Challenge of Developing Customized Approaches in Mental Health Prevention Programmes for People With Intellectual Disabilities

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KEYWORDS Coproduction; mental health promotion; prevention; wellbeing

Mental disorders, particularly depression and anxiety, are more prevalent and debilitating among people with intellectual disabilities (ID) than in the general population. Although mental health promotion and prevention of mental health disorders for those who are most vulnerable or at risk are defined as priority areas of the WHO European Mental Health Action Plan (2013), the evidence base supporting preventive mental health interventions in people with ID is still limited and more research is urgently needed. In an effort to meet the challenge of providing mental health prevention services designed for the complex needs of this population, a centre for mental health promotion and prevention, and a specialist support service for people with ID joined forces to develop a tailored mental health promotion intervention. In a first session, the participants' needs for information on mental health issues were explored. Based on the findings of the first session, two two-hour interactive information sessions were designed addressing the topics of depression and anxiety one at a time. Each session was then followed by creative activities allowing participants to respond to and process the information received in their own way and according to their own individual needs and abilities. The goal of this workshop is to exchange lessons learned and to explore different approaches in the context of mental health prevention for people with ID. Workshop participants will have the opportunity to discuss the different aspects of the intervention and to share their own experiences with the objective to improve the development of effective and impactful prevention programmes.

Individual Case Studies of Service Users With an Intellectual Disability Supported by Adult Mental Health Services West Auckland, New Zealand

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KEYWORDS Accessibility; challenging behaviour; forensic issues; networking; person-centred approach

There are challenges within the Mental Health Services in regards to treating and supporting individuals with an Intellectual Disability who present to Mental Health services with limited capacity to express how they are feeling at that time. This situation can also be complicated with challenging behaviours that result in being exited from accommodation, burn out of support networks and police interventions. We will be presenting some cases that highlight the on-going challenges in treating and supporting those individuals including their significant others to achieve their individual goals in seeking treatment in the least restrictive environment possible. Included we will be identifying the on-going challenge of breaking down stigma associated with Intellectual Disability and the treatment that should be given. Also the multi-agency approach that is required to support individuals. There are various legal Acts within New Zealand that can be utilised to support treatment and care options that will also be included within the presentation.

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Involvement and Community Participation

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KEYWORDS autonomy; empowerment; inclusive community living; participation; social inclusion

Brief description of the goals: Inclusion is more than just participation, but also a direct societal belonging (Theunissen, 2013), and it is important to shape a community in a way that basic human rights are recognized and participation is possible for all members (Dannebeck, 2012). Especially when working with people with a mental disorder or a mental disability, inclusion is a societal task, which requires action (Gitschmann, 2012) by both the people involved as well as their respective environment. This approach is based on the idea that people with a mental disability or disorder are part of our society by birth (e.g. Fischer, 2010). The major goal of this co-productive workshop is to enhance the understanding in which ways, theoretically as well as practically, communities and organizations in the grand region may implement influential measures and projects. This discussion involves, among other aspects, especially legal provisions, education, employment, living-conditions, health issues, and family life. Thus, various organizations from Luxembourg and neighboring countries will present their approach and their struggles to empower people with mental disability or disorder to a greater empowerment and to active community participation. A discussion following the views of the many important stakeholders will potentially generate a better understanding of future measures to be taken to make community participation more common than it is today. **Description of the interactive formats used and the various perspectives (stakeholders) considered**: Leah Wagner (Institut St Joseph, Betzdorf) will briefly introduce the topic and the participants. A first input round will be followed by a second round discussing the identified issues. Arthur Limbach-Reich (University of Luxembourg) looks beyond national action plans for the implementation of the CRPD (2007). Through a close examination of central fields of participation in European counties, he reveals gaps and traps in involvement and participation for people with intellectual disabilities while focusing on empirical data and experiences from the national context. Andreas Weist (Institut St Joseph Betzdorf) will present the recent development of the “Bewohnerrat” at the Institut St Joseph, Betzdorf. This council for mentally disabled residents empowers them to participate in societal and relevant decisions, and represent other residents with their wishes and recommendations. According to the individual autonomy of mentally disabled people (see EU human rights commission) is the theoretical foundation of this newly developed format. Accomplishments and difficulties will be presented and discussed. Daniela Ribeiro Silva (Mutferter Haff) will present a project, which organizes elections within the group of mentally disabled persons working on the Mutferter Haff, a therapeutical and protected workshop for people suffering from a severe and persistent psychiatric disease. This "delegation" is supposed to provide the opportunity to be completely informed about and participate actively in the management of the Haff, regarding the work of psychosocial coaching as well as the administrative and financial management itself. Ina Weilerswist (Lebenshilfe Trier-Saarburg) will present a project with the parish in Konz, in which disabled people deliver the parish letters to private homes. Another project together with the German Red Cross gives disabled people the opportunity to support the employees and inhabitants of a retirement home. Likewise, parents of people with intellectual disabilities describe their experiences regarding the possibilities of their children's participation in social life. In doing so, existing barriers and experiences with facilities as the place of residence of their children are also presented. With these diverse stakeholders we would like to develop or re-assess approaches based on people's capacities rather than deficiencies. Our workshop contains contributions from providers and facilities as well as service users and their parents. These practical projects are set into perspective by a scientific view on opportunities, best practice and legal grounds.

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INDIVIDUAL PAPERS

Sexual Culture as the Subject of Organizational Development – Towards a Sexual Culture Within the Ligue HMC

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KEYWORDS Education; ethics & human rights; prevention; rights of people with id; sexuality

Aims: Within our organization, we have set ourselves the task to focus on sexual culture and to develop the topic further throughout the Ligue HMC. **Methods**: Different levels of implementation of a sexual culture in our organization, concepts and desirable standards will be presented.

Experiences, challenges and development needs for the future are discussed. **Results**: We notice the presence of more openness about sexuality in our organization. There is a considerable increase of demands for counselling and support from people with an intellectual disability and staff members. We are more likely to accept that the persons with an intellectual disability who work and live in our organization have a right on their own sexual experience. This influences the way we are dealing with the balance between the duty of care and the autonomy of the persons with an intellectual disability. An important point was the creation of an official contact point for counselling on sexuality. **Conclusion**: Sexuality is a lifelong, evolving process, a continuous interaction between learning and personal experiences. This is true for the individual as well as for the organization. We have to raise awareness and to create the possibilities to openly discuss about sexuality and interpersonal intimacy. Sexual culture requires sexual trained staff members. It is indispensable to have a clear structure and objectives, supported by the head of the organisation, and not just an occasional and/or situational management. Furthermore concepts, transparency and participation rules within the organization are needed. In addition, it requires the accompaniment, support and understanding of sexual development in the families, in society and politics.

Mental Health: A Prominent Theme in 24/7 Online Support for Independently Living People With Intellectual Disabilities

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KEYWORDS Practice; Support; Technology

Aims: E-health applications such as Telecare are increasingly being used in the support for people with intellectual disabilities (ID). DigiContact is an online video conferencing program through which independently living people with ID can contact specially trained support workers 24/7. We explored the support needs for which people with ID use DigiContact. **Methods**: We interviewed 21 support users. In addition, support needs in 868 online contacts were registered. We followed an inclusive approach in which an academic researcher and a co-researcher worked together. **Results**: We identified four themes regarding support needs in the interviews: mental health, social contacts (conflicts with others as well as lack of contacts), practical issues, and physical health. Participants indicate that they can release stress and frustrations whenever they come up and as often as necessary, which results in less accumulation of psychological tension. The registration data show that mental health was a highly prevalent theme in online support contacts. Some themes are more prevalent outside regular, nine-to-five support hours. For example, mental health issues were more prevalent in support on weekdays and during evenings. **Conclusions**: Our results suggest that 24/7 online support is a useful (additional) way of providing services to independently living people with ID. With regard to emotional and behavioral problems, it may have a signaling and preventive function.

Comparison of Demand for Care by People With Borderline Intellectual Disabilities in the Netherlands, England, Flanders and Ontario

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KEYWORDS Borderline Intellectual Functioning; Policy; Support

Aim: The combination of access to care for people with borderline intellectual disabilities and the increasing complexity of Dutch society has led to a rapid growth in the demand for care by this group. To investigate whether the Dutch case is unique, we examine if Ontario, Flanders and England have experienced a similar development in the demand for care by people with borderline intellectual disabilities, and explore possible explanations. **Methods**: The development of the demand for care and support by people with (borderline) intellectual disabilities is determined by findings from literature and policy documents. These findings are combined with results from interviews with 5–10 experts in this field in each region. This yields an indication of explanations for this development. **Results**: As in the Netherlands, the society in Ontario, Flanders and England is becoming more complex, although the effects on care differ. In England, the number of people receiving care dropped due to austerity. In Flanders, the waiting lists grew and in Ontario there is a shift towards community-based support. Explanations for these changes are mainly found in strict access to care, shrinking social networks, and a greater need of work-replacing activities. **Conclusion**: The organisation of the care system seems to be the main driver for differences in the development of the demand for care. In other regions, the access to care for people with borderline intellectual disabilities is more strict than in the Netherlands. They are often not recognized as being in need of care.

Greater Self-Determination, New Provisions on Control Measures

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KEYWORDS policy; practice; services; staff; support

Aims: The new Act on Special Care for the Mentally Handicapped entered into force in Finland on 10 June 2016. The objective of the act is to help disabled people to cope independently in the various stages of life. Self-determination is a human right enjoyed by all.

Consequently, each individual is to have to access to information relevant to oneself in a comprehensible format.

The reinforcement of self-determination, support for independent living and reduction of restrictive measures signifies a sea change in the service culture while presenting a new type of management challenge. **Methods**: Because of revised legislation Eteva has made systematic goal-oriented preparations for the change. **Results**: Special Care Directors, a statutory organ, monitor

compliance with the mentally handicapped act by establishing operational objectives. For compliance monitoring, a special inter-administrative working party was appointed to assume responsibility for the application of the law and preparation of guidelines. It has issued guidelines concerning the content of the service and care plan, use of control measures and a reform of the decision-making procedure, client records and the duty to inform the client and his/her next of kin. The act requires consultations with the client and an expert assessment. **Conclusions**: Acknowledging the client's point of view in a new way, has changed significantly our service culture, resulted in enhanced self-determination and improved also the quality of life of intellectually disabled persons.

Handicap, Education and Child Psychiatry: A Model of Intervention

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KEYWORDS education

In September 2005, an agreement was made between the Ministry of Health, the Ministry of Education and the Centre Hospitalier de Luxembourg, in order to establish a framework for child psychiatry for children with special needs and their families. Since then, we developed a model that we continuously adapt according to the needs and our possibilities of intervention. Our interventions take place within schools in close collaboration with the people working in the field. We propose our framework in order to support the care of the children as well as at an individual, group, social or family level. We know that we cannot deny our limits regarding our interventions and that we have to remain modest compared to the capacities of psychiatry in the context of mental disability. Thus, we remain a link between others and we join a network of essential care to guarantee support that is adapted to the individual needs for each person. We propose a more detailed exploration of our intervention model with a clinical case.

POSTERS

Does the Dutch Knowledge Programme Provide a Good Example for Bridging Research and Practice?

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KEYWORDS policy; practice; research

Aim: The aim of this paper is to present the Dutch Association of Healthcare Providers for People with Disabilities (VGN) and the national knowledge programme. It consists of three components: a research policy, an educational policy, and knowledge management. Rationale: Research and practice both aim to improve the quality of care in order to provide a good quality of life for service users. Both researchers and healthcare providers acknowledge that direct support staff applying state-of-the-art approaches contribute to this. However, a gap between research and practice hinders effective knowledge transfer. The Dutch programme resulted in The National Program on Disabilities, which started in 2015 and finances knowledge development, knowledge distribution and implementation; vocational trainings which have been connected to the competences needed by direct support staff in the field of intellectual disabilities; and the “Knowledge Square”, which provides a structure to facilitate knowledge exchange. **Conclusion**: This session will reflect on whether the Dutch knowledge programme provides a good example for bridging research and practice. Reflections on the content and the working components of this knowledge programme will be considered together with its usefulness for other countries and situations.

Insight Into the Organisational Environment of Services for People With Intellectual Disabilities and Challenging Behaviours

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KEYWORDS challenging behaviour; problem behaviours; services

Aim: The aim of this project is to generate knowledge with regard to the influence of the organisational environment on the provision of support services for people with intellectual disabilities and challenging behaviours. **Method**: This project is based on action research and uses methods like thick descriptions. Sessions are held with Dutch organisations which provide support services for people with intellectual disabilities, and the Centre for Consultation and Expertise. **Results**: Based on the thick descriptions, the first results provide insight into relevant themes in the organisational environment of support services for people with intellectual disabilities and challenging behaviours. **Conclusions**: Joint exploration of different Dutch organisational environments by different members of the organisation and of the Centre for Consultation and Expertise helps to understand the influence of the organisational environment on support services for people with intellectual disabilities and challenging behaviours, and generates hypotheses for interventions conducted by the organisations.

CASE REPORT ON INDIVIDUAL INTERVENTION

SYMPOSIA

Symposium: Combining Successful Treatment and Joyfulness in a Semi-Residential Facility

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KEYWORDS attachment; developmental disorders; psychopathology; therapies

Combining Successful Treatment and Joyfulness in a Semi-Residential Facility: A Program for Anxious Children (Five Days) and a Program for Infant Mental Health (Six Days).
The aim of symposium is the conceptualisation of new therapeutic programs for young intellectually disabled children.

SYMPOSIUM - ABSTRACT 1

Research Implications of the Semi-Residential Treatment at the Banjaard

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The Banjaard is a multi-disciplinary clinic with in—and outpatient facilities for children and adolescents between 0 and 23 years of age with a psychiatric disorder and an intellectual disability (IQ <85). At the Banjaard we adapt many treatment programs for intellectually disabled children, develop new treatment program, and apply research activities to these programs.

In this symposium we will demonstrate two of these practicebased, special treatment programs recently introduced in our out patient clinic.

Research is conducted about the effect on internalizing problems in the child's behaviour before and after the therapeutic program. In our other program, we have conducted research on progress in the child-parent interaction. The results of both programs will be presented.

SYMPOSIUM - ABSTRACT 2

Clinical Implications for Anxious Children

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Children with mild and severe intellectual disabilities have an increased risk of developing psychiatric problems. Common problems are anxiety and/or an extreme degree of uncertainty. Especially for this group, we have developed a new treatment program. During this treatment, children should become more confident, develop their social skills and become less anxious. The added value of this treatment program is that children are able to practice different skills for a period of five days. In addition, children are offered a creative program, exploring the potentials of the child. During these days, we will get a profound impression of the children. It helps us to understand them better and obtain a clearer diagnosis. At the end of the week, the results will be displayed in a spectacular performance by the children themselves, accompanied by a professional artist.

During the interactive presentation we will use video materials to showcase the program. By doing so, we highlight the creative elements of this program, the effectiveness of the treatment, and the enthusiasm of the children while participating in the activities.

SYMPOSIUM - ABSTRACT 3

Clinical Implementations for Infant Mental Health

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For young children with developmental delay we have created a semi-residential Infant Mental Health program, where toddlers visit our clinic together with their parents. We focus on attachment using elements of "theraplay". By using these elements, we stimulate, motivate and guide parents during their interaction with their child, adjusted to the child's abilities and needs. By doing so, we pay attention to the importance of being responsive and sensitive towards the needs of the child in the interaction.

We also approach the attachment and interaction between parents and their child by highlighting experiences parents share with their child, supported by the implementation of attachment theories.

Parents are also aided in connecting with their child by showing them video material of their mutual interaction, which we will show in the presentation. We will also talk about the attachment theories which we use in support of the video material.

Symposium: Living With an Intellectual Disability: How to Engage Individuals' Voices and Stimulate Autonomy and Self-Determination?

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KEYWORDS Autonomy; powerful voices; self determination

Background and aim of symposium: Respect for autonomy and self-determination is important in providing good quality care to people with intellectual disabilities. In this symposium, results will be presented from three research projects aimed at gaining more insight into the level of autonomy and self-determination as experienced by people with ID, varying from people with mild ID via people with moderate ID to people with profound and multiple ID.

SYMPOSIUM - ABSTRACT 1

The Importance of Autonomy Support, Need Satisfaction, and Motivation in Adults With ID

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Aims: Self-determination is an essential dimension of quality of life. Self-determination theory (SDT) highlights the important role of autonomy-supportive environments to provide more opportunities for people to develop self-determination. According to SDT, the link between autonomy support and subjective well-being is mediated by 1) basic psychological need satisfaction, and 2) autonomous motivation. So far, no studies have been conducted to test the theoretical premises of SDT among people with mild to borderline intellectual disability (MBID). **Methods**: The tenets of SDT were tested with structural equation modeling for 186 people with MBID. The participants were aged between 18 and 84 (mean age = 40.3); 110 were male. Some participants showed additional challenging behaviors or additional diagnoses. Various validated and reliable questionnaires were developed and used to measure autonomy support, basic psychological need satisfaction, and autonomous motivation as experienced by people with MBID. **Results**: The results showed that: 1) perceived autonomy support was positively associated with autonomous motivation and with satisfaction of the needs for autonomy, relatedness, and competence; 2) autonomous motivation and need satisfaction were associated with higher well-being; and 3) autonomous motivation and need satisfaction statistically mediated the association between autonomy support and well-being. **Conclusions**: The study provides evidence for the important role of autonomy-supportive environments for people with MBID regarding well-being and basic psychological needs. Moreover, these findings support the application of SDT in the field of ID, where it may give a much needed boost to research on the psychological needs and motivational processes in people with ID.

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SYMPOSIUM - ABSTRACT 2

Do Rules in Daily Care Promote Individuals' Autonomy? The Perspective of People With Moderate Intellectual Disabilities

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Aims: In residential care for people with moderate intellectual disabilities (ID), rules are applied aimed at providing structure and safety. These rules should contribute to the promotion of the autonomy of individuals, i.e. sustaining their self-development by relevant others (Schermer, 2001). However, little is known about the perception and valuation of rules in daily care of individuals with MID themselves. **Methods**: We conducted interviews with 8 individuals with moderate ID asking for daily rules within five domains of daily life (e.g. bedtimes). Interviews were conducted during three periods of time per day, related to the (possible) occurrence of rules in these five life domains. Next, we examined the clinical files of the individuals for information regarding daily rules. Finally, support staff was interviewed regarding rules in daily care for these particular individuals. Two researchers independently carried out qualitative analysis, both inductively and deductively. **Results**: Individuals with moderate ID accept most of the applied rules and indicate reasons why these rules are applied upon them, e.g. for promoting their health. In addition, the answers provided by the individuals indicate that the opinion of support staff and relatives is important in their own valuation of rules. In case individuals experience rules as restraining, support staff indicate that they rather explain the rule than discus it. **Conclusions**: Attentiveness and an open dialogue in which rules can be discussed are imperative in providing care in which the autonomy of individuals is promoted.

SYMPOSIUM - ABSTRACT 3

Taking Into Account the Perspectives of People With Profound Intellectual and Multiple Disabilities in Decisions Regarding Restrictive Measures: The Development of a Prototype Instrument

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Aims: People with profound intellectual and multiple disabilities (PIMD) have limited ability to communicate and represent themselves verbally. Thus, decisions regarding the use of restrictive measures rely on estimations and preferences of proxies (i.e. professionals and family members). The risk of perception gaps arises. We aim to explain how we developed a prototype instrument to carefully estimate and involve individuals' perceptions of decisions regarding the use of restrictive measures. Also, a first impression of the prototype instrument will be demonstrated. **Methods**: Observations and semi-structured interviews with support staff, employees, and psychologists were conducted to collect data about daily decisions, implicit and explicit routines, and concrete examples regarding the use of restrictive measures. Observations were conducted in two residential facility group homes for people with PIMD. Analyses of observations and interview data were validated by conducting a focus group with support staff, policy employees, and psychologists. **Results**: Data from the interviews and observations were combined with knowledge elements from three related previous studies and served as input for the design of our prototype instrument. The instrument is supposed to support professionals to carefully estimate and involve individuals' perceptions of decisions regarding the use of restrictive measures. **Conclusion**: Perceptions of individuals with PIMD are easily overshadowed in cases of decisions about the use of restrictive measures. Therefore, it is relevant to conduct pilot studies and assess whether the prototype instrument supports professionals with the aim to better understand the individuals' perceptions of care and the consequences for the use of restrictive measures.

Symposium: Handicap & Trauma

Name of chair: Steve Oosterlinck
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KEYWORDS Attachment; challenging behaviour; family; life events; psychotherapy

Background and aim: We want to highlight the interaction between disability and trauma in children and adults. In intellectual disability there is a chronic trauma and a (higher) possibility of incidental trauma. We want to illustrate the interrelation of these traumas with several case studies. We want to show some important aspects of treatment.

SYMPOSIUM - ABSTRACT 1

Trauma Traumatizes

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The trauma of an individual may not only have disastrous effects on the emotional life and functioning of the individual, it also influences their family, environment and professional network. Even when the trauma remains largely wordless, it will speak out loud. I aim to substantiate this proposition with a casus. The casus concentrates on a resident in our facility, a woman with an intellectual disability and severe personality problems. The complex psychopathology, including repeated self-destructive behavior, affects everybody and confronts us with our therapeutic limits. This presentation focuses on how to understand the aforementioned dynamics, on the one hand, and how to deal with them within the facility, on the other.

SYMPOSIUM - ABSTRACT 2

Psychotherapy With Traumatized Children With Intellectual Disability: Reflections on the Therapeutic Process

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In our daily work as a psychotherapists, we meet many children with early childhood trauma and permanent chronic traumatization. In this contribution we want to present some reflections about the therapeutic work with these children with intellectual disability and severe trauma including neglect, abuse or violence. First, we want to illustrate the effects of (chronic) trauma in children with intellectual disabilities. We highlight the body-mind connection and the effects of chronic stress on the development of the brain. Through observations of behaviour we describe the disorganized attachment, and physical and verbal agitation as second skin phenomena (Bick, 1968). Further, we talk about appropriate therapeutic attitudes and interventions for these children, who are characterized by hyperarousal, disorganized attachment, and behavior problems. After a search for a therapeutic framework to work with these children, we want to discuss the therapeutic process. We meet these strongly traumatized children at a very young age and in an extremely anxious state, while keeping in mind that they the anxiety they experience feels very real to them (equivalent mode) (Fonagy). The interventions of the psychotherapist as an attachment figure and a developmental object have the aim to experience shared physical emotions. We can call this process "playful affect mirroring" (Fonagy), which is important for the formation of affect regulation. The purpose of these interventions is that these children experience their feelings and thoughts as something real and important, and yet different from the external (threatening) reality.

SYMPOSIUM - ABSTRACT 3

Trauma and Repetition

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In this lecture, we want to highlight the interaction between disability and trauma. We will introduce and compare two case studies with similar symptoms as a reaction to chronic and incidental trauma: forgetting, neglect (not-knowing), flight (fugue), restlessness, severe auto-mutilation, aggression and manipulation. For all these phenomena, there is an important cultural and contextual influence.

The following topics are included: developing healthy and secure attachments, dealing with intense feelings of shame, helping individuals to cope with traumatic experiences and therapeutic responses to cultural and religious diversity.

What are the emotional needs of this very challenged group of people? Instructors and therapists may have to act and function as a thinking and feeling self for the individual for a period of months or years, while always looking for opportunities to facilitate the patients' own capacity to think and feel for themself, developing a containing "mental skin'. Safety, holding, and containment are the key concepts.

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INDIVIDUAL PAPERS

Giving a Voice to the Speechless

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KEYWORDS Person-centred approach; Services; Staff

Care teams working with people with severe intellectual disability, like other psychosocial care teams, are faced with the challenge to maintain an individual and group equilibrium balancing between feelings of insufficiency (and the danger of helpless resignation) and phantasies of omnipotence (and the danger of selfless exposure). The referent reports about his work as supervisor with such care teams. He developed a four-step intervention program in order to promote a better understanding of the affected persons and a better functioning of the staff. Empowerment, distinction, role clarification, and the development of the team-as-a-whole are analyzed by means of the specific professional group dynamics, and adequate interventions are suggested. Supervision, either selective or in a continuous setting, can be a valid contribution to better care work.

Essential Factors in the Treatment of Mental Health Problems in MBID: A Case Study

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KEYWORDS Challenging behaviour; Empowerment; Multiprofessional approach

Introduction: People with mild to borderline intellectual functioning (MBID) are more at risk of developing psychopathology compared to people without ID. In order to be effective, treatment for both mental health problems as well as challenging behaviour (CB) often has to be adapted for this population. The aim of this study was to identify essential success factors in the treatment of a young woman with extreme self-harming behaviour. **Method**: This study was conducted at a treatment center for persons with MBID and severe mental health problems. Treatment was adapted to the needs of the patient, placing her in a central position and structurally explaining every step in the treatment process. The patient, professionals, and her family took part in weekly evaluations to facilitate commitment and empowerment of the patient. Every 6 months, an independent trauma expert was consulted. Staff was weekly coached on how to act regarding the self-harming behavior and how to stay mentally fit. Data on the frequency of self-harming behavior and restrictive measures was analyzed. Video recordings were made to facilitate the treatment process. **Results**: Self-harming behaviour and restrictive measures decreased from daily incidents to none after 2–3 years of treatment. Success factors identified by staff, the patient and her family were true compliance with and understanding of the treatment and its goals. The patient became able to explain her own diagnosis and also to reflect on her own behavior. **Discussion**: The clarification of treatment goals to all parties involved (including the patient with MBID) made it possible to create a collaborative effort, which proved to be essential for successful treatment.

On the Way to Work

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KEYWORDS Borderline Intellectual Functioning; Participation; Social Inclusion

Aim: Finding and holding onto a job is difficult for people with borderline intellectual disabilities. We therefore examine how the labour market participation of this group could be enhanced and what they need in order to secure a sustainable employment relationship. **Method**: We conduct a literature study of theoretical and empirical Dutch reports to point out under which conditions people with borderline intellectual disabilities successfully find and hold a job. **Results**: Our analysis shows that the employment chances of people with borderline intellectual disabilities begin with their visibility to employers. Once employers are more aware of the capabilities of people with

borderline intellectual disabilities, the next step is to create suitable employment. This (often) requires adaptations in the employment process, followed by a targeted recruitment and selection policy. Here, employers need help from the government and intermediary organisations. Finally, inclusive organisations are needed to ensure that employment relationships endure once they have begun. **Conclusion**: There are costs and benefits to enabling people with borderline intellectual disabilities to participate in society as fully as their capacities allow. For example, employers need to be compensated for the relatively lower productivity of employees with disabilities. Viewed from a broader perspective, this "investment" can however deliver considerable societal benefits, such as the social benefits of less isolation, less societal division, less nuisance and more participation.

Obsessive-Compulsive Disorder in an Adolescent Woman With Turner Syndrome and Intellectual Disability: A Case Report

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KEYWORDS Genetics; Neurodevelopmental disorders; Psychotherapy; Quality of life

Background and aims: The intellectual development of patients affected by Turner syndrome (TS) has a normal range. Some authors link mosaic karyotype TS to intellectual disability, but only a small number of literature about correlations between TS and mental disorders can be found (Blanc, Bourgeois, & Fontange, 1966; Prior, Chue, & Tibbo, 2000; Temple & Carney, 1993; Van Dyke, Wiktor, Roberson, & Weiss, 1991). Our aim is the description of the characteristics and treatment of TS with severe obsessive-compulsive disorder (OCD). **Methods**: A 24-year-old woman (S.) with mosaic karyotype TS, ID and OCD was referred due to a severe and debilitating form of OCD. S. showed dwarfism, acoustic agnosia, amenorrhoea, pressured speech, intellectual disability (WAIS-R = 73) with disability pension. OCD was shown since the age of 10. Compulsive cleaning was the most pervasive symptom and compromised both her and her family's quality of life. She was prescribed Fluvoxamine 300 mg and Olanzapine 10 mg, but the latter was suspended due to drowsiness. She needed brief psychotherapy to manage symptoms particularly for her low intellectual resources. Her symptoms improved slowly but significantly. **Results and conclusions**: Fluvoxamine showed a good efficacy on OCD symptoms with no side effects. Intellectual disability clearly influenced her treatment management needing a psychotherapeutic approach in support to pharmacological therapy.

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Being Me – Being Us - Being Professional

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KEYWORDS Quality of life; Staff

Background: An educational attitude is often taken as a decisive factor on which professional work is based. But what exactly is an educational-professional attitude? **Method**: Digital story telling is a method to reflect upon our actions. It's the creation of a video clip, based on the autobiography which reflects our personal values. **Results**: The result of the study was the presentation of a digital story and its transference into the educational work as a possibility to investigate this question. **Conclusion**: To approach to the subject in an educational attitude, the staff members of the inclusive kindergarden TOPOLINO /APEMH have placed special emphasis on the analysis of the individual as a person. The team uses personal creative powers and expressiveness, subjective experiences, values and self-competences besides specialised knowledge as a starting point for professional work.

POSTERS

Woman of Her Own Life – Improving the Career Management Skills of Women With Disabilities

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KEYWORDS Autism spectrum disorder; Challenging behaviour; Development; Empowerment

The purpose of this project is to prevent the exclusion of women with disabilities and promote their participation in society. The primary target group of this project consists of women with disabilities who have problems with learning, understanding, communication, and mental health. The secondary target group includes professionals working in social care, health care, education, and employment services. The professionals will be able to use the workshop model as a new form of service.

Developing the workshop model is carried out as follows. Each project partner launches a workshop group in its own area. The groups are led by project coordinators and partners assigned by project partners. Women with disabilities act as experts by experience and develop the workshop model in collaboration with professionals.

The main result of this project will be a workshop model for improving the career management skills of women with disabilities. The model can be reproduced to strengthen the capacities of any person in need of special support.

The project began in 2017 and is scheduled to end in 2019. The project is developed an coordinated by KTO-Kehitysvama-alan tuki- ja osaamiskeskus (The Support and Expert Center for Persons with Intellectuel Disability).

The Young Ones: How to Approach Young Adults With a Mental Disability Who Do Not Seem to Fit In

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KEYWORDS Autonomy; Challenging behaviour; Rights of people with ID; support

Aims: Offering appropriate support for young adults with a minor mental disability and important emotional and/or behavioral problems by adjusting care to varying requests for help and their craving for autonomy versus needs. **Methods**: We adjust customized care for a heterogenic target audience, aged between 18 and 30 years, both (semi)residential and outpatient. The past decade we started support for about 30 "difficult" young adults, with a history of numerous (failed) admissions and/or a criminal record. To get them involved in a mutual story, we offer them opportunities and space on one hand, and guide and hold them on the other hand. **Results**: These people need flexible care. Clarity, structure, guidance, empowerment, opportunities are united in the creation of a warm and safe environment: one where they can always rely on, their severe problems don't cause exclusion, what is offered is adjusted to their individual needs and bearing strength of the moment, and where there is room for their own responsibility and freedom of choice. From different views, we keep looking for a connection and keep reaching out—even when they run away, abuse substances, use aggression. This method requires conscious decisions and perseverance throughout the entire organization. Follow-up shows that long-term processes are successful. Only two persons ended the support. **Conclusions**: Young adults with a minor mental disability, "difficult" behavior and varying requests for help and assistance, need flexible persistent support with respect for their own identity. A non judgmental and positive approach delivers results.

(The Success Story Of) Music Therapy in a Luxembourg Facility for Mentally Disabled Persons

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KEYWORDS Practice; support; therapies; wellbeing

Aims: The Luxembourg Association of Music Therapy uses music to facilitate, develop and re-establish people's physical and mental balance (www.musiktherapie.lu). One of the aims is to optimize the quality of life by mobilizing resources and potentials. As a non-verbal form of expression and communication, music appeals to people's emotions, thus stimulating cognitive as well as social and creative abilities, which will in turn allow the person to deal with upcoming conflicts and challenges in life. Due to the various parameters of music (e.g. rhythm and melody), music therapy, whether active and/or receptive, generates intra-psychic and relational processes. **Method**: According to the respective needs, a licensed music therapist approaches individuals in verbal or non-verbal ways. In our facility, music therapy is regularly employed in individual and group settings. Consultancy (e.g. analysis of vocalisations and assistance in everyday contact), creating individual and collective musical panoramas of life, training (e.g. impacts of music), and coaching (e.g. analyses of the soundscapes of the facility) have become important tools. **Results**: At Yolande asbl, music therapy has proven to be effective in many ways. Diverse positive effects range from a greater understanding of the multiple forms of music to its application. Especially for people with mental disability, it is a new and creative way of communicating without words. **Conclusion**: Based on our experience, music therapy seems to be an alternative method to accompany people with a mental disability. In the future, other facilities should also assess the necessity of such a novel way of therapy.

"Duerfbuttek and Duerftreff Beim Lis" – An Inclusive Solution for Small Town Desires

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KEYWORDS empowerment; inclusive community living; participation; social inclusion

Aims: Integrating people with an intellectual impairment into the daily life of communities is one of the highest goals in modern inclusion (Gitschmann, 2012). However, the initiative may not only be taken by the community itself, but also by the people concerned. **Method**: Basic infrastructure has not been available in the small town of Roodt/Syre in Luxembourg for a long time. Hence, the branch of a local social organization for people with disabilities (elisabeth), together with the support from its partners CACTUS (a local supermarket chain) and the EU Agricultural Structure Fund (LEADER), wants to improve the quality of life in the municipality by developing trainings and jobs for people with intellectual impairments. At this organization, providing job training has been done for years at the so-called CPP (professional education center). With regard to an inclusive approach (Dannebeck, 2000), the new store ("Duerfbuttek"), built below one of the fairly autarkically living groups of the facility, will not only bring new neighbors to the area, but it is also a provider of the services needed (e.g., postal service, regional and fair trade foods & goods, elisabeth products). The "Duerftreff" will also be a coffee place, intended to be a meeting and communication center for the inhabitants of all age groups. Volunteers who want to get involved are very welcome. The two leading coordinators keep the connection to the home facility by offering various artistically-inclusive workshops (e.g. ceramics, candle production) to the public. Start of the project is June

2017. **Results & Conclusion**: First experiences on both sides will be reflected and evaluated. The focus is primarily placed on learning and further opportunities for the development of the project.

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EDUCATION, REHABILITATION AND EMPLOYMENT

SYMPOSIA

Symposium: Identifying the Key Elements of the Creation of Inclusive Employment and Job Retention for People in High Psychological Vulnerability and Mental Disabilities

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KEYWORDS Adaptive skills; Deinstitutionalisation

Aim and background of the symposium: The co-construction of inclusive spaces, variable and negotiable working hours, support and training in employability or even follow-ups by psychological and educational referents, encourage all actors to build a network to enable the person concerned to have access to lawful employment and remedial employment.

SYMPOSIUM - ABSTRACT 1

The Different Models of Professional Inclusion From a Practical View

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Aim: ATP asbl is an organisation helping people with severe psychiatric disorders and mental disabilities in their professional rehabilitation. In Luxembourg, the professional inclusion of these individuals does not seem to lead to satisfying results. **Method**: This study explains and analyses the actions taken by sheltered workshops for the professional inclusion of people with severe psychiatric disorders over the last 10 years in Luxembourg. **Results**: The results of this study will inform policy makers and persons in charge of professional rehabilitation about the actual situation in Luxembourg, highlight the specific problems in the treatment of people with double diagnoses, and present suggestions for the much needed restructuration of the actual framework.

SYMPOSIUM - ABSTRACT 2

Perceived Obstacles to the Integration of Intellectually Disabled Individuals Into the Job Market: A Sheltered Workshop's Point of View

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The general aim of this presentation is to point out obstacles complicating or impeding the process of integrating people with an intellectual disability into the job market. During the past years, we could detect a shift in the nature of the population of our sheltered workshops. The individuals are often burdened with social precarity, psychological vulnerability, intellectual delay, and possess enhanced work abilities enabling us to improve the quality of our work, but their way out of the sheltered workshops and into the job market still remains closed. The obstacles that arise can be traced back to issues linked to the intellectual disability itself in all its aspects (social, psychological, intellectual, pedagogical) as well as to current social norms (i.e. an economy based on efficiency and profitability that leaves no place for weakness, social awareness or tolerance). Another issue is the special framework the sheltered workshops offer in order to live up to the population's increased and specific needs and demands, a framework that does not exist on the job market despite some companies' efforts to hire people with an intellectual disability.

In order to facilitate the illustration of these problems, we will utilize small case studies taken from our daily practice.

INDIVIDUAL PAPERS

Peer Mentoring for Secondary School Students With Profound and Multiple Learning Difficulties (PMLD)

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KEYWORDS Education; Research; Social inclusion; Wellbeing

Aim: Individuals with PMLD may experience mental health problems which can be exacerbated by limited communication opportunities and the challenge of interpreting their behaviours (Fergusson et al., 2008). This study investigates the use of peer mentoring (PM) with such individuals, process issues and impact on well-being. Further, it is explored how far individual preferences and experiences can be ascertained as well as benefits and limitations. **Methods**: A participatory "Mosaic" methodology (Clark & Moss, 2011) was employed to gather data with five young people with PMLD aged between 14 and 16, attending a secondary special school in the UK over a 7-month period. Data were gathered using activity-based methodological tools including child-led photography, video recordings, mapping exercises, and interview conversations with students. These data were combined with researcher observations as well as nine peer mentors and ten staff perspectives to co-construct a mosaic of knowledge regarding the students' experiences. **Results**: Peer mentors' adaptation of tasks provided a fresh perspective on the students' worlds. This supported staff involved in the study to reappraise students' needs, preferences and wishes. PM was identified as reducing isolation and supporting well-being as it increased the opportunities for interactions for students with PMLD. Furthermore, benefits were identified regarding peer mentors' confidence, self-belief and empathy. **Conclusion**: This study identifies and acknowledges the challenges inherent in supporting and undertaking research with those with PMLD. It suggests that PM can be a useful tool in supporting such individuals and that the Mosaic methodology can support their participation in research.

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Measuring Job Satisfaction in People With ID Using JIGS and JDI: An Analysis Using Item Response Theory

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KEYWORDS prevention research; services; stress

Aims: Reduced job satisfaction represents risks for mental and physical health. Regular evaluation of job satisfaction is thus an important step in preventing mental health problems and challenging behavior. However, empirical evidence for applicable instruments to assess job satisfaction in people with ID is sparse. The aim of this study was to assess the usefulness of the Job Descriptive Index (JDI) and the Job in General Scale (JIGS) for the evaluation of job satisfaction in people with ID. **Method**: 129 participants with mild to moderate ID working in sheltered workshops across Luxemburg completed a questionnaire consisting of the JDI, the JIGS and the work subscale of the Residence Satisfaction Questionnaire (RSQ-WS). Additionally, comprehensibility of items as well as subjective relevance of questions was assessed. Subsequent analyses of the questionnaires were conducted using latent trait models under item response theory. **Results**: Comprehension was sufficient for all scales, except the promotion subscale of the JDI. All other scales also exhibit

good internal consistency. A high correlation between the JIGS and the RSQ-WS indicates good convergent validity. Further analyses using the generalized partial credit model indicate that most subscales contain only a relatively small subset of discriminating items. **Conclusion**: With the exception of the promotion subscale, both JIGS and JDI are applicable and useful instruments for assessing job satisfaction in employees with ID. Item response model analyses indicate possible reductions of items to increase assessment economy.

Vision, Concretism, Repetitism: Typical Artistic Design Features in Drawings by Adults With Autism and Intellectual Disability

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KEYWORDS Autism Spectrum Disorder; Diagnosis; Research; Therapies

Aims: Many people with autism spectrum disorders (ASD) show photographic memory and visual strength. Artists with high-functioning autism enrich the world of art with their unique designs and aesthetics. Geometric forms, serial structures, and the combination of images and writings are described as characteristic features. However, the artistic expression of individuals with ASD and intellectual disability (ID) has obtained little attention until now. This study assesses which specific design features can be found in in artworks created by individuals from this group. **Methods**: In order to develop a list of design characteristics, 120 paintings by individuals with and without ASD were systematically sifted. Re-occurring features in the area of form (e.g. arrangement) and content (e.g. realism) were assessed and grouped to these categories including various subdomains. The list of characteristics was tested psychometrically using a sample of patients with ASD and a control group matched for age and IQ ($N = 40$). All paintings were rated by three independent experts. Inter-rater reliability was measured by the mean absolute agreement. The selection of items was based on their discriminant validity ($Phi > .20$). **Results**: Overall, 60 design features were identified and grouped to the categories of form and content, and the different subdomains. Inter-rater reliability showed to be good ($M = 82.6\%$). Nine items discriminated distinctly between individuals with and without ASD, while line structure and repetition showed to be significant markers. **Conclusions**: The artworks by adults with ID and ASD displays specific formal design features. This may provide important diagnostic clues and support the diagnostic process in this group.

Predictors of Successful Teamwork in Care Management for People With Intellectual Disability

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KEYWORDS Adaptive skills; Challenging behaviour; Staff; Stress

Aims: Working predominantly in teams has become reality in many fields of work. Especially in the context of social and health institutions, effective teamwork is highly valued by employers, colleagues, individuals with ID, and patients alike. Following current theoretical models from team research, this study aims to identify, measure, and feedback influential states and processes in care teams. Subsequent feedback may help to build shared team awareness, foster team development and benefit the person in need. **Method**: Evidence-based indicators for effective teamwork were derived from input-mediator-outcome-input models (IMOI; Ilgen et al., 2005) and from stress-demand-resource models (Bakker & Demerouti, 2007). Relevant variables were tailored for employees working with people with an intellectual disability. In a survey study, single-item indicator scales (Nagy, 2002) were applied in two large social facilities in Luxembourg (Elisabeth). **Results**: First, we identified influential team states (e.g. goal clarity), processes (e.g. communication), and demands as well as objective and subjective ratings of teamwork quality. In the second step, we tested these indicators in regard to their importance for employees' motivation, health, satisfaction, and the handling of challenging behavior. **Conclusion**: We discuss general and specific success factors of teamwork when working with people with an intellectual disability. We introduce effective feedback methods for team members in order to support development and learning (e.g. Ellwart, Happ, Gurtner & Rack, 2015).

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Working With Intellectually Disabled People With a South Asian Family Background: User Views of Services (Part 1)

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KEYWORDS family; research; social; social inclusion

Aims: This paper describes a number of research projects on user views of services for people with intellectual disabilities with a South Asian family background carried out over the last decade. **Methods**: Qualitative methods were employed and participants were interviewed either individually or as focus groups. They included parents living in South Asia (India) and first- and second-generation parents living in England. **Results**: In England, first-generation parents expressed a number of reservations about the health and social services offered to their adult child, whereas second-generation parents appear more satisfied with services and more inclined to use them. In India, parents indicated that they are keen to embrace integration and Western models of service. **Conclusions**: Service providers would do well to invest more time and effort to understand the various socio-cultural frameworks that are used by adults with intellectual disabilities and their families when decisions are made about accessing health and social services or not.

Student-Oriented Teaching Skills for Children With Intellectual Disabilities

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KEYWORDS education

Background: Conferring to research, the profession of teaching requires exceptional training and capability in planning lessons in accordance with didactics and methods. However, lessons are often adjusted to the subject rather than to the student. **Method**: The sample of the study consisted of children with intellectual and physical disabilities, aged from 0 to 18 years. The sample was obtained from a non-profit special needs center in Jeddah, Saudi Arabia, where teachers would focus on finding methods accustomed to the students through mutual classroom supervision/observations of each other's teaching styles followed by problem-solving discussions. The school's objective was to provide children with intellectual disabilities with the opportunity to learn, live and play in a safe environment to further enhance their quality of life. **Results**: Through teachers ' observations and discussions, the central finding of the study was that teachers could acquire children's interest, attention, and concentration by using simple techniques that enhance their quality of education. **Conclusion**: Based on research findings, it is advised that teachers use methods such as videotaping and supervision to obtain information about other teachers' performances. In conclusion, the findings contribute to useful purposes of the obtained information serving as a basis for workshops and general recommendations.

POSTERS

Simulated Patients With Intellectual Disabilities - Turning the Table to Meet Health Needs

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KEYWORDS coproduction; education; empowerment

Aims: To provide high fidelity, authentic clinical simulation training to health and social care staff to meet the mental and physical health needs of people with an intellectual disability (ID). **Methods**: We worked with a local theatre company that employs actors with an ID. The actors and their support staff worked in partnership with the simulation team and clinical experts to develop the scenarios which the actors rehearsed and performed during four one day clinical simulation training events. Participants' knowledge, skills and confidence were rated before and after the training. The views and experiences of the actors were also sought. **Results**: Healthcare skills and confidence showed statistical improvements from pre—to post-course. Qualitative analyses demonstrated that participants perceived improvements in their: attitudes; communication skills; use of reasonable adjustments; inter professional working; and knowledge of key issues in working with people with ID. The actors felt that the 'tables had turned' as they were able to influence health and social care staff about what it is like to live with an ID. They felt positively valued as a paid member of staff living the values of rights, choice, independence and inclusion for people with an ID. **Conclusion**: Simulation Training in partnership with actors with an ID is a novel and seemingly effective way of providing education and training to health and social care staff to meet the often complex health needs of this population. The positive effect on the actors of their experiences demonstrates that coproduction is required and necessary.

Lights on Rights! A Reflection Focus to Promote Active Citizenship of People With Intellectual Disabilities

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KEYWORDS inclusive community living; participation; rights of people with id; self determination; vulnerability

The Erasmus+ Strategic Partnership "Lights on Rights" is made up of entities from five European countries (Spain, Slovenia, Poland, Hungary, and Sweden) that develop a cooperation program from 2015 to 2017. **Aims**: The aims of our study are to gain knowledge of the UN Convention on the Rights of Persons with Disabilities and its Recommendations in Europe, to foster respect for rights, visualize violations, develop detection strategies, and encourage the

active teaching of citizens. Further, to increase practices with the participation of people with ID, the establishment of dissemination and impact plans as well as the establishment of synergies with different European associations and forums. **Methods**: Our methods include transnational meetings involving people with ID, the development of a methodological guide to promote the rights of citizens with ID, specific scales for family members, professionals and people with ID to assess knowledge and respect for rights as well as specific scales for professionals, families and people with ID to assess the degree of discrimination. **Results**: From the beginning of the project there has been an exchange of vital, cultural and intellectual experiences in the different transnational meetings. A methodological guide for the promotion of rights at a European level is developed. A database is produced with the results of surveys and specific scales at a European level. A web page of diffusion of the project is created at https://lightsonrights.wordpress.com/and a multiplier event is organized to disseminate project results, etc. **Conclusions**: The Erasmus+ project has offered the possibility of moving forward in the full conquest of rights for people with ID. Transnational educational exchange offers people with ID an opportunity to develop experiences, to recognize and exercise their right to full citizenship.

Job Satisfaction, Job Demands, Job Resources and the Moderating Results for Personality Traits of People With Intellectual Disabilities

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KEYWORDS participation; research; support; wellbeing

Background: This study investigated the associations of job satisfaction and job characteristics (i.e. job demands and job resources) and personality, using the job demands-resources model. Based on the results of a qualitative study using Photovoice, three job demands and five job resources were included. **Method**: 117 persons with intellectual disabilities (ID), recruited from a Dutch care organization, were interviewed on their perception of the job demands, job resources and their job satisfaction. Structured questionnaires were used that were adapted from well-established instruments. Data on personality traits (extraversion, neuroticism, conscientiousness) were gathered from their employment support workers. **Results**: Job resources showed a positive association with job satisfaction, while no significant direct association was found between job demands and job satisfaction or between personality and job satisfaction. Analyses were controlled for age, which was positively related to job satisfaction. Moderation analyses showed that for people with ID with high conscientiousness enhanced job demands were associated with reduced job satisfaction, which was not the case for those who scored low on conscientiousness. **Conclusions**: In employment support for people with ID, job design seems important. Job demands often play a central role in this respect. This study points out, however, that it may be particularly important to pay attention to the level of job resources. In addition, the results indicate that adequate job design may also require paying attention to personal characteristics,

such as personality traits and age, and how these interact with an individual's perception of the job characteristics and motivation for work.

EMOTIONAL, RELATIONAL, AND SPIRITUAL ISSUES

SYMPOSIA

Symposium: Staff Coaching Based Upon Emotional Development, Emotional Availability and Mentalization

Name of chair: Filip Morisse
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KEYWORDS Practice; staff; training

The developmental approach, with focus on emotional development, has been proven to be of large value for the mental health of persons with intellectual disabilities (ID). These perspectives oblige the environment (natural or professional support) to adapt to a person's basic emotional needs, which underlines the assumption that (challenging) behavior is not situated within a person, but is rather the result of the interaction between a person and their environment. During this symposium, we will present the findings of a practice-oriented research project in a residential service for individuals with ID and severe challenging behaviour. A team of 6 caregivers and 2 supervisors who support 7 individuals participated in an intensive process of training, intervision and coaching, both individually and team-based. During these interventions, the project team used the principles of emotional development, emotional availability and mentalization. The process resulted in caregivers being more sensitive to the emotional needs of the individuals, thereby reducing challenging behaviour. This project has not only increased motivation and strengthened the role of the caregivers, it has also proven to be a preventive measure against burn-out of the caregivers. Due to the small sample size, these results should be interpreted with caution and further research on these promising findings is warranted.

SYMPOSIUM - ABSTRACT 1

Coaching a Team by Going Back to the Essence of Learning, Based on the Learning Model "High Impact Learning" by Dochy and Colleagues

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In this talk, we will illustrate a sustainable way of cultivating formal and informal learning within a team of support workers. The goal was to create a context in which a team is constantly working and

learning together, and team members strongly challenge each other to reflect critically. In order to pursue this goal, the aim was to strengthen the intra-team communication, problem-solving capacities and trust in each other. We will present the essence of this learning trajectory, based on the seven building blocks of "High Impact Learning" (Dochy et al., 2015), which contains important keys such as authentic learning (coaching on the job), flexibility, self-management, and personal coaching.

SYMPOSIUM - ABSTRACT 2

Emotional Availability, Stress-Regulation and Mentalization of Caregivers: A Coaching Framework Illustrated With A Case Study

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In supporting people with intellectual disabilities, attention is increasingly focused on adapting to a person's basic emotional needs. A quintessential need relates to being securely attached to caregivers. This is a central tenet because people with ID need relational support to promote their quality of life. To support a more secure attachment to caregivers, the framework of "emotional availability" (Biringen et al., 2005) offers inspiration. This framework is used to facilitate the caregivers' attunement to the emotional needs of people with ID. To be emotionally available, it is necessary that a caregiver is able to "mentalize". Mentalization is the process through which we make sense of each other and ourselves in terms of subjective states and mental processes (Bateman & Fonagy, 2010). Through mentalizing, caregivers become able to "emotionally understand" the behaviour of the person with ID. This process is challenged in the interaction with people with ID and severe challenging behaviour because behaviour problems provoke considerable stress in the attachment relationship. Since we know that stress of caregivers hinders their capacity to mentalize, it is of utmost importance to offer them attuned coaching to regulate and understand their stress and emotions (Ogden & Minton, 2000). During this symposium, we present our integrated model "emotional development in connection" which we practiced in our coaching of caregivers. This model will be illustrated by a single case study.

SYMPOSIUM - ABSTRACT 3

Staff Coaching Based Upon Emotional Development, Emotional Availability and Mentalization: Key-Factors and Implications

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Over the period of 1 year, an intensive action research project (based on an embedded multi-case study design) was meticulously monitored and described. Using both quantitative and qualitative evaluations, essential success factors could be identified. This has resulted in recommendations for training, coaching and an HR-policy for individual staff members and teams working with people with intellectual disabilities and mental health needs.

Symposium: Attachment in Practice

Name of chair: Jennifer Clegg[a,b]
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KEYWORDS Attachment; Intervention; Practice

Aim: To show how attachment can inform and support clinical interventions in ID. **Background and objectives of symposium**: Exponential rise in research into attachment and ID supports a range of measures and interventions in ID. This symposium introduces a practice guideline for clinicians that summarises these developments; identifies and argues for the need to address two criticisms of attachment; and elaborates new interventions grounded in Mentalization-Based Therapy.

SYMPOSIUM - ABSTRACT 1

Incorporating Attachment Theory Into Practice: Clinical Practice Guideline

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Aims: Attachment theory provides a potentially useful framework for understanding psychological distress and relational difficulties in people with intellectual disabilities. A small number of interventions drawing on attachment theory have been described in the literature (e.g. Clegg & Landsdall-Welfare, 1995; Schuengel, Kef, Damen & Worm, 2012) however there is a dearth of practical guidance on the application of the theory in routine clinical practice. This project aims to address this gap. **Method**: A working group of clinical psychologists with experience in the use of attachment theory in clinical settings drafted a set of guidelines. The views of experts by experience were sought and two contributors were identified, who provided their own perspectives. The draft was disseminated for review via established clinical networks. The document was amended in response to the feedback provided. **Results**: The guidance document 'Incorporating Attachment Theory into Practice: Clinical Practice Guideline for Clinical Psychologists working with People who have Intellectual Disabilities' has been submitted for final approval, prior to publication by the British Psychological Society (BPS; in press). **Conclusion**: The process has resulted in the production of a guidance document that will be freely available to members of the BPS and also easily accessible to non-members. A number of challenges were experienced during the development of the guideline, which will be described.

SYMPOSIUM - ABSTRACT 2

Bringing Attachment Inside the Window of Politically Acceptable Policies in ID

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Aims: To identify and seek to ease tension between critics and proponents of attachment. **Method**: Tension between critics and proponents of attachment continues to be played out in the UK's professional journal, The Psychologist (eg Meins, 2017). This paper examines two key UK books (Clarke & Clarke, 1976; Burman, 1994) to identify the origins of UK psychology's negative reception of attachment. This may have implicitly informed the otherwise puzzling dismissal of attachment in the UK's recent NICE guidance (NG 11: 2015) on ID & challenging behaviour. **Conclusions**: 1. Critics need to understand that, in common with most if not all scientific phenomena, attachment involves a way of seeing that has to be learned. 2. Proponents need to respond to the issue that arguably troubles critics, mother-blaming, if they are to enhance the political acceptability of attachment research and interventions.

SYMPOSIUM - ABSTRACT 3

Learning From Mentalization Based Therapy for Mentalization Based Support in Daily Care

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Aims: Difficulties in mentalizing can cause conflicts and therefore also challenging behaviour. Mentalization Based Therapy (MBT) is an evidence based therapy for clients with a borderline personality disorder (Bateman & Fonagy, 2012, 2016). MBT is also used as an intervention for many other psychiatric problems (Bateman & Fonagy, 2012, 2016). The research question is: What can we learn from analysing important elements in the use of MBT during psychotherapy for persons with a visual and intellectual disability for Mentalization Based Support (MBS) in Daily Care? **Methods**: The participants are children and young adults age 6 to 30 with a visual and/or intellectual disability, problematic attachment and challenging behaviour. Twelve individual psychotherapy sessions are videotaped and examined by using the MBT Adherence and Competence Scale Version Individual Therapy (April 2010: In Karterud & Bateman, 2011). **Results**: Important elements of the use of MBT during psychotherapy for persons with a visual and intellectual disability will be reported as well as how these can contribute to the use of MBS in daily practice. **Conclusions**: The findings add to the Mentalization Based Support (MBS) (Dekker & Sterkenburg, 2016) which aims to provide caregivers with the skills to stimulate the mentalization capacities of their own clients.

Symposium: Innovative Practices in Emotional Development in Persons With Intellectual Disabilities

Name of chair: Anton Došen
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KEYWORDS development; practice; support

Background and aim: Generally, it has been accepted that attunement of the environment in respect to basic emotional needs of individuals is a key element in the support and treatment of persons with intellectual disabilities (ID). This developmental approach (with proponents such as Greenspan, Cicchetti and Došen) has been shown to substantially contribute to the assessment and treatment of persons with intellectual disabilities.

In Belgium and the Netherlands, researchers and practitioners, in particular, have further developed this model by adding instruments, methods and translations into daily practice. In addition, there are innovative practices in relation to other target groups (e.g. people with autism) and also other methods (e.g. outreach treatment).

SYMPOSIUM - ABSTRACT 1

Emotional Development in Persons With ID and Autism

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Došen's model of emotional development provides an integrative perspective for understanding and assessing problem behaviour of people with autism and intellectual disabilities. In this presentation, we will present the classic incentive regulation and motivation behind certain behaviour. By using emotional development as framework and responding to specific emotional needs and requirements, we can increase the range of guidance methods.

The following topics will be presented:

- What characterizes the emotional development of people with intellectual disabilities and autism?
- Specific issues of the assessment of the emotional development with the Scale for Emotional Development–Revised[2].

Specific support issues of people with autism and intellectual disabilities, including classic incentive regulation and motivation behind behaviour.

SYMPOSIUM - ABSTRACT 2

De Draad (“the Wire”): A Metaphor for Working on Emotional Development With Parents and Caregivers

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Inspired by the work of Cluckers, Vliegen, Heijkoop, and Došen (amongst others), developmental psychology has been translated using the metaphor of De Draad (“the wire”). Explaining the social and emotional development in a comprehensive and practical manner, the project aims at facilitating the interaction between children/individuals with ID and parents/teachers/caregivers. The model is linked to the application of the recently developed SED-R^2 .The different stages of emotional development, as elaborated by Došen, are illustrated using different types of wires. Each wire has its own characteristics relating to both the child and the parent. Concepts used in educational psychology, such as joint attention, attachment, emotional refueling and exploration, are integrated in the model. In addition, new concepts are introduced (i.e. the track, the gate, the remote control, the network). Since the impact of the earliest stage in a child’s life is of crucial importance for the further stages of their development, the main focus is directed towards what is called the first wire: “drawing the wire”.

De Draad represents the bond between parents and children which is growing and evolving during the different stages of life. When education or counseling leads to tension and uncertainty, the wire may be “under pressure” and one should look for the vulnerable spot in the wire as a reference for guidance. In this presentation, De Draad is proposed as a method and the different types of wires will be presented.

SYMPOSIUM - ABSTRACT 3

Emotional Development Used as Basic Frame in Support: Outreach for People With ID and Mental Health Problems, and Their Environment

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In this session, we will present how the framework of emotional development can be translated into the daily support of the individual. For several years, emotional development has been used as an important keystone in “outreach De Steiger-De Meander”, a small outreach-team that is specifically working with adults with ID and mental health problems, and with their social network. Individuals and caregivers (professionals and social network) who are struggling with difficult behavior and mental health problems (of the individual with ID) receive from this team–always temporarily–expertise and support that can resolve a difficult situation.

Amongst other methods, this team uses emotional development and its translation into support strategies. How can caregivers even better attune to the basic emotional needs of the individual, based on the assessment of the emotional development and diagnostics of mental health problems? In other words, the focus of the support of this team is directed rather towards the environment than the individual. We do not prescribe caregivers how to act, but caregivers are made more sensitive towards reading the behavior and meeting the basal emotional needs of individuals. In addition, we will present valuable key elements of this approach.

SYMPOSIUM - ABSTRACT 4

"Great" Caregivers are Masters in "Availing Bounding"

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Persons with ID and a limited emotional development need–besides nearness, attention and love–also clarity, structure and bounding. Not only because they are often testing boundaries or even getting out of hand, but also because being regulated and bounded is a basic emotional need. In this presentation, we propose the assumption that not providing people the boundaries they need could be considered as maltreatment. This should be distinguished from emancipation or empowerment. In this session, we explore the basic need of bounding in a developmental approach. We also discuss concrete "tips and tricks" on this theme, which we call "the art of availing bounding".

Symposium: Mourning

Name of chair: Marion Kamper

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KEYWORDS Ethics & human rights; Spirituality

SYMPOSIUM - ABSTRACT 1

Ethical Issues in Nursing and Medical Care in the Context of Intellectual Disability and the User's Will. Ensuring the Best Possible Quality of Life in Difficult Medical And/Or End-Of-Life Situations

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Aims: When caring for people with an intellectual disability, people with severe intellectual disability or people with multiple disabilities, specific health and nursing aspects must be taken into account to guarantee the wellbeing and quality of life of the service users. the increase in age of the service users leads to an increase of specific age-related illnesses. this increase requires a more intensive and complex medical and nursing care. as a result, the health care for people with specific needs is changing. nursing teams, the pedagogical care team, the doctors as well as relatives are increasingly confronted with ethical issues that need to be addressed in case of a serious illness, a necessary operation or an impending end-of-life situation. **Methods**: Frequently, medical questions trigger ethical discussions as to what needs to be done/should be done:

- Is the treatment useful for the person concerned even if it is necessary from a medical point of view?
- How do we handle a situation of a service user in a palliative phase within a housing structure?
- Has the service user a written will regarding end-of-life treatment? what would the person want?
- Is the operation really necessary?
- If s "stomach probe" needs to be placed, how sensible is this in the momentary life phase of the service user? does it really make a difference in terms of health and well-being of the person or is it only a short-lived, life-extending measure?

As a consequence, apemh hébergement et services set up an ethical commission "help for decision-making regarding nursing and/or medical questions" addressing exactly those ethical questions. the commission consists of the service user concerned, their relatives, the medical team, the nursing staff, the pedagogical team as well as the management, who are coming together to discuss the facts of the current health situation, analyzing questions and making a joint decision regarding the needs and wishes of the person concerned. **Results**: The commission is convened whenever necessary, thus providing the required space for ethical discussions. the commission decides jointly in the best interest of or with the person concerned. as a result, a common attitude, shared by all partners involved, was developed, bringing more safety and clarity for carers.

SYMPOSIUM - ABSTRACT 2

"When Will Daddy Descend From Heaven?" How to Accompany People or A Group of People With Special Needs in Mourning: A Multitude of Resources, Tools, Rites

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Aims: The story of Marcel illustrates the specificity of mourning for people with special needs. How to accompany people or a group of people with special needs in their mourning process? **Methods**: Several guidelines for the announcement of the decease of a relative will be presented together with certain things to consider when you have to “say goodbye”. How to accompany people or a group of people with special needs in their mourning process will be another point discussed during the symposium. **Results**: We often use the technique of rites and other tools that will be presented in detail. Some practical examples will illustrate how their utilization enabled Marcel to overcome his mourning. **Conclusion**: The utilized tools show some paths to cope with mourning of individuals or groups of people with special needs. Some complementary caring methods will complete this illustration of best practice.

INDIVIDUAL PAPERS

Do Anxiety and Depression Influence Attentional Processing of Emotional Faces Amongst Adults With Low Ability?

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KEYWORDS Cognition

Aims: There is evidence for impaired emotion recognition in a number of neurodevelopmental disorders and functional mental illnesses. There is also substantial evidence that emotion recognition correlates with general. Processing speed correlates with the ability in cognitive tasks and anxiety slows the processing of emotional stimuli, but these effects have not been investigated in adults with an ability below average. This study aimed to investigate the impact of symptoms of anxiety and depression on speed of processing of emotional faces whilst controlling for ability. **Methods**: The participants were 42 adults with receptive language ability (PPVT-4) in each category below average. Response times (RT) were measured on a widely used visual probe task with happy and angry face stimuli. Anxiety and depression were assessed through an interview with the Beck Anxiety Inventory (BAI) and Beck Depression Inventory II (BDI-II). Screening for emotional recognition and scoring abilities occurred prior to the probe task and a mastery procedure ensured valid responses. **Results**: A significant, negative, medium-sized correlation was found between RT and receptive language, but not with any other measures of ability. The correlation between anxiety and happy face RTs was positive and reached significance, but only approached it for angry faces. There was also a significant difference in RTs for both faces between the low and high BAI groups, but the BDI was not related to either face RTs. **Conclusions**: This task was conducted with a complete sample of participants with low ability for the first time. The effect of ability on speed of processing emotional faces is not surprising, but the effect of anxiety (and not depression) suggests that attentional processing of emotion may be similar in nature to that of the general population.

POSTERS

The Stress of Parenting a Child With Down Syndrome

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KEYWORDS Family; stress; support

Aims: International studies indicate that parenting children with Down syndrome is a more stressful task than parenting children without any disability. German evaluations of that topic are scarce. This study contributes insights into the levels of stress and restrictions parents of children with Down syndrome experience in their roles as parents. **Methods**: A sample of 140 parents of children with Down syndrome was surveyed with a German parental stress questionnaire (ESF—Elternstressfragebogen, Domsch & Lohaus, 2010). The ESF consists of four scales, measuring parental stress, role restrictions, social support and the level of satisfaction with an existing partnership. Results are reported. Obtained data was compared to a standard sample. **Results**: The results of the sample indicate average values with high ranges on all four scales of the questionnaire. There are significantly higher values in parental stress in comparison to the standard sample. Furthermore, the participants experience a significantly higher restriction in their autonomy. A satisfactory partnership as well as social support can be identified as relevant influencing factors on parental stress. **Conclusions**: The results indicate a greater need of help for parents with children with Down syndrome in comparison to those of children without disabilities. Social networks and partnerships may be suitable ways to implement support.

Passport to Life: Investigating the Need for Life-Skills Training Among Young People With Autism Spectrum Disorders and Their Parents

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KEYWORDS autism spectrum disorder; intervention; support; wellbeing

Aims: In the field of autism interventions, further research is needed to identify effective strategies to promote independence (Hendricks & Wehman, 2009). This was a qualitative study with the aim to investigate: a) the views and needs for self-efficacy in relation to adulthood transition as expressed by young people with autism spectrum disorders (ASD) and their parents; b) their experiences of previously accessed training and support; c) the type(s) life skills that support may consider beneficial and would wish to access in the future. **Methods**: Data were collected through 20 semi-structured interviews with 10 young people in the age group 11–17 years, and 10 mothers. Data were analysed using Thematic Analysis facilitated by NVIVO. **Results**: Thematic analysis resulted in six main themes: 1) interests and activities, 2) challenges, 3) transition to adulthood, 4) desired training and support, 5) experiences of support, 6) identifying and accessing support. **Conclusion**: Participants' experiences regarding the support they had received around life skills were quite diverse and mothers were not always aware what kind of support was available and how they could access it. Mothers wanted to take a step back from playing a central role in supporting the young person and expressed the need for mentoring that would guide young people through secondary school and early adulthood.

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ETHNICAL AND CULTURAL ISSUES

INDIVIDUAL PAPERS

Working With Intellectually Disabled People With a South Asian Family Background: User Views of Services

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KEYWORDS Family; research; social; social inclusion

Aims: This paper describes a number of research projects on user views of services for people with intellectual disabilities with a South Asian family background carried out over the last decade. **Methods**: Qualitative methods were employed and participants were interviewed individually or as focus groups. They included service users themselves and mothers who had been involved in arranging a marriage for their adult son or daughter. **Results**: Adults with ID regard themselves as living two separate lives between their families and the services they use. Most value both but are keen to move towards a more Western orientation. Mothers who have been involved in arranging a marriage for their son or daughter stressed that stigma associated with disability in addition to complex legislation makes it difficult to successfully engage in the transactional processes required by their culture and some are therefore prepared to consider alternative (Western) options for their child's future. **Conclusions**: Service providers would do well to invest more time and effort to understand the various socio-cultural frameworks that are used by adults with intellectual disabilities and their families when decisions are made about accessing health and social services or not.

Experiences With Specialised Mental Health Services for Adult Patients With Intellectual Disabilities in the Migrant Population: A Qualitative Study

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KEYWORDS Diagnosis; ethnopsychiatry; family; psychiatric disorders

Background: In the last years, thousands of refugees have come to Norway and other Western countries. However, mental health services for adults with ID and additional mental illnesses within the migrant population is an understudied topic. Clinical experience indicates that professionals struggle when providing services to adults with ID and additional mental health issues in this population. **Objectives**: The objective of this study was to investigate the families' experiences of mental health services for a family member with intellectual disability. In addition, we wanted to know if there is need for special adjustments in the assessment and treatment of patients with ID in the migrant population. **Methods**: As this is an understudied topic, we chose a qualitative approach. Three families and the patients' residential caregivers were interviewed. The interviews were taped, transcribed and consequently analysed. Results: The families expressed that the employment of professional interpretation would have been an advantage when communicating with mental health services. The professional lingua and psychiatric diagnoses may be unknown, and it could be difficult to describe symptoms and difficulties related to mental disorders, lacking specific language for such problems. The professional caregivers supported the answers from the families. **Conclusion**: The findings in this pilot study are in line with findings of studies examining mental health in the general migrant population. Mental health services for adults with intellectual disability in the migrant population must include the families.

GENETICS, ETIOPATHOGENESIS, AND TRAINING

INDIVIDUAL PAPERS

Advantages and Caveats of Neurobehavioral and Cognitive Assessment in Rare Genetic Disorders With Moderate to Profound Intellectual Disabilities

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KEYWORDS genetics; neuropsychology; psychopathology

Background: The increase in defined genetic causes of intellectual disabilities (ID) creates the need for instruments which differentiate between the level of functioning and syndrome-specific neurobehavioral and cognitive characteristics. The present study investigates the use of four simplified tablet-based neuropsychological test (CANTAB) and a semi-structured clinical observation (ADOS-2) in patients with rare genetic syndromes who have moderate to profound ID. **Method**: Inclusion comprised a biological age above 3 years and a genetically confirmed causative monogenetic disorder resulting in ID. In total, 56 subjects participated. The Vineland Adaptive Behavior Scale interview was completed to calculate a developmental age. Thereafter, the subjects performed the Autism Diagnostic Observation Schedule-2

(ADOS-2) and four simplified tasks of the Cambridge Neuropsychological Test Automated Battery (CANTAB), the Motor Screening Test (MOT), Pattern Recognition Memory (PRM), the Intra-Extra Dimensional Test Shift (IED), and Paired Associate Learning (PAL). **Results**: For the CANTAB, a cut-off in the developmental age was defined at which test application was successful. Correlations were assessed between test performance and subject characteristics. Overall performance was also measured for ADOS-2, and specific factors within the ADOS-2 were distinguished for clinical importance. **Discussion**: Our results indicate an additional value of using simplified CANTAB tasks and the ADOS-2 in the ID population to differentiate between the level of ID and syndrome-specific neurobehavioral and cognitive features. The results of these tests are helpful in diagnostic procedures, formulating personalized treatment and guidance as well as to enhance specific knowledge about genetic syndromes.

Neurological and Psychiatric Phenotype in Adults With 22q11.2 Deletion Syndrome and Basal Ganglia Calcifications

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KEYWORDS genetics; neurobiology; psychiatric disorders

Aims: Calcifications of the basal ganglia (BGC) are observed in about 0.5–1.0% of routine computed tomography brain (CT) scans. BGC can indicate a calcium metabolism disorder and may be associated with a variety of psychiatric and neurological symptoms. In 22q11.2 deletion syndrome (22q11.2DS), in addition to intellectual disability, there is an elevated lifetime risk of hypoparathyroidism/hypocalcemia (~80%), psychiatric and neurologic manifestations, including psychotic disorders (~25%), seizures (~40%), and movement disorders. The potential connections between these manifestations are however poorly understood. **Methods**: To begin to address the potential effects of BGC in 22q11.2DS, we reviewed lifetime medical records for relevant clinical data in individuals with BGC from a well-characterized Canadian adult 22q11.2DS cohort (n = 286, median age 30.6 years; n = 86 with CT scan data). **Results**: Ten (11.6%) of 86 adults (6 male, 4 female; median age 39 (24–57) years) with 22q11.2DS and CT data had BGC (6 bilateral, 1 unilateral, 3 unspecified), detected at median age 22.5 (17–56) years. Although seizures were the most common known reason for CT (4/8, 50%), there was a lifetime history in all 10 (100%) of psychotic disorder, 9 (90%) of movement abnormalities (4 tremors, 4 tardive dyskinesia, 2 rigidity), and 8 (80%) of seizures. Nine (90%) had a history of hypoparathyroidism/hypocalcemia. **Conclusions**: The results support an association of 22q11.2DS with BGC, and the possibility that neurological and psychiatric features may be particularly prevalent in these patients. Future studies are needed to understand how brain calcification may relate to the neuropsychiatric phenotype of 22q11.2DS.

HEALTH NEEDS, POLICY, SERVICE SYSTEM, AND TRAINING

SYMPOSIA

Symposium: Innovative Tools for Implementation of Quality Management of Mental Health in ID

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KEYWORDS person-centred approach; practice; services; staff

Background and aim of symposium: In mental health, quality management is a daily challenge for services providing care for people with intellectual disabilities. In order to cope with this challenge, they develop methods and tools to increase the skills of staff and to reinforce quality of their practices. This symposium presents three different experiences of skill enhancement: one by creating a new tool, one by knowledge management and one by improving professional practices.

SYMPOSIUM - ABSTRACT 1

Quality of an Ambulant Service: The Courage to Ask

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Background: Quality assurance is important for every service. For an ambulant service it is even more important and challenging at the same time: the outcome of the work is assessed subjectively by the individual and not seen by the management. **Method**: The access to quality assurance is to ask the individuals about their satisfaction, but since it is difficult or impossible to find fitting surveys for each service, the best way is to create a new survey. **Results**: Examples of a survey will be presented, together with the advantages and risks of a survey of the individual's with ID perspective. **Conclusion**: Even though the results of such a survey may only point out tendencies, the creation of an new survey is worth the work and cost. The presentation will show how it can be conducted, and how to convince the management and staff members of its benefits.

SYMPOSIUM - ABSTRACT 2

Use of Knowledge Management for the Development and Networking of New Skills for Health Care Workers in Intellectual Disability

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Background: The study has been conducted in an organization that provides care to individuals with ID and problems with mental health. Knowledge management is one of the means available to managers to increase professional skills, capitalize knowledge, and promote exchanges of practices. On this basis, the creation of an internal network is possible. Internal networking consists of the dissemination of newly adjusted skills, so that the organization increases the quality of its care by better satisfying the needs of individuals. **Method**: The starting hypothesis is that the existing potential is sufficient for the establishment of an internal network. However, the knowledge capital needs to be strengthened, which is conducted through making knowledge explicit that was hitherto implicit. Second, new concepts are introduced into the theoretical corpus in order to develop an innovation in practice. Third, new know-how is disseminated to front-line staff by improving existing practices. **Results**: The presentation reveals the methodology of setting up an internal network in an accommodation organization for people with intellectual disabilities and it analyzes the added value of such an approach. Conclusion: Taking mental health into account in intellectual disabilities may be complex. Increasing professional skills is a major factor in developing quality and effectiveness of care.

SYMPOSIUM - ABSTRACT 3

Questioning Our Professional Practice in Order to Increase Support Quality - Soft Violence: It Is for Your Own Good!

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Background: Questioning a professional practice is considered as a guarantee of quality for the different teams. In everyday life, good intentions may lead to soft violence. These are points when the relationship breaks down, when the child is not the centre of concern anymore. **Method**: By analysing the key phases in a day, through small sentences, gestures or looks, it is possible to spot soft violence and to rectify them. In a climate of trust and respect, this exercise allows the team to think about the ways to improve the quality of the support. **Results**: This method increases the team's cohesiveness and stimulates the respect of the values that are essential for the child's development. The aim is to meet the child's needs so that it can grow up in a climate that respects it as a relevant stakeholder. **Conclusion**: In a welcoming context, questioning professional practice in a simple way improves the quality of service.

INDIVIDUAL PAPERS

Nutrition in Adults With Multiple Developmental Disabilities

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KEYWORDS developmental disorders; research; vulnerability; wellbeing

Aims: The aims of the study were to explore the nutritional status of adults with multiple disabilities as well as examine their food intake and eating ability. **Methods**: The population chosen for this cross-sectional study consisted of 18 individuals aged 25 to 74, receiving round-the-clock nursing care in a rehabilitation center in Finland. The nutritional status was assessed through anthropometric measurements and laboratory tests. The dietary records were collected and the meals of some participants were photographed. The eating ability was evaluated with a structured questionnaire. **Results**: The body mass index of more than a half of the participants (n = 10) was in the normal range, less than one third (n = 5) were underweight, while a sixth (n = 3) were overweight or obese. Body weights and circumferences were mostly below the 10th percentile in comparison to the reference data. The markers of protein nutrition (P-Alb, P-Prealb) were close to the bottom limits of the reference ranges. On average, intakes of dietary fiber, unsaturated fat, protein, folate, vitamin D, and iron were below the recommended level. **Conclusions**: Almost all study participants were in a state of protein malnutrition. The quality of diet had room for improvement. Especially the protein and fiber contents, and the fat quality of the diet were inadequate. The nutrition of individuals who have eating difficulties or whose eating depends on others warrants further attention. Interdisciplinary collaboration is needed to solve the nutritional challenges for these individuals.

Growing Up With Neurofibromatosis Type 1 and Tuberous Sclerosis Complex: Concerns and Care Needs of Young Adults

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KEYWORDS Behavioural Phenotype; Epilepsy; Life span; Neurodevelopmental disorders; Support

Aims: Neurofibromatosis type 1 (NF1) and tuberous sclerosis complex (TSC) are autosomal dominant neurocutaneous disorders associated with lifelong tumor growth propensity and neurocognitive impairments. Although adults often receive care for the tumor growth phenotype, psychosocial needs are often not met. In order to provide optimal care for these vulnerable patient groups, we explored the care needs of young adults with NF1 and TSC. **Methods**: A qualitative study was performed using semi-structured group interviews, exploring concerns and healthcare needs in medical, psychological and socio-economic

domains, with an emphasis on the transition from pediatric to adult care. Various focus groups of patients and parents were conducted as well as individual interviews. Transcription, coding and thematic analyses were performed using ATLAS.ti software. **Results**: Concerns were classified according to the International Classification of Functioning and Disability (ICF) and included mental health problems, concerns about future life and morbidity, limited independence, cosmetic problems, unavailability of adequate care, and problems with work and social participation. Expressed care needs included access to NF1 experts in all domains, daily living support, care for mental health and socio-economic participation, closer communication between health care providers, and need for more information in general. Parents reported high stress levels and difficulties with their parental role. **Conclusions**: Results indicated many and diverse concerns and healthcare needs, both during the transitional period and in adulthood, in medical, mental health, and socio-economical domains. Recommendations for multidisciplinary follow-up and care infrastructure emphasize the importance of continuity of care during the transitional period, for patients as well as their parents.

eHealth Use in Support, Psychological Treatment and Therapy for People With Intellectual Disability: Results of Two Systematic Literature Reviews

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KEYWORDS technology

Aims: eHealth is an emerging field at the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies (Eysenbach, 2001). eHealth is also increasingly used for people with intellectual disability (ID). In order to provide an overview of the effectiveness of eHealth in people with ID, two systematic reviews were conducted; one review focused on eHealth use in support of people with ID, and the second review was concerned with eHealth use in psychological treatment and therapy of people with ID. **Methods**: For these two reviews, seven bibliographic databases (Embase, Medline, Cochrane, Web of Science, PsycINFO, CINAHL, and Google Scholar) were systematically searched for relevant articles published in English between January 1996 and June 2016. The search strategy was based on the PICO approach specifying population, intervention/exposure, comparison, and outcome (Liberati et al., 2009). **Results**: In total, 3855 articles were retrieved for both reviews. The results of both systematic reviews will be presented in relation to various topics: effectivity for people with ID, treatment areas, quality of life domains, features of used technologies, and the role of professionals. **Conclusion**: The implications for practical use of eHealth in a health care context will be discussed in the light of opportunities for empowerment, independency, specific treatment goals, and the contribution to scientific knowledge about eHealth use in support and treatment of people with ID.

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Discovery Awareness (DA): Addressing the Relational Perspective of Quality of Care and Support

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KEYWORDS challenging behaviour; person-centred approach; practice; staff; training

Aim: To describe how Discovery Awareness addresses the balance between the implicit knowledge of relational practice and the drive for paper-based plans in the support of people with ID and behavioural challenges. **Method**: A review of current policy drivers and good practice for care and support services is contrasted with the theoretical rationale for DA and how it is implemented. **Results**: Support plans are often referred to in government guidance and policies for services for people with ID. Evidence from these ‘plans’ are often used to assess the quality of support provided by services. It is always difficult to capture the relational contexts which are essential for an individual to explore themselves, their environment and relationships. Support staff and their practice leaders also struggle to develop these relational skills. DA provides a way that care staff can explore their tacit knowledge and help them develop their sensitivity to a client. Using video recordings, a DA coach facilitates highly structured meetings with support staff, practice leaders and other staff, that begins an internally motivated process of change. Staff discover their awareness of a client, enabling increased atunement, safe attachment and thus a low-stress context which motivates a client’s ability to explore. **Conclusion**: Discovery Awareness offers a way to help a range of staff to explore the relational aspects of the support they provide to people with disabilities which cannot be described clearly or objectively in care and support plans.

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POSTERS

Bodyweight and Associated Risk Factors in Adults With Intellectual Disability: Results From a Clinical Cross-Sectional Study

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KEYWORDS Autism Spectrum Disorder; dementia; obesity; psychiatric disorders

Aim: People with intellectual disability (ID) have a shorter life expectancy, higher mortality rates, and suffer more often from various physical and mental diseases (Bittles et al., 2002; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). Obesity is an important risk factor for various disorders. This cross-sectional study examines bodyweight and its risk factors in a clinical population of adults with ID. **Method**: The prevalence of underweight, normal weight, and overweight was determined by the body mass index (BMI). A multiple logistic regression analysis assessed risk factors for alterations in body weight. **Results**: Approximately one out of two men and two out of three women with ID and mental disorder were overweight. Female adults with mild and moderate ID, increasing age, Down syndrome, behavioral disorders, and a less supported living situation were associated with a higher risk for obesity. People with dementia and autism spectrum disorders showed a lower risk for obesity. Medication did not affect the body weight. **Conclusion**: Especially young women with ID and mental disorders were at risk for obesity. The respective factors may support the development of specific prevention programs to reduce the risk of overweight and thereby lead to better mental and physical health in people with ID.

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Validation of the Fragile X Syndrome (FXS) Behavioral Phenotype According to Hagerman et al. (2009)

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KEYWORDS genetics; neurodevelopmental disorders; rehabilitation

Aims: This study aims to empirically validate the behavioral phenotype according to Hagerman et al. (2009) among men with FXS presenting an intellectual disability. **Methods**: Eighteen men with FXS were paired by age and level of intellectual disability to 18 men with Down's syndrome. Three instruments were used to measure the behavioral features of the participants: Aberrant Behavior Checklist—Community (Aman, Burrow & Wolford, 1984), DASH-!! (Matson, 1995) and Quebec Adaptive Behavior Scale (Maurice et al., 1997). **Results**: Five of the 12 features of the behavioral phenotype of Hagerman et al. (2009) are significantly more present in men with FXS: poor eye contact, excessive shyness, anxiety, hand biting and symptoms of autism spectrum disorder. **Conclusions**: This research partially confirms the FXS behavioral phenotype of Hagerman et al. (2009) in men with a moderate intellectual disability. The identification of the behavioral phenotype's features in men with FXS may be clinically relevant as it allows specialised service providers to specify their service offer based on the needs of this population.

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A Bioresponse System for Caregivers of Adults With Severe or Profound Intellectual Disabilities

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KEYWORDS Staff; Stress; Technology

Introduction: Caregivers of adults with severe or profound intellectual disabilities experience daily challenges in interpreting the individuals' subtle, non-verbal communication behaviour. **Aim**: We developed a bio-response system–a skin conductance sensor sock connected to a Shimmer 2R biophysical sensor and an Android app—to provide caregivers with additional insight and to support them in noticing and interpreting the individuals' signals. **Design**: The sensor sock (when connected to the sensor) collects skin conductance data and sends it to the app via Bluetooth, where the data is depicted in the shape of a flower. The flower changes in size according to changes in the general arousal level and displays more petals when stronger responses to stimuli in the environment are measured. **Method**: In a pilot study with one caregiver and one blind individual with a severe intellectual disability, behavioural observations were compared with skin conductance measurements during six observations (two daily caregiving situations on 3 days for an average of 15 minutes per situation). An independent observer scored the individual's behaviour during the observations using the bio-response app. **Results**: This comparison revealed the bio-response system's ability to reflect the individual's arousal levels and to detect alterations in arousal levels before the observer can detect these changes in the individual's behaviour. **Conclusions**: The caregiver's behaviour could be reinforced by the system's measurements, since these can reflect changes in arousal, which cannot be communicated by the individuals themselves. The bio-response system proves to be a feasible support system, however, more validations are required.

INDEPENDENT LIVING AND INCLUSION

SYMPOSIA

Symposium: Furthering Participation and Inclusion of People With Intellectual Disability in Society

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KEYWORDS participation; rights of people with ID; social inclusion

Background and aim of symposium: Despite great advances in participation and social inclusion of people with intellectual disabilities (ID), people with ID experience lower levels of participation in society compared to non-disabled people. In this symposium, possible barriers hindering societal participation and inclusion of people with ID will be discussed along with examples of how the Academic Collaborative Center—Living with an ID strives to structurally and successfully include the perspective of people with ID in (research) projects.

SYMPOSIUM - ABSTRACT 1

Public Perceptions Towards People With Intellectual Disabilities

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Aims: The United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) states full and active participation in society as a fundamental right of persons with disabilities (UN, 2006). Public stigma is an important barrier to full participation in society for people with intellectual disabilities (ID). Since little research is conducted on ID-related stigma, this study aims to examine public stereotyping of people with ID. **Methods**: A representative sample of the Dutch population (N = 892) participated in a cross-sectional survey. Stereotypes were assessed with an 18-item stereotype Likert scale (e.g. "people with an intellectual disability are friendly"). Second, participants were asked to provide a short description of people with ID. The stereotype scale was analyzed using exploratory factor analysis, the open question was qualitatively analyzed using a general inductive approach. **Results**: Four stereotype factors were demonstrated: "sociable'", "in need of help", "nuisance" and "difficult learners". Participants scored low on the 'nuisance' stereotypes and high on the other stereotype factors. Qualitative analysis yielded additional stereotypical perceptions of people with ID, e.g. lower level of social skills and higher level of dependency. **Conclusions**: The Dutch general public views people with ID as "sociable", "in need of help", "difficult

leaners'", and not so much as a "nuisance". Lower levels of social skills and higher levels of dependency were found to be additional stereotypical traits. The demonstrated stereotypes may hinder participation in society of people with ID. Furthermore, possible internalization of these stereotypes by people with ID might lead to lower self-expectations regarding participation in society.

SYMPOSIUM - ABSTRACT 2

Living With Support: Experiences of Individuals With Mild Intellectual Disabilities

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Aims: In providing support, professionals may contribute to furthering participation and inclusion of people with (mild) intellectual disabilities (MID). As the perspective of people with ID has become a central aspect in support provision, the aim of this study is to gain insight into how people with MID define and perceive being supported by professionals with respect to their participation and inclusion in society. **Method**: Non-directive, semi-structured interviews were carried out with 6 individuals with MID living in community-based settings. The interviews were conducted in an open and flexible manner, while the interviewer remained open to other subjects raised by the participants themselves. Data were analyzed using Interpretative Phenomenological Analysis, which entailed a detailed and systematic exploration of how people make sense of their personal and social world. **Results**: Preliminary analyses indicate that feelings of non-participation and exclusion were experienced by some participants. In addition to providing emotional and practical support, we found that professionals play a vital role in guiding individuals within society. Participants highly appreciated activities undertaken together with professionals that were experienced as part of "normal" life (e.g. having a chitchat, going out for dinner), fulfilling their need of social relatedness. **Conclusion**: This study will result in recommendations for professionals and support practices on how participation and inclusion can be supported and enhanced.

SYMPOSIUM - ABSTRACT 3

Collaboration Between Science and Practice: Structurally Including Perspectives of People With Intellectual Disabilities

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Aims: The Academic Collaborative Center—Living with an Intellectual Disability (ID) strives to build a bridge between science and practice. In doing so, evidence-based and practice-based knowledge is equally valued, and the perspectives of people with ID and their relatives are structurally included in all (research) projects. **Methods**: The Academic Collaborative Center involves people with ID and/or their relatives as participants in all research projects. In addition, people with ID collaborate as co-researchers in scientific studies and partners in advisory groups. **Results**: First, in research projects involving people with mild to profound ID and/or their relatives as participants, the experiential knowledge of the participants is successfully included. These projects cover a wide range of topics, including, for example, the viewpoint of people with mild ID on the emotional support within their social networks, and the perspective of people with moderate and severe ID concerning restrictive measures. Second, collaborating with people with ID as co-researchers resulted in national funding to jointly examine the effects of this collaboration with respect to participation and inclusion. **Conclusions**: The Academic Collaborative Center provides conditions to structurally and successfully include the perspectives of people with ID and their relatives. Moreover, examining the collaboration between people with and without ID will result in recommendations on furthering the participation and inclusion of people with ID in society.

Symposium: Social Networks of People With a Mild Intellectual Disability: Their Own Perspectives

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KEYWORDS family; networking; support

Background and aim of the symposium: Supportive social networks are crucial for facilitating social inclusion and better quality of life (QOL) of people with intellectual disabilities (ID). In this symposium, results will be presented from studies that focus on the characteristics of these networks as well as experienced support from these networks as perceived by people with ID themselves.

SYMPOSIUM - ABSTRACT 1

Social Networks of People With ID: An Exploration of Functional Characteristics and Ways for Enhancement

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Aims: Supportive social networks are crucial for facilitating social inclusion and better quality of life (QOL) of people with intellectual disabilities (ID). However, little is known about the functional characteristics of social networks of people with ID (e.g. provision of emotional or practical support). Therefore, this study explores these characteristics as well as the results of an intervention aimed at their enhancement. **Methods**: First, data were gathered from 33 young adults with mild to borderline ID using the Maastricht Social Network Analysis (MSNA) to map their social networks. Next, the results of a social network intervention in the lives of five participants were explored from several perspectives (i.e. participants with ID, their support workers and trainers), using mixed methods (i.e. interviews and questionnaires). **Results**: People with ID experience practical as well as emotional support coming mainly from professionals. A qualitative analysis of the intervention revealed the vulnerability of participants and their networks, but also the benefits experienced in the intervention, such as decreased loneliness. **Conclusion**: Functional characteristics of social networks of people with ID and the role of professionals are discussed with respect to enhancing quality of life and social inclusion.

SYMPOSIUM - ABSTRACT 2

An Exploration of Family Configurations of People With a Mild Intellectual Disability

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Aims: Relationships contribute to a better quality of life because they have a protective function against mental health problems. Since family members are a stable factor in the lives of people with a mild intellectual disability (MID) with or without challenging behaviour and psychiatric disorders, they represent a large part of their relational network. Besides, they are a primary resource of care and support, which makes them central to psychological health. Since little is known about the view of people with MID on their own family configurations (in terms of emotional support), this study investigates their perspectives. **Methods**: A random selection of 150 individuals with MID were interviewed using the Family Network Method (Widmer, 1999) to measure the significance of the family members and the (reciprocal) emotional support among the listed family members and the individual. Moreover, demographics of the listed family members were collected and questionnaires about challenging behaviour of the individual were filled out by their key worker. Network measures were computed using UCINET software. **Results**: A cluster analysis was carried out in order to group family configurations. The configurations were grouped by similarities of network measures and behavioural aspects. **Conclusion**: This study gives an insight into family configurations of people with MID according to their own perspectives. The results are helpful for professionals to become aware of and focus on significant (supportive) others in the network of the individual. Thus, people with MID can be supported in strengthening their network with significant others, since relationships contribute to a better quality of life.

SYMPOSIUM - ABSTRACT 3

Family Networks of People With Mild Intellectual Disabilities: Their Own Perspectives

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Aims: To enhance social inclusion of people with mild intellectual disabilities (MID), there is an emphasis on supporting individuals to forge stronger links with their local community and increasing informal networks of support. To a great extent, informal networks of people with MID are shaped by family members. Since little is known about support in family networks of people with MID, this study aimed to (1) map family networks of a relatively large sample of people with MID with a focus on emotional supportive ties, and (2) to relate network characteristics to the individuals' well-being and mental health. **Method**: A random selection of 150 individuals with MID were interviewed individually about their family networks using the Family Network Method (FNM). The FNM identified (1) who people with MID consider to be (significant) family members, and (2) the emotional supportive ties among all network members. In addition, data on subjective well-being and mental health were gathered. Network measures (e.g. network size, density, network composition) were computed using statistical software for social network analysis (UCINET) and further analyzed using SPSS. **Results**: This study provides insight into (1) the ways in which individuals with MID define their family contexts and the emotional support they provide, and (2) how these family contexts are related to experienced well-being and mental health. **Conclusion**: Results of this study add to family support and social capital theory, and lead to recommendations for support practices on how to optimize the use of support in family networks of people with MID.

Symposium: Involvement and Community Participation

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KEYWORDS autonomy; coproduction; empowerment; rights of people with ID; self determination

Background an aim of symposium: Community participation is an important step on the way to self-representation and self-determination for people with intellectual disabilities. In this symposium, we present examples of best practices and experiences in working together with people with ID on their self-representation in a co-productive and constructive way within their facility.

SYMPOSIUM - ABSTRACT 1

Co-Construction and Co-Conceptualisation of a Resident Council: People With Intellectual Disabilities and Professional Mentors Work Together to Plan and Implement a Resident Council

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Aims: the focus of this project was to empower people with id in necessary skills as communication, planning, organization, analysing, problem solving, and to enable them to make their own decisions in the creation process of the resident council. **Methods**: during 3 months, six workshops were organized for the elaboration of the council. up to 18 people with id and up to 6 professional mentors participated in this project. the professional mentors had the task to provide appropriate information for the participants with id, so that they could acquire the necessary skills and knowledge to participate actively in the workshops and make their own decisions. the professional mentors' role became increasingly blurred during the workshops and their support in individual units with the participants or in small working groups. communication was a very important part of the project. the professional mentors used easy language, repetitions, illustrations and examples. **Results**: the co-construction process was successful and the resident council came into reality. people with id have gained self-confidence, self-responsibility and pride from their involvement in the process. professional mentors recognized the participants as experts in change and development management. **Conclusion**: this best practice shows how people with id can be empowered to co-construct a resident council, from conceptualisation to the final realisation. this approach is a way of self-determination and empowerment, which can be useful in future projects.

SYMPOSIUM - ABSTRACT 2

From the Residents' Council to the Delegate to the Expression of the Users: 20 Years of Experience. The Evolution of the Platforms of Participation, Places of Expression and Exchanges

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Aim: Within the Tricentenaire, users have been involved for 20 years in decisions affecting themselves, among others in the councils of residents. Over the years, several other platforms of expression and initiatives have been established in order to allow users to engage tproactively in a co-construction process. These platforms have been set up to involve users in all decisions affecting them, from the consultation to the co-decision an the co-evaluation; encourage spaces favorable for dialogues and a common decision-making, in order to promote co-productions; develop communication tools adapted to the skills of the users in order to enable them to participate actively as autonomously as possible. In order to pursue the

optimization and the development of the co-production in our service, the decision was made to set up the function of “delegate for the expression of users”. **Methods**: Since the implementation of its quality approach in 1999, the Tricentenaire has always ensured that users and staff are directly involved in discussions and decisions. The participation of users was built in a co-production approach. In addition, we use easy language as a communication tool. **Results**: Different platforms were set up: the group “exchange of good practices”, the committee “flavour and health”, a brochure-writing committee, and a proof-reading group. Further, various tool were developed: meeting materials, a platform folder, visualization support. **Conclusions**: This contributions aims to highlight the process undertaken over 20 years around the participation of the users in our services: accompanying the users in their active participation, the involvement of the teams, the co-evaluation of the different services, the role of the delegate for the expression of users an the future prospects, etc.

INDIVIDUAL PAPERS

Perspectives and Transition Experiences of Adolescents and Young Adults With Disabilities

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KEYWORDS autonomy; development; participation; social inclusion

Aims: The focus of the presentation is the specific situation of young people with disabilities during their transition into adulthood. **Methods**: The presentation is based on 51 guideline-based qualitative interviews with adolescents and young adults with a disability. The study was conducted within the framework of the Luxembourg Youth Report 2015 (Willems, 2015). **Results**: The aspirations and ideas of young people with disabilities about being and becoming an adult are hardly different from those of their able-bodied peers. For them, too, being an adult primarily means financial, emotional, and social independence and autonomy. Nevertheless, it is obvious that for them the transition to self-reliant, independent adult life is more difficult: Only one in seven of those questioned had found their first job on the labour market and one in two were still living with their parents. **Conclusion**: Our conclusion is that for adolescents and young adults with a disability, the transition to adulthood presents a disproportionately tough challenge compared to their able-bodied peers. Sociological and psychological theories (Hurrelmann & Quenzel, 2012; Havighurst, 1972) consider the successful accomplishment of certain developmental tasks as a master challenge of youth. Young people with disabilities have to cope with the same developmental tasks as young people without disabilities. However, achieving them is much more difficult, not only because of their physical, mental or psychiatric impairment, but also because of the lack of respect and the stigmatisation they experience in daily life.

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Are Children With Intellectual Disabilities Fully Included and Their Rights Fulfilled in Portugal?

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KEYWORDS rights of people with ID

This report provides an overview of the situation of children with intellectual disabilities (ID) in Portugal, with a particular focus on five areas: protection against abuse, family support and (de-) institutionalisation, health, education, and participation of children in different areas. The overall aim is to reinforce the implementation of the UN Convention on the Rights of the Child (CRC) from the perspective of children with ID providing scientific evidence to inform and stimulate policy development in those areas. The objectives were to review existing statistical and other quantitative data available in the 2001 and 2011 State Reports to the UNCRC Committee and related NGO reports. This study combines three basic research resources: official facts and figures (data analysis); professional opinions (qualitative assessment): national experts assessed the implementation of the CRC for children with ID using an evaluation model; and voices of children and their parents were heard in the focus groups and interviews. An assessment tool designed for this purpose was used. Each item was scored regarding the existence, implementation and monitoring of legislation. Results showed that CRC implementation from the perspective of children with ID is far from satisfactory in all five areas. While some attention has been paid to education and health, the country should also focus on other areas such as abuse and participation of children with ID. Despite progress and positive developments in education and de-institutionalisation, many children with ID continue to face segregation. Suggestions regarding how the government could contribute to change are presented.

Daughters of Fortune: Research Into the Stories of Parents With Learning Disabilities With a Learning Disabled Perspective

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KEYWORDS coproduction; family; research; rights of people with Id

Aims: The numbers of people with learning or intellectual disabilities (ID) becoming parents are increasing, yet, as a group, they are known to face multiple disadvantages in their parenting role. An innovative project funded by the Wellcome Trust has allowed Mind the Gap, the largest UK inclusive theatre company for people with ID, to collaborate with a researcher, to collate and share stories about the experiences of parents with ID through academic research alongside a number of different creative processes (including forum theatre, a national touring theatre production, and film). This paper presents themes from the research qualitative analysis, as well as reflections made by the research team on the process of inclusive research. Methods: Ten parents with ID were interviewed by a small research team including a principle researcher with ID. This user-led research methodology allowed collection of detailed accounts of the parents' experiences. The audio-recorded interviews were transcribed and analysed qualitatively using Thematic Analysis, with continued involvement from researchers and participants with ID, to enhance research quality. **Results & Conclusions**: Themes from the qualitative analysis of the parents' experiences are presented collaboratively with one of the principle researchers with ID, together with some of the creative output from the project, namely a short film, and our reflections on the inclusive research process.

LEGAL (JURIDICAL) AND FORENSIC ISSUES

SYMPOSIA

Symposium: New Ways to Increase Awareness of Freedom Restrictions: Measures, Effectiveness of Expert Teams and Action Research with Support Staff

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KEYWORDS challenging behaviour; research; rights of people with ID; self determination; services

Background and aims: In this symposium, research will be presented that focuses on identifying and reducing freedom restrictions on both meso- and micro-level within care settings for people with intellectual disabilities. First, Schippers et al. will discuss the effectiveness of a multidisciplinary expert team that supports teams to reduce freedom restrictions for individuals (micro-level). Second, Bekkema et al. have carried out action research on exploring freedom restrictions with support staff and will present results of the observations of support staff. Furthermore, they will analyze support staff's reflections and present advice on how to identify freedom restrictions in organisation (meso- and micro-level). Third, Huijs et al. will present results of the development of a measure for care organisations to register involuntary care in accordance with legislation. Using discussion through Delphi methods, they aim to realize a measure that helps to effectively monitor the use of freedom restrictions in line with legislation on freedom restrictions and on the protection of individuals (meso- and micro-level).

SYMPOSIUM - ABSTRACT 1

Effects of A Multidisciplinary Approach on the Use of Freedom Restrictions in Care for People With Intellectual Disabilities: A Clustered Randomized Trial

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Aims: This study determined the effect of a multidisciplinary expert team on the use of freedom restrictions in a care organization for people with intellectual disabilities. The expert team used a protocol method which included various interventions. A treatment plan was drafted in which origins and persistence of every freedom restriction were hypothesized. Various standardized interventions were used to test hypotheses and attain treatment goals. A broad definition of freedom restrictions was used to include every measure that is restrictive for a person with an intellectual disability in a specific situation. **Method**: In a clustered randomized trial, 50 24-hours care units were randomly divided in an experimental and control group, both containing 25 units each. A mandatory and standardized registration system of the health care organization was used to assess the use of freedom restrictions. Restrictions were registered every two months. The intervention phase included a period of two months, which was used as baseline. The duration of the intervention phase varied between 6 and 21 months. **Results**: At the moment, all units have finished the intervention phase and final registrations of restrictions are conducted. Preliminary results show reduction of freedom restrictions, while full results will be presented at the conference. **Conclusions**: One important lesson learned was the importance of consensus and commitment of the full team of support staff, professionals, and the multidisciplinary expert team to carry out the intervention.

SYMPOSIUM - ABSTRACT 2

Exploring Freedom Restrictions Through Action Research: Participative Observation Studies of Support Staff in Care Services for People With Cognitive Impairments

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Aims: Although support staff have a key role in (preventing) the use of freedom restrictions and have valuable knowledge, their role in research is often limited. The aim of this study is to explore freedom restrictions through observations by support staff working in ID care services and elderly care services. **Methods**: Six participatory observation studies were carried out in six long-term care services involving a joint research team of support staff and university staff. The following steps were taken in each service: 1) a research team meeting on freedom (restriction) and how to carry out observations, 2) 3-hour observations in different settings followed by a reflective interview, 3) a "think tank" meeting with the research team, 4) writing a practical guidebook, 5) a presentation for the management. **Results**: Support staff observed a diversity of freedom restrictions as well as good practices that may prevent freedom restrictions. Examples include freedom to choose your own food, freedom to go outside, and a responsive care attitude of support staff. Moreover, support staff identified several underlying factors which possibly influence the use of freedom restrictions such as shortage of time and personnel, and the effects of living in a group. **Conclusions**: The research team explored a mix of freedom restrictions, good practices, and underlying factors that possibly influence the use of freedom restrictions. We found indications that the awareness of support staff related to freedom (restrictions) has increased.

SYMPOSIUM - ABSTRACT 3

Reporting Use of Coercive Measures From a Dutch Perspective

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Aims: The future Dutch legislation on reporting involuntary care implies that only measures carried out in the face of resistance should be externally reported. Many concepts in the new Dutch Care and Coercion Act [Wet zorg en dwang] are not formally defined. Instead, the legislator has left it to those working in the field to decide how they should be interpreted. Therefore, consensus needs to be reached regarding which forms of involuntary care should be externally reported. In practice, external reporting might be affected by environmental and other factors. This study aims to identify which forms of involuntary care should be externally reported and how this external reporting is influenced by environmental and other factors. **Method**: In this study, we used an expert meeting and the Delphi method to understand the different views on external reporting and the use of coercive measures. In total, 68 professionals working in 5 care organisations participated in three rounds of the Delphi method. **Results**: The experts who participated in this study endorse the importance of a real-time external reporting system. They believe that standardized and reliable reporting of involuntary care can be achieved, however, certain aspects remain unclear. In the Delphi method, the findings of the expert meeting are further explored. Findings tell us that in order to achieve standardized and reliable external reporting, the field needs more concrete definitions than provided by law, especially on the recognition of involuntary care and resistance, but also on the forms of involuntary care that are only vaguely described in the Act. Furthermore, it is important that there will be consensus about what to report under which circumstances, since environmental factors have a major role in the judgment of whether care is involuntary. **Conclusions**: In this paper, we will discuss whether the legal position of individuals is (better) protected if care providers register only those forms of involuntary care where there is obvious resistance. In this case, many forms of resistance are overlooked, which may violate the legal protection of individuals with intellectual disabilities.

INDIVIDUAL PAPERS

Personal Experiences of the Criminal Justice System by Individuals With Autism Spectrum Disorders

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KEYWORDS Autism spectrum disorder; forensic issues

Background: The processes of arrest, investigation, trial and imprisonment are often extremely difficult for individuals with autism spectrum disorders (ASD). **Method**: In the present study, nine offenders with ASD were interviewed about the circumstance surrounding the criminal acts they committed: their views of the arrest, the police interrogation, the trial and the defence, and their experiences of being in prison and/or life following the offence. The participants were eight men and one woman. Diagnoses were made according to ICD-10 criteria (WHO, 1992). All men were diagnosed with Asperger syndrome, and the woman with ASD and intellectual disability. At the time of the interview, four participants lived in sheltered homes operated by the municipality, one lived in a forensic mental health security ward and one in a special residential accommodation for individuals with mental health problems. Three participants were in prison at the time of the interview. Three of the others had previously served a prison sentence. **Results**: All nine individuals described a range of different and often negative experiences with the Criminal Justice System (CJS). For example, several individuals remained confused either about the reasons for their arrest or about the trial proceedings, and none felt that their defence lawyer fully understood them or presented their case well. However, the majority of those given a custodial sentence coped well in prison, probably due to the high levels of structure and firm frameworks in that environment. Explanation factors associated with the offences indicated that ASD characteristics, such as misunderstandings, obsessions, and idiosyncratic beliefs and/or behaviours, were frequently involved, but stress was the most common explanation provided by the participants. **Conclusions**: The findings suggest limited understanding of ASD within the CJS, which needs to be significantly improved in order to secure legal protection of these individuals. Unnecessary misunderstandings, anxiety and violence could be avoided if the police and the CJS, in all countries, were to learn more about ASD, and how to approach and talk to individuals with this condition.

Gender Dysphoria in Patients With Learning Disabilities in Forensic Settings: A Descriptive Study

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KEYWORDS Forensic issues; gender-related issues

Aims: Gender dysphoria (GD) is characterised by a marked difference between the individual's expressed or experienced gender and the gender others would assign him or her (American Psychiatric Association, 2013). The prevalence of GD in the general population lies around 1%. Prevalence in the LD population is unknown, but one study suggested it may be as high as 12.9%. There have been no studies to date examining the prevalence of GD in individuals with LD in secure settings. **Methods**: A questionnaire was designed and sent out to all the locked rehabilitation services, low secure and medium secure units (both NHS and private) with dedicated LD wards in the East of England region. **Results**: Our results show a prevalence of 8.19% in this population. **Conclusions**: Our study supports the assertion that gender dysphoria is higher in the LD population than the general population. Within the forensic setting, the results are broadly similar. Further research is needed to establish the underlying reasons for this trend, and any association between GD and offending behaviour.

LIFE EVENTS, ENVIRONMENT, AND FAMILY

INDIVIDUAL PAPERS

Quality of Life and Inclusion: A Journey in the World of Cinema

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KEYWORDS inclusive community living; quality of life

Aims: The aim of this work was to foster the access and full participation of people with intellectual disability (ID) in the world of cinema. **Method**: For two years, a director has led theatre workshops with a group of people with ID particularly interested in the cinema. He has selected, among these, the actors for a movie, and has written the screenplay based on their own characteristics. **Results**: The film set has provided an environment which allowed everyone (both professional actors and persons with ID) to express their own potential by being themselves within a community and by promoting equal opportunities. People with ID experienced a great inclusion in all aspects of the filmmaking: both in planning and in acting. Two of them have also taken part in the Hollywood Film Festival together with the production team. Both have chosen proper clothing for the event; they have built good and important relationships, they have received compliments and recognition, and even signed autographs, just as professional actors without disability would. Travelling to Hollywood was the fulfilment of a dream. **Conclusion**: This experience of inclusion has required time, space, effort and resources; nevertheless, it

has improved the quality of life of 8 persons with ID. It has helped to increase public awareness of ID issues and to create a fairer and more cohesive community of cinema.

Family Functioning in Rare Genetic Syndromes: What Is the Burden for the Parents?

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KEYWORDS family; genetics; stress

Background: An increase in genetic diagnoses in neurodevelopmental disabilities results in an increased demand for counseling. Many studies focus on clinical aspects in the patients, but less attention is paid to family functioning. This study focuses on family functioning in rare causative monogenetic disorders of ID and aims to identify interfering factors. **Methods**: In total, 51 families with a child (biological age 3–40) diagnosed with a (genetically confirmed) rare monogenetic disorder resulting in ID participated. The parent(s) were asked to complete the General Functioning subscale of the Family Assessment Device (FAD) and answered an online questionnaire about their educational level and parental psychopathology. Measures were obtained about adaptive as well as maladaptive functioning of the patients (Vineland Adaptive Behaviour Scale, mini Psychiatric Assessment Schedule for Adults with Developmental Disabilities, Child Behavior Checklist). Additionally, an ADOS-2 play observation was performed to clinically examine the patients and quantify autism spectrum symptoms. Results: Mean FAD scores and correlations with specific patient as well as parent characteristics will be presented. Differentiation of characteristics related to pathological stress levels will be made. **Discussion**: Our results will be compared to those of several common chronic (somatic and psychiatric) diseases in order to place these on the continuum of the disease burden. Implications for clinical practice are formulated in order to help (para-)medical professionals recognizing pathological stress levels prematurely.

Being the Mother of a Child With an Intellectual Disability in the Arab Society: The Contribution of Internal and External Resources to Personal Growth Among Arab Mothers of Children With/Without Intellectual Disabilities

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KEYWORDS family; resilience; stress

Our study explored the unique experience of mothers of children with intellectual disabilities (ID) in the Arab society in Israel, a group that has been almost completely overlooked in literature. Our aim was to examine the contribution of internal resources of a sense of coherence, mental health, and coping strategies as well as the external resource of social support for stress and personal growth among mothers of children with ID (N = 89) in comparison to mothers of children with typical development (N = 105). The results show that mothers of children with ID were characterized by higher levels of stress and greater use of problem-focused coping strategies than mothers of children with typical development. The resources contributing to personal growth included the number of children, level of education, sense of coherence and problem-focused coping strategies. Additionally, personal growth was associated with high levels of well-being only among mothers of children with ID indicating that due to the unique status of these mothers in the Arab society, they must achieve emotional adjustment before they can experience personal growth. In addition, there was a negative association between the level of stress and the levels of well-being among both groups, but this association was stronger among mothers of children with disabilities. In contrast to previous findings, there was no association between personal growth and the level of stress in either group suggesting that regardless of unique circumstances, personal growth is related to the actual experience of motherhood, the most significant and central role of a woman in the Arab society.

Socio-Environmental Factors and Intellectual Disability: A Study of Relation

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KEYWORDS education; inclusive community living; participation; social inclusion

Aims: The current literature indicates that people with intellectual disability (ID) present quantitative and qualitative peculiarities regarding various socio-environmental factors in contrast to the general population. The identification of these factors could contribute to to preventing health issues, developing effective rehabilitative/therapeutic interventions, and promoting inclusion. The aim of this study was to assess the association between a number of socio-environmental variables and the condition of ID, with particular reference to personal history and life context. **Methods**: A sample of 125 participants with ID attending residential or clinic/rehabilitative services across various regions in Italy was questioned using the ISTORIA (Indagine Storiografica Organizzata per il Ritardo Intellettivo Adulto), a semi-structured questionnaire designed to investigate clinical and personal history of the patient. Scores obtained were statistically processed through frequency analysis and calculation of correlation indexes. **Results**: Significant correlations were found between family, educational/professional environments, and inclusion in the community. Positive relationships within the family were associated with higher participation in community life as well as with a higher

level of education. Further associations concerned relationships with individuals or groups outside the family, changes of living arrangements, and the level of environmental stimulation. **Conclusions**: Our findings are in line with those from previous research in supporting the importance of investigating the mechanisms involved in the acquisition of social skills in people with ID through family dynamics and participation in community life. The results should also raise awareness in clinical, educative, and rehabilitative practices.

NEUROLOGICAL AND PHYSICAL ISSUES

POSTER

Adults With Rare Childhood Onset Epilepsies

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KEYWORDS epilepsy; life span

Background: Childhood onset epilepsy syndromes show highly variable clinical outcome with regard to seizure remission and patient’s cognitive and adaptive development. Doose syndrome (myoclonic-atonic epilepsy) is known to have an unpredictable prognosis (As, Gabriel, & Ms, 2015) whereas Jeavons syndrome (eyelid myoclonia with absences) is associated with no or mild cognitive defects (Trivasano et al., 2011). The clinical course of these epilepsies in adulthood is poorly known. **Methods**: Here we describe the clinical outcome of patients with Doose ($n = 4$, two males, one female, aged 36–46) and Jeavons ($n = 3$, all females, aged 21–53) epilepsy. All participants completed neuropsychological evaluations (WAIS-R, WAIS-III, WPPSI-R, Nepsy). **Results**: All patients with Doose epilepsy met the criteria of ID (mild to severe) and have severe psychiatric co-morbidities and neurodevelopmental disorders. Only one has been seizure free. One of them has had psychotic periods, one mood disorders and two of them have had aggressive behavior. 3/4 of patients with Jeavons epilepsy met the criteria of ID (mild to severe). All have neurodevelopmental disorders. Two of them have had significant difficulties with their social relationships and behavior but inactive epilepsy. One has had psychotic periods. One patient has suffered yearly from one to two secondarily generalized seizures whereas the other patient has been seizure free, apart from numerous daily eye-lid myoclonias. **Conclusions**: These case reports suggest that the management of individuals with childhood onset epilepsies requires a careful long-term clinical follow-up to identify the specific seizure types and associated comorbidities, including neuropsychological disorders. Unrecognized neuropsychological (just like other undiagnosed) disorders may result in psychic and social problems.

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PERSON-CENTERED APPROACH AND QUALITY OF LIFE

SYMPOSIA

Symposium: Parenting Children With an Intellectual or Developmental Disability

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KEYWORDS Attachment; Problem Behaviours; Stress

Background and aim of symposium: Parents face a range of challenges in raising a child with an intellectual or developmental disability. This symposium consists of four papers which aim to explore some of the challenges experienced by parents and families, and to present research work examining ways in which parents and families can be supported.

SYMPOSIUM - ABSTRACT 1

From Early Adversity to Behaviour Problems Through Parenting: The Family Stress Model in Families of Children With an Intellectual Disability

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Aims: The Family Stress Model (FSM) proposes that disrupted parenting mediates the path between earlier parental psychological distress and later child outcomes. The aim of the study was to test this model among families of children with an intellectual disability (ID) in relation to children's behaviour problems. **Methods**: We analysed data available on 555 children with ID who had participated in the UK's Millennium Cohort Study. Family poverty and parental psychological distress were measured at 9 months. Parenting in the early years focused on adversarial parenting and positive relationship between the ages of 3 and 5 years. Children's behaviour problems were examined at ages 7 and 11. **Results**: Structural equation models examined whether parenting mediates the path from early adversity to children's behaviour problems in mid-childhood (step 1) and whether mediation took place through increases in adversarial parenting, decreases in positive relationship, or both (step 2). Analyses are ongoing, however results at the moment appear to indicate that adversity in early life has a significant effect on child behaviour problems in mid-childhood and this path is significantly mediated by parenting, in particular adversarial parenting. **Conclusions**: Findings seem to suggest that the route to behaviour problems in mid-childhood begins with poverty and parental psychological

distress in the first few months of the child's life. Families of children with ID are more likely to experience poverty, and high levels of parental distress. In addition, adversarial parenting mediates the route from early adversity to later behaviour problems.

SYMPOSIUM - ABSTRACT 2

The Relationship Between Parents and Their Child With a Significant Developmental Delay: An Exploration of Differentiated Attachment Behaviour

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Aims: Recent articles have discussed the association between attachment (in)security and challenging behaviour in people with intellectual disabilities. Empirical research on attachment behaviour of children with significant developmental delay (DD) is limited. This article examines the extent to which these children display differentiated attachment behaviour towards their parents and explores its association with child and parent characteristics. **Methods:** Questionnaires concerning attachment behaviour and parental support were administered and video recordings of the parent-child and stranger-child interaction were collected at home in 20 families with a young child with a significant DD. **Results:** Children displayed attachment behaviour to some degree and differentiated the amount thereof according to their interaction partner during the (play)interaction. In general, children with additional disabilities (comorbid with the cognitive delay) differentiated the amount of observed attachment behaviour towards their parent vs. the stranger to a lesser extent. **Conclusions:** The current research supports the relationship-specificity of attachment behaviour and indirectly suggests the development of an attachment relationship between children with a significant DD and their parents.

SYMPOSIUM - ABSTRACT 3

Realization of the Family-Centered Approach in Home-Based Support for Families With Children With an Intellectual Disability in Flanders: Opinions of Parents and Professionals

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Aims: This study concerned the realization of the family-centered approach (FCA) in home-based support (HBS) for families with children with intellectual disabilities (ID) in Flanders and the comparison of parents' and professionals' opinions about this aspect. In addition, the relation between parents' educational level, the education of the professional, and his/her experience in offering HBS on one side, and parents' and professionals' opinions regarding the realization of the FCA on the other was considered. **Methods**: A survey was conducted. Families and professionals were randomly selected by services offering HBS to families with a child (0–18 years) with an ID. Parents of participating families (N = 58) and their family workers (N = 46) completed the Helpgiving Practices Scale and the Enabling Practices Scale. **Results**: The FCA appeared to be largely present in HBS according to both families and professionals, however, in general, higher scores were found for families than for professionals. With respect to professionals' answers, parental educational level turned out as an important factor for parental autonomy in the family-professional collaboration. **Conclusions**: The present findings confirm previous research on the realisation of the FCA. By including and comparing both the parent and the professional perspective, a nuanced view on the realisation of the FCA in Flemish HBS was obtained. However, to fully understand the family-professional collaboration, further research should pursue the concrete meaning, interpretation, and elaboration of FC-behaviours by families and professionals in HBS.

SYMPOSIUM - ABSTRACT 4

A Community-Based Parenting Intervention for Parents of Children With a Disability: Outcomes in the Australian Stepping Stones Triple P Project

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Aims: The high prevalence of behaviour and emotional problems in children with developmental disabilities has been well established. This project aimed to decrease the rate of behaviour and emotional problems in children with a developmental disability. **Methods**: The Stepping Stones Triple P parenting programme was made available to the parents of children with an intellectual or developmental disability aged 2–12 years, across Queensland and Victoria in Australia. Parents completed a range of measures at pre intervention (baseline), post intervention, and at follow-up assessing for example child behaviour and emotional problems, parenting style and sense of competence, family functioning, psychosocial wellbeing, along with a range of demographic variables. **Results**: More than 1,000 families have participated in the study. Data will be

reported in relation to the primary outcome of child behaviour and emotional problems. Child, family, and environmental factors that may influence child outcomes and treatment response will be explored in relation to child behaviour outcomes. **Conclusions**: The implications of the results in relation to the provision of family-focused interventions at a population level will be discussed.

CO-PRODUCTIVE WORKSHOPS

Interpersonal Relations and ICT

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KEYWORDS Technology

Aim: The aim of our co-productive workshop is to exchange insights in recent research and experiences concerning ways in which interpersonal relations, and information and communications technology (ICT) contribute to the mental health of people with intellectual disabilities. During a recent Dutch conference, the participants stressed the importance of research regarding persons with intellectual disabilities (severe to mild ID). We will share studies conducted in the Netherlands and in the UK as well as our vision on the contribution of ICT to mental health and interpersonal relations. During the co-productive workshop, possibilities for collaboration will be discussed. Furthermore, exchange of experiences in this field of study will be shared and collaborative innovative research will be explored.

INDIVIDUAL PAPERS

Understanding the Quality of Life Predictors of Citizens With and Without Intellectual Disability

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KEYWORDS inclusive community living; quality of life; rehabilitation; social inclusion

Aims: Quality of life (QOL) allows an improved understanding of the personal outcomes, and is increasingly being used to guide the policies, services, and professional practices that are directed towards addressing the support of people with intellectual disability (ID). This proposal aims (1) to analyse and compare QOL of citizens with and without ID, and (2) to examine the personal and environmental factors that can predict QOL for both groups of participants. **Methods**: Data were collected from 1,264 individuals with mild or moderate ID levels (M = 31.36, SD = 10.55) as well as from 665 participants without ID (M = 36.42, SD = 15.44). QOL was evaluated with the Portuguese version of the Personal Outcomes Scale, which includes eight domains and three factors (Simões, Santos & Biscaia, 2016). **Results**: The results highlighted higher QOL for citizens without ID. However, there were no statistically significant differences in the emotional and physical well-being domains. Living circumstances, employment status, health status, and diagnosis were major predictors of QOL of adults with ID. Additionally, age, employment status, and health status had largely predicted the QOL scores of the general population. **Conclusions**: Our findings provided insight into how policies, services, and support need to change in order to enhance personal outcomes and decrease the gaps among citizens regarding their QOL. Knowledge of the personal and environmental factors that predict QOL allows catering to the needs of each person with ID as well as to rethink personalized support based on the socio-ecological model of human functioning.

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A Systematic Review Evaluating the Effectiveness of Active Support

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KEYWORDS intervention; participation; quality of life; services; staff

Aims: The aim of the present study was to synthesise all available evidence on the effectiveness of Active Support. Active Support is a person-centred model of care aiming to improve the quality of life of adults with intellectual disability (ID) by maximising meaningful engagement in daily life activities. Previous reviews have suggested that Active Support improves engagement in activities, and increases staff support, but were inconclusive regarding other potential effects (e.g. challenging behaviour). These reviews were not comprehensive or systematic, and new research has been published recently, making an updated and systematic review synthesis timely. The review aims to review all evidence regarding the effectiveness of Active Support in improving outcomes of adults with ID in residential settings, and also to describe the views of adults with ID and/or support carers about Active Support. **Method**: A systematic search covering 10 scientific databases identified peer-reviewed publications meeting the following inclusion criteria: a) participants are adults with ID in social care, b) implementation of Active Support, c) published in English. Data are being extracted using a standardised form. Quality assessments

will be undertaken on included studies. **Results**: Work is currently ongoing. We expect to be able to report full findings by the time of the conference. **Conclusions**: Results from this review will enhance our understanding of the effectiveness of Active Support and ultimately inform the development of further evaluative work. In practice, findings will enable the better informed use of Active Support as an intervention to improve the quality of life of adults with ID in residential settings.

Outcomes From Mental Health and Behavioral Interventions for Children With Dual Diagnosis

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KEYWORDS behaviour therapy

We compared the effectiveness of providing mental health and therapeutic behavioral services (TBS) against a standard mental health management approach for children with dual diagnosis of severe mental illness and intellectual disability based on a 1 year study. TBS is a short-term and intensive, behavioral modification treatment for eligible youth ages 5–21 who are engaging in behaviors that place them at risk of hospitalization. Though time-limited, TBS provides the child with skills to effectively manage the behaviors that are jeopardizing his/her quality of life. We employed the Child and Adolescent Needs and Strengths (CANS) survey to monitor our outcomes. CANS is a multi-purpose tool developed for children's services to support decision making, including level of care and service planning, to facilitate quality improvement initiatives, and to allow for the monitoring of outcomes of services. In the past year, our clinic served 158 children and their families in the County of Santa Clara, California. Fifty-eight children were eligible for TBS and entered the program while 100 did not meet the severity criteria and instead received the standard mental health care. Data-based evidence shows that children in the TBS program manifested symptom reduction and improvement in quality of life, and that their families experienced a decrease in the stress levels of parenting.

New Findings on the Use of the Italian Adaptation of the Family Quality of Life Survey

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KEYWORDS quality of life

Aim: In the last two decades, family quality of life (QoL) has emerged as an important research framework in the field of intellectual disability (ID). The aim of this study was to examine the reliability and validity of the SIQF (Strumento d'Indagine della Qualità di Vita della Famiglia), the Italian adaptation of the Family Quality of Life Survey (FQoLS) of the Centre for Public Health of the University of Toronto. **Methods**: The FQoLS was translated into Italian and consequently adapted through three trial-based revisions. Afterwards, the SIQF was used with 228 members of families including a person with ID. Participants were consecutively recruited among those attending residential or clinic/rehabilitative services across various Italian regions. **Results**: The SIQF showed good internal coherence (Cronbach's $\alpha = 0.83$) and inter-rater reliability (Cohen's $K > 0.91$). The interviewed families reported a low level of QoL in the areas of support received from other persons and from services, leisure and recreation, and interactions in the community, whereas familial relationships, (preparation for a) career, and the influence of values obtained the highest QoL scores. **Conclusions**: The assessment of family QoL seems to represent a useful step in the interactive relationship between family members and professional carers/services for the identification and sharing of tailored rehabilitative goals.

QuIQ (Quick Instrument for Quality of Life): An Instrument for a Rapid Assessment of Generic Quality of Life

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KEYWORDS quality of life

Aim: Among new patient-oriented outcome measures, the Generic Quality of Life (GQoL) has gained a central place and has come to represent a valid endpoint in most settings, especially for the field of intellectual disability (ID). However, most studies still refer to Health-Related QoL, and the tools for the assessment of GQoL present many issues related to the complexity of structure and administration time. The aims of this study were the evaluation of psychometric properties of a rapid tool for the assessment of GQoL named QuIQ, and the assessment of QoL in a sample of people with different levels of ID. **Methods**: The sample consisted of 240 persons with ID who underwent assessment with the QuIQ. A part of them were also assessed with the BASIQ, the Italian adaptation of the Quality of Life–Instrument Package. QuIQ contains the same areas of the BASIQ, but has a lower number of dimensions to be rated and a faster score attribution (visual analogue scale), which allows time saving by around 60%. **Results**: The QuIQ showed good internal coherence ($\alpha = 0.92$), inter-rater reliability ($K > 0.93$), and concurrent validity (> 0.8). The highest QoL mean scores were those for "belonging", whereas "psychological being" scored lowest. No statistical differences were found between the different levels of ID. **Conclusions**: Findings seem to show good psychometric characteristics of the QuIQ, further suggesting that it could be possible to apply rapid QoL assessment to people with ID across the range of ID severity. This could have important implications for the spread of use in the future and integration of rates regarding different proxies and settings.

An Alliance for the Quality of Life of People With Intellectual Disability

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KEYWORDS mental health promotion; support; wellbeing

Introduction: For over 15 years, Ampans (a charity organisation for intellectual disability) and Althaia (a university and healthcare network) have worked together in a cooperation agreement aimed at ensuring improvements in the independence of people with intellectual disability and their quality of life in the following areas: employment integration of people with disabilities, social integration of people with disabilities, cooperation in health and mental health needs. As a result, both organisations are customers, providers and allies. With regard to behavioural alterations, we are providers (Althaia provides mental health services to Ampans), allies in knowledge management (we jointly manage a postgraduate course in mental health and behavioural alterations in people with ID, and organize the biennial State Congress in Behavioural Alterations) and, in turn, Ampans provides services for Althaia. **Method**: To tackle behavioural alterations or mental health problems in people with ID, we follow two complementary lines of work: a) preferential individual monitoring in a normalising sphere (Children's/Young People's Mental Health Centre or the Adults Mental Health Centre) depending on people's age, and b) the leadership of a core team comprised of an Althaia psychiatrist and an Ampans psychologist to provide support, and the subsequent dissemination of plans and interventions in both Ampans and Althaia (the intervention culture and model are based on positive behavioural support). Internal leadership teams have been established for the different services, which lead the professionals trained on the postgraduate course. **Results**: There are practically no emergencies and hospital admissions due to behavioural alterations. With the application of positive interventions, behavioural alterations have significantly decreased. The emotional well-being of both people with ID and the people who help and support them has improved. The value of the acquisition of knowledge has increased significantly in the interventions by professionals. **Conclusions**: The work based on a comprehensive assessment of people and the functional integration of resources, facilitated by an involvement of the management teams of both organisations, mental health and social and education services, improves people's behaviour, the way in which professionals work, and the quality of life of people with ID together with all related interest groups.

POSTERS

Transnational Study on the Knowledge of Rights and the Perception of Discrimination in People With Intellectual Disability: A Comparison of Results Between Answers of Relatives, Professionals and People With Disabilities in Five European Countries

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KEYWORDS empowerment; rights of people with ID; self determination; vulnerability

Objectives: For people with ID, full social inclusion and active citizenship are not yet a reality. Policies to remove physical barriers have not spread to mental barriers. Attention models suggest that people with ID have to become active contributors to the common good. Our objective is to investigate the knowledge of the UN Rights of Persons with Disabilities of 2006 in three groups: Persons with intellectual disability, families, and professionals, all from the five countries, analyzing how their participation in the project has contributed to improve this knowledge. **Methods**: Several questionnaires were employed in the three groups of participants. A sample was extracted from the residential and community resources specialized in intellectual disability of the five participating countries that responded voluntarily. The scale of perception of discrimination to people with intellectual disability and a questionnaire on the Rights of Persons with Disabilities were employed. **Results**: In total, 544 subjects were assessed (229 people with disabilities, 194 professionals, and 121 relatives). The distribution of participants regarding the countries was as follows: Spain (158), Sweden (41), Hungary (132), Slovenia (99), and Poland (114). Statistically significant differences were found regarding the knowledge of rights and fewer differences regarding the perception of discrimination, where people with disabilities presented a better knowledge than families and professionals ($p < 0.001$). Moreover, persons having a disability for a longer period of time who answer the questionnaire alone and live alone score better in the knowledge of rights. Significant differences in the taxes of responses of people with disabilities were found regarding their place of residence, but not regarding families and professionals. **Conclusions**: The study of the knowledge of the Rights of Persons with Disabilities in all the groups involved, at a transnational level, helps to define the areas in of improvement, knowledge and violations of rights. The information gathered shall contribute to full inclusion and active citizenship of people with intellectual disabilities.

Preventive Group Intervention for Adolescents With Mild Intellectual Disability and Their Parents

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KEYWORDS diagnosis; empowerment; intervention; prevention; quality of life

Aims: The aims of this project were twofold. The first aim was to pilot a psychoeducational group intervention for adolescents with mild intellectual disability, including parallel sessions for parents. The purposes of the intervention were to improve: a) the participants' understanding of the diagnosis; b) their coping with everyday challenges; c) their social network. The second aim was to monitor the progress of the adolescents in the pilot group within a range of psychosocial domains. **Methods**: The intervention consisted of six group sessions, attended by one group consisting of 8 adolescents (aged 15–17) with mild intellectual disability, and was lead by 2 clinical psychologists. During the sessions, themes related to the adolescents' life situation, diagnosis, autonomy, coping and well-being were addressed, with a mix of lectures, practical

assignments, role-play, and discussions. The parents attended parallel sessions lead by a clinical psychologist and a clinical social worker. Themes related to diagnosis, social services, family life, and transition into adulthood were addressed. Group cohesion was emphasized, each session started with both groups having dinner together, and social interaction among group members was encouraged. Data was collected pre and post intervention without a control group. Parents and teachers completed a questionnaire including questions on the adolescents' well-being, adjustment, and social and emotional functioning. The adolescents participated in a short semi-structured interview using Talking Mats. **Results**: Preliminary qualitative evidence indicates that both adolescents and parents established friendships during the intervention, and gained increased understanding of the implications of the diagnosis. Quantitative results and more in-depth qualitative data will be presented. **Conclusions**: The pilot study yielded promising results, encouraging further implementation and rigorous evaluation.

PSYCHOPATHOLOGY AND PROBLEM BEHAVIOURS

SYMPOSIA

Symposium: Who's Challenging Who?: A Co-Produced Training Course to Improve Staff Empathy and Attitudes

Name of chair: Samantha Flynn

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KEYWORDS challenging behaviour; coproduction; intervention; services; training

Background: This symposium describes the theoretical basis, development, and subsequent evaluation of a staff training intervention (Who's Challenging Who?) which aims to improve staff attitudes and empathy towards adults with an intellectual disability who had been labelled as having challenging behaviour. The aim of this symposium is to provide an overview of the project development, the quantitative evaluation of effectiveness of the staff training intervention, and to present data from interviews with the trainers and participants of the training, exploring their experiences.

SYMPOSIUM - ABSTRACT 1

Theoretical, Empirical and Co-Production Background for Who's Challenging Who?

Richard Hastings[a] and the Who's Challenging Who? Trial Team

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Aims: Providing a theoretical and empirical basis for undertaking the Who's Challenging Who? training course. **Methods**: Three theoretical/conceptual perspectives informed the Who's Challenging Who training course:

(1) Hastings' extension of models of challenging behaviour to include a functional perspective on carer behaviour.
(2) The contact hypothesis as a guide for attitude change.
(3) Co-production with people with intellectual disabilities.

All three perspectives will be described in terms of their contributions to Who's Challenging Who. The empirical background for the training course came from two systematic reviews of the experiences of people with intellectual disabilities and their carers. **Results**: The systematic reviews focused on meta-syntheses of qualitative data and identified a number of themes in the experience of people with "challenging behaviour" and their carers, including: difficulties accessing expert support, battling with services and professionals, and the negative and positive contributions of staff attitudes and behaviours in challenging behaviour services. **Conclusions**: General psychological theory, bespoke challenging behaviour theory, the process of co-production, and existing research evidence on experiences within services can all be used to inform staff training interventions focused on challenging behaviour. Explicit interventions targeting staff empathy and attitudes are currently missing from evidence-based approaches such as Positive Behavioural Support.

SYMPOSIUM - ABSTRACT 2

Co-Producing the Who's Challenging Who Training Course With People With an Intellectual Disability

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Aims: Describing the process of developing the Who's Challenging Who? training package with involvement from three trainers with an intellectual disability. The final training package will be described and examples of the training content will be given. **Methods**: We developed the Who's Challenging Who? training package with significant involvement from the trainers with an intellectual disability, and by referring to relevant theory and systematic literature reviews. Who's Challenging Who? is a brief training package which is delivered by two trainers (one of whom has an intellectual disability and has previously been labelled as having challenging behaviour). **Results**: The training is multi-faceted and explores the real experiences of people with an intellectual disability in six areas: communication, problems at home, medication, restraint, inclusion, and qualities of support staff. The training also highlights what people with an intellectual disability would like to see happe and is supplemented by the trainers' own experiences throughout. **Conclusions**: Who's Challenging Who? has been developed and delivered in partnership with people with an intellectual disability in paid roles as expert advisors. This approach has enabled the trainers to influence the training package and research project development, and to indirectly advocate for other people with an intellectual disability and challenging behaviour.

SYMPOSIUM - ABSTRACT 3

A Cluster Randomised Controlled Trial to Test the Effectiveness of Who's Challenging Who to Improve Support Staff Attitudes and Empathy Towards Adults With Intellectual Disability and Challenging Behaviours

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Aims: Investigating the effects of a novel manualised staff training intervention (Who's Challenging Who?) on support staff attitudes and empathy towards adults with an intellectual disability and challenging behaviours. Secondary aims include investigating the effects on the incidence of challenging behaviour and use of restrictive practices. **Methods**: A large cluster randomised controlled trial (RCT) was delivered with services randomised in a 1:1 ratio to the Who's Challenging Who? training or to a waiting list control. Outcome measures have been collected at baseline, 6 weeks, and 20 weeks post randomisation. **Results**: To date, 118 services were randomised and 235 staff members were included. Twenty five training sessions were delivered in two phases. Baseline data have been gathered for all staff members, alongside follow-up data for the first phase of the study (58 residential settings). Follow-up outcome data for the second phase (60 residential settings) are currently being collected. We will report on the preliminary results at the conference using multilevel regression models. **Conclusions**: If found to be effective, Who's Challenging Who? will be a useful addition to staff training within intellectual disability services for people who have been labelled as having challenging behaviour.

SYMPOSIUM - ABSTRACT 4

Trainer and Trainee Experiences of Engaging With the Who's Challenging Who? Staff Training Course

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Aims: We aimed to understand how both trainers and trainees experienced the Who's Challenging Who? training package, and whether there were any perceived long-lasting changes attributable to the training. **Methods**: Semi-structured interviews were undertaken with the four trainers (three with an intellectual disability), seven service managers, and six support staff members. Interviews were transcribed verbatim and analysed using thematic analysis. **Results**: Interview topics for the trainers included: experiences of

being trained to be a trainer, being a trainer, and the effect of the training on their wider lives. Interview topics for trainees included: experiences of training, development and implementation of an action plan stemming from the training, and any noticed changes in practice since the training. Qualitative evaluation of the training, from both the trainers' and trainees' perspectives will also be included. **Conclusions**: Results from the interviews with service managers and support staff will provide a depth of data, which will assist in the interpretation of the quantitative results. Data from staff and trainer interviews may also help to effectively translate the research findings into practice by offering invaluable insights into trainer and trainee experiences of this novel approach to intellectual disability staff training.

Symposium: The AUP Multi-Centre Study: A Clinical Study on Autism, Intellectual Disability and Psychiatric Disorders

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KEYWORDS Autism spectrum disorder; developmental disorders; psychiatric disorders

Background and aim of the symposium: The AUP multi-centre study is an ongoing clinical treatment study. The study was established to contribute to valid psychiatric diagnoses and individually tailored services for individuals with autism spectrum disorders (ASD) and intellectual disability (ID) in need of specialised mental health services. Eight centres participate in the study. Patients with ASD and ID with behaviour problems who are referred to one of the centres or are under suspicion of having psychiatric disorders are recruited for the study. The patients are assessed three times: at referral, after one year and after two years. Three different lectures will be presented: on diagnostics, environmental risk factors, and intervention.

SYMPOSIUM - ABSTRACT 1

Psychiatric Assessment in ASD/ID: A Case Study

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KEYWORDS Assessment; autism spectrum disorders; psychiatric disorders

Background: The identification of psychiatric disorders in people with autism spectrum disorder (ASD) and intellectual disability (ID) poses considerable challenges: There are few appropriate assessment tools; symptoms of ASD may be difficult to separate from symptoms of a psychiatric disorder; and people with ASD and ID usually have difficulties in self-report. Differentiating

ASD and psychosis seems to be particularly challenging. **Method**: A case study was performed to explore the diagnostic decision-making and strategies employed in the assessment of a young man with ASD and ID who eventually was diagnosed with a psychotic disorder. Both assessment tools from the AUP study as well as more conventional assessment tools were utilized. **Results**: Data gathered with various assessment tools and observations from the inpatient stay will be presented together with post-treatment data and data from follow-up sessions. **Conclusion**: The present study contributes to the few previous reports on identification of psychosis in this population and may assist clinicians in conducting more accurate psychiatric assessments. Although no tools have been validated for the assessment of psychosis in people with ASD and ID, the current study demonstrates that conventional assessment tools can be useful in such assessments. Factors likely to increase or decrease their apparent usefulness will be discussed together with observations from the current case, which may point a direction for future research on psychosis in individuals with ASD/ID in general.

SYMPOSIUM - ABSTRACT 2

Adverse Life Events in the Occurrence of Anxiety and Depression Among Adults With Autism and Comorbid Intellectual Disability

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KEYWORDS anxiety; autism spectrum disorders; depression; risk factors

Background: People with autism and people with intellectual disability seem to be vulnerable for developing anxiety and depression. People with both autism and intellectual disability (APU) may be especially vulnerable. Several studies have shown an association between exposure to life events and psychological problems in the neurotypical population, but only few have examined this association among adults with APU with comorbid anxiety and depression. **Methods**: The present study used data from the AUP multi-centre study on a subsample at T1 and compared the occurrence of adverse life events between adults with APU and comorbid anxiety and depression (n = 18), and adults with APU without comorbid anxiety and depression (n = 12). Support staff and family informants provided data on symptoms of anxiety and depression as well as exposure to adverse life events during the past twelve months. **Results**: The adults with comorbid anxiety and depression experienced significantly more adverse life events during the past twelve months. The seemingly small, daily hassles may be a greater indicator for vulnerability in this group. **Conclusion**: These data offer support for the status of adverse life events as a risk factor for anxiety and depression in adults with APU. Life events are likely to be pertinent in clinical work with people with APU. To establish adverse life events as a causal risk factor, prospective research needs to examine the mechanisms behind the impact of life events on psychological well-being.

SYMPOSIUM - ABSTRACT 3

Patients', Family Members' and Professional Carers' Experiences of Psychoeducational Multifamily Groups for Participants With Intellectual Disabilities and Mental Illness

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KEYWORDS autism spectrum disorders; intellectual disabilities; intervention

Background: Psychoeducational multifamily groups (PMG) are of interest for adults with ID because family work is one of the best researched psychosocial interventions for patients with psychosis, encompassing reduction of relapse, compliance, and increased social functioning. There is a dearth of articles addressing psychoeducational multifamily groups for adults with intellectual disabilities/autism. **Objectives**: The objective of this study was to investigate the participants' experiences of being part of a psychoeducational multifamily group especially adjusted for participants with intellectual disabilities. **Methods**: The group intervention had been slightly modified due to the participants' intellectual disabilities. Four patients, their close relatives, and community professional caregivers were interviewed in depth using a semi-structured scheme. The four patients had participated in different groups. Three of them had autism spectrum disorder in addition to intellectual disabilities and mental illness. **Results**: Topics discussed in the group sessions encompassed friendship, personal economy, hygiene, understanding of mental illness, and the need for help. A basic meal was served at every group meeting. The experiences were favorable. **Conclusion**: Psychoeducational multifamily groups seem to be a favorable intervention for patients with intellectual disabilities and additional mental illnesses. Patients with an autism spectrum disorder in addition to intellectual disability also profited from attending the PMG. The families got to know their relative or patient in new ways, including seeing them mastering the situation of being in a group.

Symposium: Beat-It: The Process and Outcomes of Large Scale Randomised Control Trial of Behavioural Activation Compared to Guided Self-Help for People With Intellectual Disabilities and Depression

Name of chair: Andrew Jahoda

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KEYWORDS dual diagnosis; psychiatric disorders; psychopathology; psychotherapy; research

People with intellectual disabilities are often excluded from psychosocial therapies, which are usually the treatment of choice for people suffering from depression. The reasons for this include a paucity of evidence and the lack of manualised approaches adapted to the life experience and circumstances of people with intellectual disabilities. Therefore, the aim of this symposium is to present an

overview of the BeatIt trial, a large-scale randomised control trial of behavioural activation compared to a guided self-help attention control intervention. The talks will provide a background to the trial and the adaptation of the interventions, an overview of the conduct of the trial and whether the interventions were delivered with fidelity to the manual, before describing the outcomes of the trial and findings from a nested qualitative study.

SYMPOSIUM - ABSTRACT 1

A Rationale for the Trial and Adaptation of the Behavioural Activation and Guided Self-Help Interventions for People With Intellectual Disabilities and Depression

Richard Hastings and the BeatIt Trial Team

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Aims: Behavioural activation is a psychological therapy that has been shown to be as effective as CBT in tackling depression. The advantage for adults with intellectual disabilities is that behavioural activation is less dependent on verbal communication. The question was whether it would be possible to recruit participants for a large-scale, multi-site trial of an individual psychological therapy for people with an intellectual disability. **Methods**: The participants were randomised to behavioural activation (BeatIt) and guided self-help (StepUp), an ethical alternative therapy. These were both manualised approaches adapted for people with intellectual disabilities. Participants were followed-up at 4 months, 8 months and 12 months post randomisation. Participants were recruited from sites in Scotland, England and Wales using a multipoint recruitment strategy. **Results**: The target recruitment was set for 166 participants and the final total achieved was 161 participants. The key challenges to achieving recruitment were not only identifying individuals who have intellectual disabilities and depression, but also recruiting and training a sufficient number of therapists to deliver the interventions. **Conclusions**: Successful recruiting for this trial offers hope for developing the evidence base for using psychological therapies with people who have intellectual disabilities. Lessons were also learned about the considerable challenges to be overcome.

SYMPOSIUM - ABSTRACT 2

Fidelity to Protocol and Therapy Quality in the BeatIt Study

Dave Dagnan[a] and the BeatIt Trial Team

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Aims: The paper will present an overview of the fidelity approach in the BeatIt study and describe the characteristics of therapists and supervision, and the development of a measure to assess the "quality" of therapy delivery that is designed as a non-specific therapy process measure for structured and manualised therapies. **Methods**: Therapist demographic and supervision data were collected. A non-specific therapy process measure was developed based on previously available fidelity measures. Therapists in both arms recorded two therapy sessions that were rated by independent research associates (144 fidelity recordings were available for analysis), 45 recordings were also rated by a further research associate to determine inter-rater reliability. **Results**: The data indicated that the therapists were predominantly nurses, had no accredited therapy training and received a mean of one supervision for every 1.8 therapy sessions. Therapist in both arms provided a high quality of therapy and closely followed the manuals. The scale had good internal reliability (alpha = 0.76). Further detailed data for the psychometric properties of the non-specific therapy process scale will be presented. **Conclusions**: The fidelity data shows that the core protocol for the recruitment of therapists and implementation of supervision was followed and therapists provided high quality of therapy that was consistent with the manuals. The non-specific therapy process measure will support the development of therapy process research for people with intellectual disabilities.

SYMPOSIUM - ABSTRACT 3

Participant, Supporter and Therapist Experiences of Psychological Interventions for People With Mild/Moderate Intellectual Disabilities and Depression in the BeatIt Trial: A Qualitative Analysis

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Aims: Qualitative analyses of people's experiences of psychological interventions can complement quantitative trial data. However, qualitative research concerning people's experiences of psychological interventions with people with intellectual disabilities and mental health problems is sparse. **Methods**: Within the BeatIt trial of behavioural activation (BeatIt) versus an attention control guided self-help intervention (StepUp), semi-structured interviews were conducted with purposive samples of people with intellectual disabilities who had completed therapy (15 BeatIt, 10 StepUp) and carers who had supported the person throughout therapy (11 BeatIt, 10 StepUp). Six focus groups were conducted with trial therapists (15 BeatIt, 11 StepUp). Framework analyses using transcripts of participant, supporter and therapist interviews/focus groups generated themes and sub-themes related to specific and non-specific aspects of the interventions. **Results**: People with intellectual disabilities, supporters and therapists were generally positive about both interventions, reporting positive impacts on people's lives from a starting point of depression. Participants and supporters were willing to try therapy in the perceived absence of alternatives. All groups identified specific aspects of each intervention, but also non-specific factors such as a clear structure and focus, good therapeutic relationships, accessible materials, and the positive contribution of supporters

were commonly mentioned by all groups across both interventions. Suggestions for improvement included greater personalisation of materials and therapy sessions, ensuring that supporters were reliably present and engaged, and that the environments outside therapy sessions were supportive. **Conclusions**: Carefully designed adapted psychological interventions for people with intellectual disabilities and depression can be delivered in ways that are positively experienced by participants, supporters and therapists.

SYMPOSIUM - ABSTRACT 4

The BeatIt Trial Outcomes: Comparing the Effectiveness of Behavioural Activation for Depression in Adults With Intellectual Disabilities With an Attention Control Intervention

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Aims: The trial investigated the effectiveness of behavioural activation (BeatIt) for people with intellectual disabilities and depression. BeatIt was compared with a guided self-help (StepUp) intervention. **Methods**: This was a single-blind randomised controlled trial, with follow-up at 4, 8 and 12 months post randomisation. In total, 161 participants were randomised (BeaIt 64; StepUp 77). They were aged over 18 years and had clinically significant depression. The primary outcome measure was the Glasgow Depression Scale (GDS-LD). **Results**: There were no statistically significant group differences in the effects of StepUp and BeatIt on GDS-LD scores at the 12 month primary outcome point. However, there were statistically significant differences within group reductions in both arms of the study at 12 months (−4.20 for BeatIt and −4.46 for StepUp). Reductions occurred between baseline and follow-up at 4 months, immediately following therapy, and there were no changes between 4 and 12 months. There was no economic evidence to suggest that BeatIt may be more cost-effective than StepUp. However, treatment costs for both groups were only approximately 4–6.5% of the total support costs. **Conclusions**: Primary and secondary outcomes, and economic data showed no evidence for BeatIt being more effective than StepUp. Although not supported with a robust experimental design (i.e. a Treatment as Usual comparison is lacking), all data sources are consistent with a conclusion that both BeatIt and StepUp are active and potentially effective interventions.

Reference

Jahoda, A., Melville, C. A., Pert, C., Cooper, S. A., Lynn, H., Williams, C., et al. (2015). A feasibility study of behavioural activation for depressive symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *59*(10), 10–21. doi:10.1111/jir.12175

Symposium: The Treatment of Psychiatric Disorders, Especially Depression, in People With Intellectual Disabilities

Name of chair: Heidi Hermans[a,b]

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KEYWORDS intervention; psychopathology; psychopharmacology

Background and aim of the symposium: Although depression is a common disorder in adults with intellectual disabilities, treatment options are not well studied. Our aim is to give an overview of current non-pharmacological treatment options, to present our experience with bright light therapy in this specific population, and to present the possibilities of pharmacological treatment.

SYMPOSIUM - ABSTRACT 1

A Systematic Review of Non-Pharmacological Interventions for Adults With ID and Depression

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Aims: Depression is a common psychiatric disorder in adults with intellectual disabilities (ID). As depression can occur in all levels of ID, our aim is to evaluate non-pharmacological interventions for all adults with ID and depression. **Methods**: An electronic search in six databases (Embase, Medline, Web of Science, Cochrane, PsycINFO and Google Scholar) completed with manual searches in reference lists of included papers and manual searches in reference lists of relevant systematic reviews. Inclusion criteria have been defined prior to the inclusion of the papers and PRISMA guidelines have been followed. All papers have been screened independently by two reviewers. **Results**: 4267 papers were screened on their title/abstract and 112 papers were completely read. Twenty-four papers were included in the final review. Different treatment options for adults with ID and depression are discussed regarding their effectiveness and the level of evidence. **Conclusions**: There is a lack of evidence-based interventions for adults with ID and depression. Some interventions seem to be promising to decrease depressive symptoms, but further investigation is necessary to expand the treatment options in this population.

SYMPOSIUM - ABSTRACT 2

The Applicability of Bright Light Therapy in Adults With Intellectual Disabilities

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Aims: Bright light therapy (BLT) is effective in the treatment of depression in the general population. It may be a good treatment option for adults with intellectual disabilities (ID) too. However, its applicability and effectiveness have not been studied in groups of adults with ID yet. Our aim is to study the applicability of BLT in adults with ID. **Methods**: BLT was offered to 14 adults with moderate, severe or profound ID for two weeks, using a 10,000 lux light box. Applicability of BLT and change in depressive symptoms were studied with questionnaires. **Results**: BLT was successfully applied for ≥10 days in 10 participants. It was also applicable in participants with rather severe challenging behaviour. Before BLT, 9 participants scored above the cut-off score of the ADAMS depressive mood subscale. After BLT, 6 of them scored below cut-off. **Conclusions**: BLT is applicable in adults with moderate, severe or profound ID. Its effectiveness as a treatment for depression in adults with ID should be further studied.

SYMPOSIUM - ABSTRACT 3

A Multicenter Randomized Controlled Trial for Bright Light Therapy in Adults With Intellectual Disability and Depression: Obstacles and Challenges

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Aims: There are limited treatment options for adults with intellectual disabilities (ID) and depression. In the general population, Bright Light Therapy (BLT) is an effective intervention for depression. Knowledge about the antidepressant effect of BLT in adults with ID is lacking. The aim of this study is to investigate the effect of BLT on depression in adults with ID. **Methods**: Participants with ID (IQ≤ 70) and depressive symptoms were randomized into one of the three study groups (Group I: 10,000 lux bright white light, Group II: < 499 lux bright white light [placebo] and Group III: regular care [control group]). BLT was provided for 30 minutes a day, in the morning before 12 a.m., over a period of 14 days. **Results**: Different obstacles and challenges are faced in the preparation period of the study, during the inclusion period and regarding measurements. These obstacles and challenges

will be discussed. **Conclusions**: It can be difficult and challenging to execute a RCT to investigate the effect of BLT in adults with ID and depression. Nevertheless, it is necessary to conduct these kinds of studies to contribute to the improvement of our knowledge about evidence-based treatment options for adults with ID and depression.

SYMPOSIUM - ABSTRACT 4

Results of Psychopharmacological Treatment of People With Intellectual Disabilities

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Aims: In the care of people with intellectual disabilities (ID), high use of psychopharmacology is frequently observed. As consulting psychiatrists in large service facilities for people with ID we are regularly consulted with questions concerning psychopharmacology. After 5 years of experience in this field, it can be concluded that these questions are always complex and often general guidelines do not apply. This study gives an overview of the results of psychopharmacological consultations in the care of people with intellectual disabilities. **Methods**: Retrospective chart review of all psychiatric consultations between July 2012 and July 2016. **Results**: In total, 610 patients were attended by a psychiatrist. Their age varied between 4.9 and 77.4 years. Psychiatric diagnoses covered the whole spectrum of psychiatry, with autism (35%), depression (20%) and ADHD (19%) as the most frequent diagnoses. One third of patients did not use any psychopharmacological medication yet. One third already used two to eight psychopharmacological medications. In 60% of the patients, adjustment of medication has been advised. In 40% of the patients, effects could not be assessed due to lack of follow-up. Collected follow-up results varied: Positive results were often only reached after several adjustments in medication. Eventually, in two-thirds of patients a positive result could be reached. **Conclusion**: Psychiatric consultation in people with ID and especially advice on medication is complex, but can lead to positive results, which are often reached after more than one adjustment in pharmacological treatment.

Symposium: Autism Spectrum Disorder

Name of chair: Rita Kreins

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Fondation Autisme Luxembourg

KEYWORDS autism spectrum disorder; challenging behaviour; staff; support

SYMPOSIUM - ABSTRACT 1

Using the Comportemental Approach in Facing Behavior Problems – Help to Find Strategies and Pedagogical Support

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Aims: The purpose of our group of analysis of the behavior disorders presented by the people with Autism Spectrum Disorder living at our institution, is to reduce these behavior disorders in order to increase the quality of life of each of the users and giving a support for the staff, avoiding an appeal to a specific medication and assuring the implementation of a regular follow-up in front of various behavior problems. **Methods**: By multiple observations and a strategic analysis peeling any facets of the behavior raising problem, the group verifies various ways of acting, emits hypotheses and contributes by multiple reflections to the adaptations possible and necessary to propose for the support of the daily work of the educational teams and thus for the best of the target user, by taking into account his personality, its interests and its needs. **Results**: The analysis of the behavior problems helps the team to understand the reason of WHY the person with Autism acts in this way and gives them (team and user) possibilities to find new ways of getting out of this difficult and repeated negative way of functioning. **Conclusions**: An analysis of a specific behavior problem, having an objective view of the person and by taking distance regarding on this behavior, is important for remedying the behavior disorders and deciphering them messages.

SYMPOSIUM - ABSTRACT 2

Psychopharmacology in Autism Spectrum Disorders: Reducing Medications is Possible at the FAL

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KEYWORDS Psychopharmacology; Autism Spectrum Disorders

Aims: Psychopharmacology in Autism Spectrum Disorders (ASD). is generally used as main intervention to manage behavioural problems. Antipsychotics and other medications have been studied to impact on ASD core symptoms without receiving evidence of efficacy. The objective of this paper is to review evidences regarding medication treatments and through a ten years protocol for the reduction of psychotropic medications among the Fondation Autisme Luxembourg services to show that they must be used only if necessary and in association with behavioural interventions. **Methods**: The Medline, PsycINFO, and available national and international guidelines were searched. A sample of 40 adults with ASD diagnosis attending the FAL services after having conducted clinical, biological and behavioural tests and analysis faced a gradual reduction of psychotropic medications.

Results: Few studies were identified and the strength of evidence was insufficient in this population. We have reduced more than 60% both in the neuroleptic and anxiolytic drugs, comparing different medications by defined daily dose. **Conclusions**: The results show that benzodiazepines should be avoided because no effective, few new generation antipsychotics result to be helpful for the behavioural management, while SSRIs and mood stabilizers in managing depression and anxiety symptoms. This is possible only if a behavioural treatment is associated. There is a marked lack of data on use of medication treatments. To support their use in ASD, good-quality research is needed.

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SYMPOSIUM - ABSTRACT 3

Empowerment of the Next Generation of Self-Advocates; How Can We Help?

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KEYWORDS Self-advocacy; experiential workers; autism; developmental perspective

Aims: Self-advocacy is becoming an essential part of development in how we move forward within the world of autism, whether it be in the areas of education, healthcare, mental health or research. How is our developing view regarding autism changing the future perspective of people with autism?

I work together with Dr. Martine Delfos whose theory of the Socioscheme about the developmental perspective on autism and the Mental Age Spectrum Within 1 Person (MAS1P) theory is being supported by the newest research and is also being embraced by the people themselves.

Challenges regarding people being heard, sometimes for the first time in their lives and broken trust are themes which run through all of my work and my reason for working within this world.

How can we make sure people with autism are regarded first as a human being, rather than being focused on the diagnosis, even when working as self-advocates and experiential workers? This is an important dilemma we are facing when integrating self-advocates with professionals. **Methods:** By using the theory of the Socioscheme together with the MAS1P we see a broad mental age spectrum with a delayed and accelerated development, with ages younger and older compared to a persons' actual calendar age. Meaning we cannot judge someone on their physical age as we may overestimate someone's abilities and set them up for failure. We also see a cognitive acceleration which also needs to be acknowledged in order to address someone on the cognitive level which is beyond their calendar age.

How can we help people with autism empower themselves by using the starting point of the developmental perspective to achieve their dreams? Involving people with autism in the development of standards within their own country where self-advocacy is used in an innovative way and fitting with the concept of equality. **Results:** I will share my experiences working with self-advocates who just want to share their story and experiential workers who work as professionals within the various areas' in The Netherlands.Working from the perspective of the person with autism and their capabilities instead of the perspective of the organisation who wants to involve self-advocates is done by differentiating between what sort of project fits with someone's capabilities. **Conclusions:** My work in The Netherlands has shown that it is possible to support people with autism in their dreams of making a difference for other people with autism, no matter what the developmental level is. Whether this is being an integral part of a working group, giving incidental documentation feedback, being involved in a local project or guiding, treating or coaching a person with autism.

Luxembourg and FAL are open to work together with self-advocates and a tone can be set where we work from the perspective of connecting to the person as a whole and making sure we do not only use someone but that we help him or her work towards whatever life goals they may have.

Symposium: Equipping Staff to Meet Challenging Behaviour

Name of chair: Jennifer Clegg[a,b]

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KEYWORDS challenging behaviour; staff

Aim: Ballatt & Campling (2011) argue that ordering staff to be kind will always fail, because it underestimates the human challenges encountered in mental health work. This symposium considers the scandals that intermittently erupt within environments intended to care for people with Intellectual Disability (ID): not only in hospitals but also in the community. It then examines the difficulties community staff face in balancing people's rights, safety and quality of life needs; and explores the impact of an intervention, Heijkoop's Discovery Awareness, that aims to support staff to better understand and attune to challenging people.

SYMPOSIUM - ABSTRACT 1

Scandals: Where and Why They Happen

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Background: Deleuze (1968) argued that creativity and renewal emerge not from thesis and antithesis, but from seeing how to engage with repeating events in new ways. This paper considers possible reasons for the abuse scandals that recur in ID, in order to support prevention rather than continuing to pour resource into post-hoc inquiries. **Approach**: review of evidence and ethics. **Conclusion**: Much ID policy is predicated upon success stories of people with ID managing their own lives, holding jobs & taking a normal place within the world. Yet this denies the evidence that people with ID who also have severe mental health problems or show challenging behaviour face a range of difficulties. They are likely to live in socially deprived environments, often have a precarious sense of self, are prone to relapse, and are rarely able to manage their emotional lives independently. Enabling them to flourish requires considerable skill.

SYMPOSIUM - ABSTRACT 2

Care Staff as Unheard Stakeholders

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Background: Recent policy changes in England represent the final phase of deinstitutionalisation, affecting 0.4% of people with intellectual disability and/or autism who have complex needs and still reside in public or private hospitals or similar. Government data indicate mixed progress in supporting this population to move into more appropriate specialist community accommodations closer to home. Community support staff often spend the most time with service-users, yet are the least heard voices about why placements succeed and fail. **Method**: Managers and support staff (n = 13) working in specialist community placements were interviewed about perceived barriers and facilitators to implementing this policy. Transcripts were subjected to Thematic Analysis. **Results**: Participants identified difficulties balancing people's rights, safety and quality of life needs. They felt the system's expectations of them are hard to deliver within the resources, legislation, values and support models provided them. Multi-disciplinary expertise was highly valued when it provided both emotional and practical support, least valued when perceived to be overly-blaming or inspectorial. Specialist health input was considered to withdraw prematurely for those people with intellectual disability and autism who have the most complex mental health and/or behavioural needs. **Conclusions**: Support staff require greater multi-disciplinary understanding and allegiances to navigate the complex and often contradictory interface of ideology and practice, rather than feeling they are the final link in a chain expected to connect them. Recommendations about how this might be achieved for the most challenging populations are provided.

SYMPOSIUM - ABSTRACT 3

Engaging With Uncertainty: Interpreting Patient Behaviour in Discovery Awareness (DA) Sessions

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Background: Staff who work with people with intellectual disabilities (ID) and challenging behaviour routinely interpret difficult to understand behaviours. How staff understand the actions or intentions of a patient with challenging behaviour can have implications for how they work with them in practice. One way of exploring these interpretations is to study the way staff talk about the meaning of shared patient's behaviour with their colleagues during a specific video-analysis based intervention which aims to support staff. **Method**: Conversation analysis (CA) was used to study ID staff interactions over 9 hours during DA sessions with 6 adults with ID admitted to a specialist service for assessment and treatment of mental health problems or challenging behaviour. **Results**: Participants navigated taking a position on what the patient may be thinking or feeling by building uncertainty into their presented stances, and tying their interpretations to their own subjective view though sensorial formulations such as 'it feels'. Analysis revealed self-declared changes of 'seeing' where participants alter their stance both in light of contrary readings, and in relation to their own previous stance. **Conclusions**: DA sessions provide a context within which staff can articulate their own assumptions of patient behaviour. CA analysis demonstrates that DA acts as a space in which uncertainty is made explicit, and where tacit readings of behaviour can be explored. This can lead to new insights about the patient, or to personal interpretations being questioned.

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Symposium: The Triple-C Model: Treatment and Support of People With Severe Challenging Behaviour

Name of chair: Hans van Wouwe

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KEYWORDS Challenging behaviour; integrated care; research; support; training

Background and aim of symposium: Triple-C is a practice-based intervention, which is used in the Netherlands to support people with an intellectual disability (ID) and challenging behaviour (CB). In this symposium, the Triple-C model, staff training and coaching, and scientific research on Triple-C will be presented in three separate presentations.

SYMPOSIUM - ABSTRACT 1

The Triple-C Model: A Different Approach to Supporting People With an Intellectual Disability and Challenging Behaviour

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Aim: ASVZ, a health care organisation for people with an intellectual disability (ID) in the Netherlands, developed the Triple-C model to support people with ID and challenging behaviour (CB). The three Cs stand for client, coach and competence. We will demonstrate that taking human dignity instead of behaviour as a starting point leads to a very different approach. **Method**: The model has a vision and a method which are inseparable. The vision of Triple-C is to focus on the fulfillment of the human needs of the individual in order to improve their quality of life. To meet these human needs, the method includes three pillars: 1. working on an unconditional supportive relationship, 2. providing meaningful daily activities and, 3. taking a different perspective at the CB of the individual. **Results**: By focusing on these human needs in the treatment of people with ID and CB, the goal of the treatment will change from diminishing CB to influencing the individuals' environment by addressing their needs. According to Triple-C, the environment determines people's behaviour, so if you change this environment, the behaviour of the person will change as well. As a result, the quality of life of the individuals will improve and the CB will decrease. **Conclusion**: The Triple-C model provides guidance to professionals who support people with ID and CB in a humane way in order to let them experience a normal life as much as possible.

SYMPOSIUM - ABSTRACT 2

Supporting Triple-C Professionals: Training and Coaching

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Aim: Working according to Triple-C can be difficult, especially in stressful situations. Providing unconditional support and meaningful activities to a person who shows severe CB requires specific skills and

knowledge. Therefore, in order to apply Triple-C successfully, a significant precondition is to provide on-the-job training and coaching by experienced Triple-C professionals. In order to meet this precondition, Triple-C developed a policy to embed this training and coaching in practice. **Method**: Triple-C professionals are trained in recurring meetings. The trainings are focused on becoming more skilled in the system of the Triple-C model, which is supporting the individual. The system consist of support staff, the team captain, the manager, and psychologist, each of them having fixed roles and tasks within the treatment of the individual. During these meetings, feedback and in-situ training is conducted by the team captain, psychologist, and an experienced Triple-C coach. Also, specially developed images to visualise elements of the treatment are used to explain the Triple-C vision and method more accurately.

Another significant element of implementing Triple-C is on-the-job coaching. Support staff is coached in daily situations by their team captain, who is considered to be a Triple-C expert. Furthermore, during monthly meetings with the support staff, cases are discussed interdisciplinary. **Results**: When they are trained and coached regularly, professionals become better skilled and have a better understanding of Triple-C, which results in a better application of the model in practice. **Conclusion**: Successful implementation of the Triple-C model requires training and coaching embedded within the organisation.

SYMPOSIUM - ABSTRACT 3

First Steps in Developing a Scientifically Grounded Description of the Practice-Based Triple-C Model, a Method to Support People With an Intellectual Disability and Challenging Behaviour

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Aim: This study presents how a widely used practice-based method will become an evidence-based method. The practice-based method Triple-C is widely used in the Netherlands to support people with an intellectual disability (ID) and challenging behaviour (CB). Our aim is defining Triple-C and its possible effects by delineating the method's components and investigating how they inter-relate. This will result in a guide for support staff based on scientific evidence in order to provide high-quality care to people with ID and CB. **Method**: First, we conducted a content analysis of official documents about the Triple-C method. Resulting themes were subsequently discussed in interviews with the founders of Triple-C. Next, we presented the results to clinical experts and integrated their feedback for verification. Finally, to represent the collected data in a systematic way, a logic model was developed. A logic model is a visual way to present an understanding of the relationships between the resources of the method, the activities, and the results to achieve. **Results**: As a result of this logic model, we were able to define the Triple-C method in making its constituting elements and the relations between these elements explicit. **Conclusion**: Scientific evidence is needed to provide high-quality mental health interventions for people with ID and CB. Using a systematic approach, scientific evidence can be generated through a practice-based intervention so it can become an evidence-based intervention.

Symposium: Challenging Behaviours

Name of chair: Christian Happ[a,b]

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KEYWORDS challenging behaviour; disruptive behaviors; intervention; multiprofessional approach; problem behaviours

Background and aim of symposium: The term "challenging behaviour" has been discussed in many contexts (e.g. Dieckmann, Haas & Bruck, 2007). This symposium offers the opportunity to not only discuss this issue with experts from different contexts and countries, but also to compare various approaches to conceptualize, approach and work with challenging behaviour of people with intellectual disability.

The presentations in this symposium range from a practical view in facility settings over an overview of selected theoretical approaches and established programs to a field study testing expert and lay hypotheses regarding challenging behaviour. Questions, answers and a lively discussion, moderated by the chair of the symposium, will round off the event.

SYMPOSIUM - ABSTRACT 1

People With Challenging Behaviours and Quality of Life: A Necessary and Possible Fit!

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Aims: The SSBL looks after 320 adults of which 30 are regarded as individuals with difficult and challenging behaviours. For them, the SSBL has compiled a special support concept, designed its own architecture and infrastructure, and created special employment conditions. **Method**: These 30 persons are cared for in six groups of 5 persons each. The care concept is designed in such a way that the stay in the residential groups can take place indefinitely and without concrete therapeutic goals. The main perspective is the greatest possible installation of quality of life on the basis of the individually important and significant needs of each person.

This is the basis for the overall benefit plan, with different daily schedules, activities as well as freedom-limiting measures and crisis intervention plans. The service planning documents the resources and services an individual can provide themself or with support. The SensiQoL instrument records the quality of life. The architecture and infrastructure are characterized by large rooms. Private rooms which have their own enclosed outdoor space, bathrooms with two (escape) doors, and time-out rooms. Special roles and job descriptions were created for the staff, to divide the time in direct care and office work as well as opportunities in the field of further education and training. **Results & Conclusion**: With these three basics support concepts, infrastructure, and employment conditions, the SSBL has succeeded in offering a place to live for those individuals who were no longer accepted in other facilities. We are happy to share our story.

SYMPOSIUM - ABSTRACT 2

Tri.A.S.: The Trier Aggression- and Safety Program

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Aims: People with mental disability or autism spectrum disorders sometimes show provocative, damaging, self-injurious and massively aggressive behaviours. These problematic behaviours are an intense stressor for the whole system, which often irritates the people involved, leaving them helpless and stressed even beyond the currently faced situation. **Method**: The Tri.A.S. program is a complex psychological and pedagogical approach combining scientifically-based psychotherapy procedures (i.e. behavioural therapy, systemic family therapy) with the practical experience of over 30 years of daily counseling in facilities for disabled people.

The Tri.A.S. program empowers care givers of disabled people to work independently on comprehensive, sustainable and effective treatment methods adapted to the particular system and the individual. In addition to the measures of a crisis interventions and de-escalation in the critical situation, primarily organizational, medical, institutional, educational and other solutions are also available (e.g. problem description, effect analysis, changing behaviour, framework conditions, technical/organizational safety measures).

The aim of the program is to provide people with disabilities with an appropriate, valued and compassionate treatment to reduce the problematic behaviour, to open up resources and to allow all those concerned to ease the common interaction patterns. The program typically used in facilities consists of two parts: a pedagogic-therapeutic treatment plan and physical protection techniques. **Results**: Positive effects of the Tri.A.S. program at the ISJB range from a more self-confident behaviour of certain employees to a generally more competent working environment.

Conclusion: Results show that the program is a highly valuable method to treat challenging behaviours.

SYMPOSIUM - ABSTRACT 3

Child & Adolescent Psychiatric Aspects as Part of a Multidisciplinary Approach in the Treatment of Inpatient Mentally Disabled Youth With Comorbid Psychiatric Disorders

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Aims: Severe mental disabilities in children and adolescents are frequently linked to several comorbid psychiatric disorders like autism spectrum disorder, ADHD, disruptive behaviour or affective

disorders. According to Munir (2016), between 30% and 50% of children and adolescents suffering from intellectual disability (ID) or intellectual developmental disorder (IDD) have at least one co-occurring mental disorder. **Method**: These additional comorbid disorders require a specific diagnostic approach to characterize their severity and symptomatology. Furthermore, patients with intellectual disability (F70-F79 in the ICD-10) and comorbid psychiatric illnesses often benefit from multimodal approaches containing behavioural and pharmacologic interventions (e.g. to reduce aggressive outburst in autism spectrum disorders or behavioural therapy in anxiety disorders). According to recent studies, unfortunately only 1 in 10 children or adolescents with co-occurring mental disorders receive the specialized mental health services and care they need. **Results**: In a holistic treatment approach, regular psychiatric outpatient consultations play an important role in the supervision and planning of a coherent treatment plan in mentally disabled children residing in professional full-care homes. Direct contact between the child's and adolescents' psychiatrist with patients living in facilities and their professional caregivers is primordial in modern multidisciplinary care. This allows a comprehensive approach, providing good long-term outcome for the patients. **Conclusion**: Various aspects of the child & adolescent psychiatric approach for mentally disabled children and adolescents in institutional settings will be highlighted and characteristic pitfalls will be elucidated.

SYMPOSIUM - ABSTRACT 4

Challenging Behaviour – A Survey Study

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Aims: The term "challenging behaviour" has become increasingly important in the German-speaking professional discourse since the 1990s. This replaced concepts attributed to the individual (e.g. "behavioural disorder", "problem behaviour") and drew attention to a social positioning of the phenomenon. It originates in the American concept of "challenging behaviour", while Dieckmann, Haas and Bruck (2007) distinguish between HV (herausforderndes Verhalten; challenging behaviour) and SHV (schwerwiegendes herausforderndes Verhalten; serious challenging behaviour). **Method**: A survey was conducted, involving more than 200 employees of a facility for people with an intellectual disability. All respondents are more or less concerned with this topic during their daily work routine. **Results & Conclusion**: The results of the survey are linked to the Luxembourg term "Troubles du comportement" and current social science studies on this topic. The resulting hypotheses, questions and consequences for the care of people with intellectual disability and HV/SHV are derived and presented for discussion.

References

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Symposium: Reducing Restraints in Individuals With Intellectual Disabilities

Name of chair: Herman Wouters

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Foundation Marguerite Marie Delacroix, Tienen, Belgium

KEYWORDS Behaviour therapy; challenging behaviour; intervention; problem behaviours; staff

SYMPOSIUM - ABSTRACT 1

Reducing Restraints and Restrictive Behavior Management Practices in Individuals With Intellectual Disabilities and Autism Spectrum Disorders: The Contribution of Applied Behavior Analysis

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Aim: Restraints and Restrictive Behavior Management Practices (RRBMPs) are stigmatizing, often dangerous and usually indicate a failure to implement effective behavior management practices. The aim of this workshop is to review the evidence for safe reduction of RRBMPs. **Method and Results**: This paper will review the literature on safe reduction in RRBMPs and will include a systematic review of experiments in this area. Applied Behavior Analysis (ABA) offers a unique perspective in understanding the functions of RRBMPs for both the person restrained and the person implementing restraint. In addition, ABA has developed a number of specific intervention procedures, such as restraint fading; use of restraint as a reinforcer; rapid restraint analysis; other forms of functional assessment and analysis; and behavioral skills training to teach caregivers effectively which can result in effective treatment. **Conclusion**: Safe reduction of RRBMPs is possible and may even be achieved within 6–12 months in some circumstances. It commonly involves tracking use of RRBMPs, goal setting, staff training to give staff alternative behavior and feedback.

SYMPOSIUM - ABSTRACT 2

Reduction of Use of Restraints for Persons Restrained 24 Hours a Day

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Aims: Restraining a person with severe intellectual disability 24/7 to prevent serious self-injurious or aggressive behaviour is not the best approach. The quality of life of the concerned person is seriously jeopardised. This way of working can also cause other problem behaviour. **Method**: We looked at the progress of a few residents who had been restrained day and night to control their problem behaviour. Using a comprehensive new treatment plan inspired by the multimodal functional approach developed by W. I. Gardner (USA) we managed to give them much more freedom. We focused on a few elements that were important in their treatment: a change of residential unit, looking for caregivers motivated to cope with the problem behaviour in alternative ways, taking risks, learning alternative strategies, the use of video analysis to give us another and different impression of the person (method Jacques Heijkoop, Netherlands), etc. **Results**: This experience shows that it is possible to reduce and even to stop the use of prolonged restraints. The life of those involved became richer, they had better social contact, and the problem behaviour was also reduced.

SYMPOSIUM - ABSTRACT 3

A Commitment Statement for Reducing the Use of Restraints in the Region of Flanders (Belgium): A Joint Challenge From the Field

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Aim: In 2012, some organisations in Flanders contested the lack of a legal framework when it comes to the use of restraints in the care of intellectually disabled persons. We met together to explore our needs and concerns about this topic. Confronted with the finding that restraints are used more often than necessary, we would like to achieve progress in reducing their use. This includes using fewer restraints, using them less often, and using them for shorter periods of time. **Methods**: The group started a peer-learning project with visits to each other's organisations, learning about each other's practices. We also visited the Netherlands, to study the current Dutch legislation and to see ourselves how it could be put into practice. **Results**: All this resulted in an inspirational event where we reached more than 200 participants, all willing to take a critical look at their own practice. We built on this experience by preparing a commitment statement about consciously dealing with restraints. The statement mainly aims to increase awareness of the issue, giving a broad description of what is to be understood by the word restraints. From this follows a list of 13 proposals meant to challenge our daily practice.

We are pursuing the ratification of the commitment statement on different levels: senior management, middle management and practitioners; to ensure a thorough change in culture. **Conclusion**: We are in the midst of an ongoing process of change in the accepted approach to the use of restraints in Flanders. The commitment statement is valuable as a means to increase awareness and establish a reduction in the use of restraints in the care of intellectually disabled persons.

CO-PRODUCTIVE WORKSHOPS

MID/BIF and Trauma in Patients in Functional Assertive Community Treatment Teams: An Unmet Issue in Treatment

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KEYWORDS borderline intellectual functioning

Aims: The aim of this presentation is to discuss the impact of identification of Trauma and mild and borderline intellectual disability in mentally ill individuals. Only little is known about the prevalence of people with MID/BIF (moderate ID wit IQ 50–70 and borderline intellectual functioning) in chronically and seriously mental ill patients (SMI). As we know from literature, people with MID/BIF are more at risk to be confronted with traumatic life experiences (Hatton and Emmerson, 2004). In a study with 288 outpatients in service at a Functional Assertive Community Team (FACT) we identified MID/BIF in 41% of the individuals, while a possible post-traumatic stress disorder as assessed with the trauma screening questionnaire was detected in 55%. Patients with an experience in more than 6 items in the TSQ showed more often above threshold HONOS scores (OR = 3.6, $p < 0.001$). Patients with a MID/BIF also showed more often above threshold HONOS scores (OR = 2.1, $p < 0.001$). These findings suggest that MID/BIF and trauma are both associated with an impaired mental state, demanding special attention of treatment teams. **Goals**: The goals were to learn from practical experiences through the presentation of two specific treatment modalities which are interlinked. The first modality is trauma stabilisation through a community nurse. This approach concerns an assessment and mobilisation of the strengths of the individual in the context of their environment and, in collaboration with the family, also stressors, traumas and other issues. The second modality is narrative systems therapy, an approach where the patient and their family is invited to observe their own experience of trauma and discuss the impact of trauma on their daily life. The most important issue in this treatment is how to speak the same language as the patient.

Description of the interactive formats and the various stakeholders considered: The stakeholders of the suggested approach concern the mentally impaired psychiatric patient within the complete context of their family and next of kin. After a short presentation on the relevance of identifying MID/BIF in the daily practice of mental health care, the two treatment modalities are illustrated with practical case descriptions. The assessment tools used in treatment are explained. Participants of the workshop are invited to provide input from their own experience.

Reference

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INDIVIDUAL PAPERS

Self-Injurious Behaviour in a Woman With Mild Intellectual Disability and Co-Occurring Psychiatric Disorders: Using the Self-Harm Scale

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KEYWORDS challenging behaviour; dual diagnosis; staff

Aims: Self-injurious behaviour (SIB) is one of the most detrimental behaviours for both the person showing the behaviour and for their environment. Structured clinical assessments of SIB, including when and where it occurs, are scarce. The aim of the present study is to increase our knowledge about SIB incidents that are documented directly through observation in their natural context and to learn more about the self-injurious behaviour of individuals showing a high rate of SIB. **Methods**: Staff completed a Self-Harm Scale (SHS) form every time they witnessed SIB in individuals with mild to borderline ID and co-occurring psychopathology. The individuals displaying the most self-harming behaviour were interviewed together with their psychologists. **Results**: During an observation period of 41 weeks, 104 SIB incidents of 8 individuals (24%) were reported. One woman showed more than half of the incidents (53%), consisting mostly of head-banging and cutting. The incidents mostly took place in her own room in the evening. If support staff was able to identify triggers, the most often mentioned trigger was psychological. These results were also confirmed by both the woman and her psychologist. **Conclusions**: SIB is a serious problem in people with mild to borderline ID. Both interpersonal (e.g. interactions) and intrapersonal triggers (e.g. mental state) are reasons for individuals to show SIB. It is important to consider both types of triggers, as they can differ among individuals.

Could There Be a Role for Electroconvulsive Therapy or Deep Brain Stimulation in the Management of Self-Destructive and Aggressive Behaviour?

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KEYWORDS behaviour therapy

Aims: Our objective was to evaluate the underlying causes behind treatment-resistant aggressive behaviours, which often lead to coercive means (Bjelogrlic-Laakso, Aaltonen, Dorn, & Arvio, 2014). Also, the possible severe adverse effects caused by the use of second-generation antipsychotic (SGA) medication have been acknowledged. **Methods**: The diagnostic challenges and the other treatment options such as electroconvulsive therapy (ECT) and deep brain stimulation (DBS) were reviewed in the light of literature and our own clinical experience (D' Agati, Chang, Wachtel, & Reti, 2017). **Results**: SGAs may be effective for the treatment of irritability, aggression, self-injury and stereotypic behaviour in autism at least in short term use (Politte & McDougle, 2014). However, children appear to be more vulnerable to SGA-induced adverse effects than adults, as illustrated by our case example.

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Autism Spectrum Disorder, Intellectual Disability, and Emotional Functioning: Relatedness and Particular Impact on Challenging Behavior

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KEYWORDS autism spectrum disorder; challenging behaviour; development; developmental disorders

Aims: Persons with an intellectual disability (ID) show high rates of challenging behaviour (CB), especially in cases of co-occurring autism spectrum disorder (ASD). The aim of this retrospective study was to examine the relatedness and impact of ASD, the severity of ID, and the level of emotional functioning in CB. **Methods**: The study was conducted at a special outpatient unit (clinical sample) for adults with ID and comorbid mental or serious behavioural problems (N = 560). The assessment of ASD, level of ID, and emotional functioning was part of the regular clinical assessment process. The Scheme of Appraisal of Emotional Development (SAED) was used to measure emotional development (ED) and the Aberrant Behaviour Checklist (ABC) for CB. A correlation analysis and the Mann-Whitney test assessed the relatedness of ASD, ID, and ED (N = 560). A multiple regression analysis was computed to determine the effect of ASD, the level of ID and of ED on the severity of CB (n = 278). **Results**: ASD significantly correlated with the severity of ID (r = .205*) and lower levels of ED (r = -.354*). This decrease occurs

independently of the level of ID. Multiple regression analysis revealed the level of ED to be the most important predictor for CB (n = 278; OR = −5.97, 95% CI: −9.81; −2.14). **Conclusion**: For persons with ID and ASD, the level of emotional functioning has a substantial effect on the severity of CB. Thus, the assessment of the level of emotional functioning is essential to provide adequate care for adults with ID, ASD, and CB.

Suicide Behaviours in Persons With ID or ASD: Understanding to Prevent

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KEYWORDS intervention; prevention; research; suicide

Aim: Although they are known to exist, suicidal behaviors (SB) have rarely been studies in relation with ID or ASD. These behaviours are an important sign of distress and it is necessary to better assess their presence. The current study is part of a research program aiming to better understand suicide risk in these persons, develop and evaluate a process to support clinical judgement in the assessment of suicide risk (IDAUS-Process). It presents the development and evaluation of the IDAUS-Process, describes the instrument and its application in clinical and community settings. **Method**: A prospective qualitative study was designed, where 50 clinicians were trained to use the IDAUS-Process. They tested it with their clients, when concern about suicidality arose in the course of their interactions. The study took place over a five months period in 2016–2017. Data was collected from the instrument, a brief questionnaire filled out by clinicians and an interview to describe their experience, the strength and weaknesses of the IDAUS-Process and suggestions for improvement. **Result**: A corrected version of the IDAUS-Process was developed from their evaluation. It is not a standardised rating tool, but is a support process aiming to accompany and guide clinical judgement and decisions. **Conclusion**: IDAUS-Process contains four areas of investigation to support decision making regarding the identification of potential suicidal persons, acute and long term risk assessments. It includes specific risk factors, cognitive, affective and social characteristic of persons presenting with ID or ASD, the concept of “the development of a suicide option”.

Regulation of Personal Space by Socio-Economical Interactions in Adults With Autism Spectrum Disorders: An fMRI Study

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KEYWORDS Autism spectrum disorder; cognition; neuro-imaging

Aims: Personal Space (PS) is an area which an individual tries to maintain around themself. Developmental and psychiatric disorders influence the regulation of PS. Importantly, in the case of autism spectrum disorders (ASD), a condition characterized by deficits in interpersonal interaction, the regulation of PS is often altered compared to typically developing (TD) children. Due to the importance of regulation of PS, this study aimed at extending the previous findings about the ASD adult population and to investigate the behavioral and neurophysiological underpinning of PS and its modulation by different types of social interactions. **Methods**: Fifteen ASD and 15 TD matched participants underwent fMRI investigation while performing a modified version of the stop-distance paradigm for measuring PS preferences. In particular, participants were presented with several prerecorded videos from a first-person perspective: an actor moving a predetermined number of steps towards them. They were asked to specify how comfortable they perceived the observed distance. In order to see the effect of social interaction on PS perception, the participants and the confederate played a one-shot trust game session, in which cooperative and non-cooperative interactions were experimentally manipulated. After the game, the participants were confronted a second time with the distance task, in order to measure PS preference variation due to the type of social interaction (cooperative or not) previously experienced. **Results**: We observed a significant modulation of the trust game on the PS, as TD participants showed increased comfort toward the cooperative player and increased discomfort towards the non-cooperative one, associated with modulation of emotional brain areas (bilateral insula). Notably, we observed the same effect in the ASD population on the behavioral level, but reduced insular activity on the neural level, suggesting that the perception of a cooperative (or not) interaction has a different impact in the ASD population. **Conclusion**: A better understanding of these behavioral characteristics and the neuronal mechanisms underlying them could improve the overall ability to understand the development of ASD.

Emotional Egocentric Bias in Autism Spectrum Disorder: Behavioral and Neurophysiological Evidence

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KEYWORDS autism spectrum disorder; cognition; neuro-imaging

Aims: Empathy, the ability to feel with another person, has already been widely studied in both neurotypical as well as clinical populations, being fundamental for everyday social interactions. However, such a social skill is not free from error. Since humans primarily use their own emotions and perceptions in guiding their thoughts about conspecifics, self-projection mechanisms can lead to empathic judgments that are egocentrically biased towards one's own perspective—resulting in an emotional egocentricity bias (EEB). In this context, the ability for a self-other distinction (SOD), namely the cognitive component of empathy, plays an essential role during empathic interactions, mainly because it avoids confusion between the self and emotions of others. Since multiple studies have shown impairments regarding Theory of Mind in individuals with autism spectrum disorders (ASD), it may be possible to observe difficulties in distinguishing their own feelings from those of other individuals. **Methods**: By means of a virtual ball-tossing game, aimed at inducing congruent or incongruent feelings of social inclusion/exclusion between the participant and a confederate, we investigated the ability of SOD in 17 participants with ASD together with 17 matched controls both on a behavioral and neurophysiological level. **Results**: The results indicated a significant EEB during incongruent emotional empathic judgments. Interestingly, autistic subjects exhibited significantly more egocentric empathic judgments than controls when the degree of alexithymia was kept constant, underpinned by differences in brain activity in the right temporal junction. **Conclusions**: The present study adds valuable preliminary insights to the investigation of social cognition in this population.

Screening and Diagnostic Assessment of Neurodevelopmental Disorders and Mental Health Comorbidity in a Male Prison

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KEYWORDS Autism spectrum disorder; developmental disorders; diagnosis; epidemiology; forensic issues; neurodevelopmental disorders; psychiatric disorders; psychopathology

Aims The aim of the study was to identify neurodevelopmental disorders and difficulties (NDD) and comorbidity of mental health diagnoses in a male prison. The study used standardised tools to carry out screening and diagnostic assessment of the attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and intellectual disability (ID). **Method** The adult ADHD self-report scale (ASRS), 20-item Autism Quotient (AQ-20) and the Learning Disability Screening Questionnaire (LDSQ) were used to screen 240 male prisoners. Prisoners who screened positive on one or more of these scales or self-reported a diagnosis of ADHD, ASD or ID were further assessed using the Diagnostic Interview for ADHD in Adults (DIVA), adapted Autism Diagnostic Observation Schedule (ADOS) and the Quick Test. The Mini-International Neuropsychiatric Interview (MINI) was used to establish mental health diagnoses. **Results** Of the 87 prisoners who screened positive for NDD and were further assessed, 70 met the study's diagnostic criteria for ADHD, ASD or ID. Most of those with NDD (51%) had previously gone unrecognised with a high proportion (51%) identified through staff- or self-referral to the study. In all groups high rates of mental health comorbidity was also found. **Conclusion** The study demonstrated that improving awareness and providing access to skilled, standardised assessment within a male prison can result in increased recognition and identification of NDD. Keywords attention deficit hyperactivity disorder; autism spectrum disorder; diagnosis; intellectual disability; prison; screening

Caregivers of Individuals With Dual Diagnosis of Intellectual Disabilities and Psychopathology: Burden and Post-Traumatic Growth

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KEYWORDS dual diagnosis; family; quality of life; services; support

Aims: Family members play an important role in supporting people with a dual diagnosis of intellectual disability and psychopathology in seeking services to meet their needs. Research has highlighted the risk of a burden on caregivers along with the possibility that facing challenges may actually lead to adaptation and growth. The aim of the present study is to examine the relationship between help-seeking behaviors (HSB), caregiver burden and caregiver post-traumatic growth (PTG). **Methods**: One hundred and fifty family caregivers of individuals with dual diagnosis aged 13–25 completed a questionnaire which included, amongst others, the Caregiver Burden Scale, the General Health Questionnaire (GHQ), the Parental Attitudes Toward Psychological Services Inventory (PATPSI), the Actual Help Seeking Questionnaire and the Post-Traumatic Growth Inventory (PTGI). **Results**: In this presentation, we will show results on the correlations between help-seeking behaviors, burden and post-traumatic growth among family care givers of people with dual diagnosis. **Conclusions**: Discussion of those factors (mainly HSB) that lead to burden or growth (PTG) in caregiving carry the potential to improve family caregivers' quality of life and their ability to take care of their family member with a dual diagnosis. These findings will contribute to the developing of a body of knowledge regarding post-traumatic growth and help-seeking behaviors.

Studying the Core ASD Phenotype, Adaptive Functioning and Associated Psychiatric Comorbidities in the EU-AIMS Longitudinal European Autism Project (EU-AIMS LEAP)

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KEYWORDS adaptive skills; autism spectrum disorder

Aims: We examined whether there are sex, age and IQ differences in ASD symptomatology, adaptive functioning and symptoms of anxiety, ADHD and depression in this large cohort of 437 children and adults with autism spectrum disorder (ASD) and 298 individuals with typical

development (or mild intellectual disability without ASD) between 6 and 30 years and IQ from 50 to 148. **Methods**: Core ASD symptoms were measured using the ADOS and ADI-R, while dimensional measures of ASD symptomatology were derived from the SRS-2, CSBQ, AQ, RBS-R and SSP. Symptoms of associated psychiatric conditions were measured using the DSM-5 rating scale for ADHD and the Beck Inventories for Anxiety (BAI) and Depression (BDI). Level of intellectual abilities and adaptive functioning (Vineland) were also assessed. **Results**: On both observational (ADOS) and on questionnaire measures (SRS-2, RBS-R), ASD symptom severity was lower in adults compared to adolescents. Males had higher ASD symptom scores than females on clinician-rated, but not on parent-reported measures. In adults only, females had better adaptive functioning than males. Effects of sex and age were also assessed for psychiatric symptoms. Inattentive and Hyperactive/Impulsive ADHD symptoms were greater in males than females with ASD and adults scored lower on both symptom domains than children and adolescents. **Conclusion**: The well-established phenotypic heterogeneity in ASD is well captured in the LEAP cohort. The accelerated longitudinal design will enable us to track trajectories of the ASD phenotype and co-occurring conditions over development and relate these to the wide range of candidate biomarkers also tested.

Exploring the Effectiveness of Non-Symbolic Augmentative Communication for Adults With Intellectual Disability, Autism Spectrum Disorder and Challenging Behaviour

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KEYWORDS autism spectrum disorder; intervention

Aim: This study aims to evaluate the effectiveness of individualized non-symbolic augmentative communication strategies for adults with intellectual disability and autism spectrum disorder (ASD). Methods: Five minimally verbal adults with ASD and severe intellectual disability participated in our replicated single-case experiment study. Based on the administration of the ComFor (Verpoorten et al., 2016) and a video observation, an individualized intervention plan for augmentative communication was designed for one activity. Transitions between activities and different steps or choices within the activity were communicated by recognizable sensations, presenting functional objects, or by assembling or matching methods. The single-case experiments comprised a baseline (1–2 weeks) and intervention phase (1–3 months). The outcome variables–level of independence, quality of mood, and severity of challenging behaviour–were measured with an observation form for caregivers on a daily basis. Additionally, semi-structured interviews were administered to clinicians (n = 10) to evaluate experienced feasibility and effectiveness of the intervention. **Results**: For all participants, improvement on one or more outcome measures was seen during the activity after augmentative communication was implemented. Effect size measures showed stronger results for the level of independence compared to mood and challenging behaviour. By using HLMs to aggregate the single-case results, significant effects for all three outcome measures were found at the group level. Based on the interviews, several challenges and facilitating factors of the implementation of this intervention will be discussed. **Conclusions**: This study provides the first empirical evidence to support the use of non-symbolic communication strategies for minimally verbal adults with ASD and intellectual disability.

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Psychiatric and Psychological Support for Adolescent Woman With 22q11.2 Deletion Syndrome and Intellectual Disability: A Good Outcome

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KEYWORDS family; genetics; psychiatric disorders; psychopharmacology

Aims: The 22q11.2 deletion syndrome (22q11.2DS) occurs in around 1:4000 live births. The phenotype is variable and involves multiple organ systems with high rates of associated psychiatric disorders and intellectual disability (ID) (Philip & Bassett, 2011; Squarcione et al., 2013). We report the case of an adolescent (20 years) woman (M.) with 22q11.2DS and ID in an outpatient treatment since 2011, with a combination of psychopharmacology and psychological support, showing good outcome. **Methods**: During the SCID-I interview in 2011, M. had psychotic symptoms (visual hallucinations, interpretative thoughts, disorganized behaviors) and obsessive-compulsive symptoms with trichotillomania. At WAIS-R, an IQ of 67 was assessed. She scored at the Vineland Scale = communication: 256/266; daily living skills: 138/402; socialization: 202/268; and motor skills: 111/144. She also had medical comorbidities (orthopedic, immunitary). M. was already on Haloperidol 1 mg with considerable side effects. Psychiatrists shifted from Haloperidol to Aripiprazole 15 mg + Venlafaxine 150 mg and psychologists started a psychoeducational intervention in the fields of autonomy, relations with parents and friends, and challenging behaviors. **Results and conclusions**: After 6 years of treatment, M. shows no psychotic symptoms anymore, reduced obsessive-compulsive symptoms, more compliance with the regular visits for her medical problems, regular attendance at her sheltered employment and the activities of the Association AiDel22 as well as reduced challenging behaviors at home. She accepts her disability and she copes with it, she feels good staying with other friends with ID, while her parents still show resistance and expect M. to live like people without ID. These clinical improvements are likely due to the combination of psychopharmacology and psychological support (for M. and her family).

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Re-Defining the Boundaries Between Intellectual Development, Autism Spectrum, and Schizophenia Spectrum Disorders in the Neurodevelopmental Perspective

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KEYWORDS psychiatric disorders; psychopathology; research

Aims: Recent evidence of clinical overlaps, familial co-aggregation, and shared genetic alterations support a neurodevelopmental deviation presenting a probable common vulnerability factor for psychiatric syndromes inside and outside the DSM-5 meta-structure of neurodevelopmental disorders. The aim of the present paper is to identify commonalities and differences within clinical and neuropsychological characteristics of intellectual developmental disorders (IDD), autism spectrum disorders (ASD), schizophrenia spectrum disorders (SSD) and their combination, in order to contribute to a future re-definition of diagnostic criteria. **Methods**: This was a transversal observational descriptive study. We assessed a sample of 61 adults with a diagnosis or pervasive features of IDD, ASD or SSD according to the DSM-5, randomly or consecutively recruited among those attending the psychiatric services of CREA (Research and Clinical Centre), San Sebastiano Foundation (Florence, Italy), the Department of Neurological and Psychiatric Sciences of the University of Florence (DNPS-UF), and other service providers in Tuscany. The entire sample underwent a complex assessment according to the following scheme: (a) demographic and anamnestic data; (b) IQ and specific cognitive functions; (c) psychopathological tools package; (d) psychiatric clinical evaluation. **Results**: The age of onset, interest towards others, hallucinations, flattened mood (and behavioural equivalents), irritability, scores at block design, digit span, and digit symbol were found to be the most useful dimensions for differentiation. **Conclusions**: Our findings usefully integrate the indications found in literature on clinical factors to distinguish between the three diagnostic groups, and the co-occurrence of ASD and SSD with IDD.

Autism Spectrum Disorder – A Vulnerability Factor for Psychiatric Comorbidity in Adults With Intellectual Disability? A Literature Review

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KEYWORDS Psychiatric disorders; psychopathology; vulnerability

Aims and methods: The research on autism spectrum disorder (ASD) as a risk factor for psychiatric comorbidity in adults with intellectual disability (ID) is still scarce and findings are controversial. Most studies show a higher prevalence of psychiatric disorders in people with ID or ASD than in the general population, which seems to further increase when the two neurodevelopmental disorders co-occur. In this paper, we mapped the literature in order to specify the effect that an ASD may exert on the emergence of other psychiatric disorders in persons with ID. **Results**: Among the 5256 papers which met the search criteria, 27 were identified to be adequate to answer the mapping question. In adults with ID, ASD is reported to frequently co-occur and to be associated with a high rate of challenging behaviours (CB) and the full range of psychiatric disorders. Most replicated findings were related to mood, anxiety and eating disorders. Only few studies did not find any statistically significant difference between adults with ID plus ASD and adults with ID only. Differences in findings seem to depend on a variety of factors, such as diagnostic overshadowing, the scarcity of specific assessment tools, consideration of the introspective and communication difficulties, incompleteness of medical records, and low reliability of information sources. **Conclusions**: In persons with ID the co-occurrence of ASD increases the vulnerability to the full range of psychiatric disorders. Due to the relevant implications for prevention and clinical management, further research with stronger evidence is imperative.

Personality Disorders in Intellectual Disability: A Prevalence Study

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KEYWORDS dual diagnosis; psychiatric disorders; psychopathology

Aims: The co-occurrence of personality disorders (PD) is one of the most debated issue in the field of psychiatry in intellectual disability (ID) and low-functioning autism (LFA). The personality traits of individuals with ID and LFA, both normal and pathological, may influence the presentation and form of PD to such an extent that they could become impossible to be diagnosed. Difficulties in obtaining the information being essential for a diagnosis, following current diagnostic criteria, and low sensitivity of diagnostic tools are other major clinical issues. Thus, epidemiological data on PD in persons with ID are scarce and inconsistent. The few available studies show a high prevalence of the cluster BPD, mostly borderline and antisocial PD (BPD and APD). This study aims to review the literature to date, and to estimate the prevalence of BPD and APD in an Italian sample of individuals living in different settings. **Methods**: Around 800 adults with ID and/or LFA attending clinical and rehabilitative centres across Italy underwent a complex clinical and instrumental psychopathological assessment. Descriptive statistics were accomplished for both background and clinical characteristics, with specific reference to PD. **Results**: Contrary to literature reports, our findings show the prevalence of PD in ID to be high in all the three clusters, perhaps because there are still no specific evaluation tools. The rate increases in males and in those with moderate-to-severe ID. **Conclusions**: Further research is needed to identify more effective diagnostic strategies and tools.

Psychiatric Comorbidity in Adults With Autistic Spectrum Disorders: Preliminary Results in an Italian Sample

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KEYWORDS Autism spectrum disorder; psychopathology

Aim: Up to 42% of adults with autism spectrum disorder (ASD) have at least one psychiatric comorbidity. However, epidemiological studies to date are limited in quantity and quality; generalizability of available data is limited by the lack of use of assessment tools adapted to communication impairment or co-occurrence of intellectual disability (ID). In fact, persons with neurodevelopmental issues and psychiatric disorders often show atypical signs. **Method**: In the present study, 317 persons with ASD attending clinical or rehabilitative services of San Sebastiano Foundation, Florence, Italy, were consecutively screened for the co-occurrence of psychiatric disorders through the Systematic Psychopathological Assessment for People with Intellectual and Developmental Disabilities, General Version (SPAIDD-G). **Results**: The study sample showed a high co-occurrence of ID, with the following percentages of severity: no ID 4.6%, borderline 3.9%, mild ID 9.1%, moderate ID 27.7%, severe ID 34.0%, profound ID 20.7%. At least one over-the-threshold score was found in 47% of the participants (OTS; >0.5/1). The prevalence of OTS for the specific psychiatric disorders were estimated as follows: psychosis 21.4%, depression 18.0%, mania 19.9%, anxiety 19.9%, OCD 58.7%, eating disorders 13.4%, oppositional-defiant disorder 41.6%, impulse control disorders 34.2%, personality disorders of dramatic and anxiety clusters 25.8% and 52.2% respectively. **Conclusions**: Our results are in line with those found in literature, except for the higher prevalence of ID. Our data suggest that in persons with low-functioning ASD psychiatric comorbidities might be higher than reported in literature, especially if using appropriate assessment tools.

The Effects of Training Programs for Direct Care Staff Working With People With Intellectual Disabilities and Aggressive Behaviour: A Meta-Analysis

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KEYWORDS Challenging behaviour; staff; training

Aim: Two separate meta-analyses were conducted to measure the effect of training programs on staff behaviour (11 independent studies, 86 effect sizes) and on the aggressive behaviour of persons with intellectual disabilities (7 independent studies, 40 effect sizes). **Method**: A 3-level random effects model was used for both meta-analyses to account for both within and between study variance. The following inclusion criteria were defined to select studies for the two meta-analyses. First, the study had to focus on a training for direct care staff working in a care facility for people with ID. Second, we included only studies on staff training with a relation to the aggressive or challenging behaviour of their clients with ID. Third, the studies had to have a control group in order to compare the results of the training in the experimental group with the results of a control group. Finally, the studies had to report about the effects of the training on staff or clients' outcomes in a way that made it possible to calculate an effect size. **Results**: showed that staff training was moderately effective in changing staff behaviour, but did not have any significant effects on the reduction of aggressive behaviour of persons with ID. The type, content and goal of training did not moderate the effects of staff training, whereas sample and study characteristics did. **Conclusion**: The way a training program is delivered to staff may be much more important than characteristics of a training.

Problem Behavior in Cornelia de Lange Syndrome

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KEYWORDS behavioural phenotype; dual diagnosis; problem behaviours

Aim: Problem behavior like self-injury is a common phenomenon in the Cornelia de Lange syndrome (CdLS). Only few studies focused on the symptomatic (topografic) and functional profiles of self-injurious, aggressive, stereotypical, and compulsive behaviors. The aim of the study was to gain more information on the prevalence of these different behaviors. **Methods**: The Behavior Problem Inventory (BPI; Rojahn et al., 2008), the Questions about Behavioral Function Scale (Matson & Vollmer, 1995) and the Compulsive Behavior Checklist (CBC, Gedye, 1992) were used to collect data on 70 persons with CdLS. **Results**: Results include a high prevalence and early onset of self-injury. Furthermore, high correlations between aggressive, stereotypical and compulsive behaviors could be detected. In addition, the results point out that primary functions of self-injurious behavior may be associated with the genetic syndrome itself. **Conclusions**: The results quantify the need for special interventions concerning the primary function of problem behavior and early intervention. The associations between the different types of problem behaviors demand further research.

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Problem Behaviours and Major Depressive Disorder in Intellectual Disability and Autism: A Contribution of PET and MRI

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KEYWORDS Autism spectrum disorder; challenging behaviour; psychiatric disorders

Background: Previous literature demonstrates a high association between problem behaviours (PB) and major depressive disorder (MDD) in intellectual disability (ID) and autism (ASD). Neuroradiological literature about this topic is still scarce. **Aims**: The present study aims at integrating neuro-imaging findings (PET, MRI). **Methodology**: Two groups with mild-to-moderate ID and ASD with PB (n = 30; MDD = 15) and without (n = 12; MDD = 1) were formed. PB was assessed by the Dutch version of Disturbing Behavior Scales for Intellectual Disability. MDD was screened with the use of the DM-ID (Diagnostic Manual-Intellectual Disability). Every patient received a structural MRI (volumetry hippocampus and amygdala) and at least every second patient a PET scan **Results**: MDD versus no-MDD as a whole (± PB) demonstrated hypermetabolism cerebellum, brainstem, pallidum. Furthermore, MDD in ID, ASD, PB versus no PB correlated with hypermetabolism in cerebellum, and hypometabolism in the middle frontal and precentral gyrus. PB (+/- MDD) first PET scan versus second PET scan (after a minimum 6 months of treatment) demonstrated hypometabolism of the precentral gyrus. In the case of no-PB and MDD versus no-MDD, hypometabolism cerebellum and precentral gyrus could be screened. PB and MDD versus no-PB and no-MDD demonstrated hypermetabolism pallidum.

Summarizing the structural MRI results, the volumes of the hippocampus and amygdala did not show a significant correlation with PB or MDD. **Conclusion**: ASD, PB and MDD in ID

are mutually enhancing factors in hypometabolism precentral gyrus and mid-frontal gyrus. MDD and PB in ID and ASD are correlated with hypermetabolism cerebellum and pallidum. PET data are discussed in relation to the high association between PB and MDD in ID and ASD.

Problem Behaviours and Major Depressive Disorder in Adults With Intellectual Disability and Autism

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KEYWORDS Autism spectrum disorder; challenging behaviour; psychiatric disorders

Background: The high prevalence of problem behaviours (PB) in persons with intellectual disability (ID) and autism spectrum disorder (ASD) has been associated by some researchers with a proportionate frequency of major depressive disorder (MDD), which has a different representation in persons with ID and ASD than in the general population, mostly as changes in behaviour. Nevertheless, evidence is still scarce. **Aims**: The present study aims at evaluating the rate of MDD in persons with ID and ASD presenting PB. **Methods and Procedures**: Two groups of persons with mild-to-moderate ID and ASD, with and without PB, underwent a complex clinical (Diagnostic Manual – Intellectual Disability) and instrumental (Reiss Screen for Maladaptive Behaviour; Mini Psychiatric Assessment Schedule for Adults with Developmental Disabilities) assessment. **Outcomes and Results**: The prevalence of MDD was found to be significantly higher in the group with PB. The severity of depressive symptoms resulted in a strong correlation with the scores of the instrumental assessment of PB. **Conclusion and Implications**: Our findings support previous literature on a high association between PB and MDD in persons with ID and ASD. The level of the equivalency between specific MDD symptoms and different PB demands further investigation.

Highlights

(1) Persons with intellectual disability and autism spectrum disorder showing problem behaviours showed a significantly higher prevalence of major depressive disorder than those who do not show problem behaviours.
(2) The severity of depressive symptoms resulted in a strong correlation with scores of the instrumental assessment of PB.
(3) Among problem behaviours, verbal aggression was found to be the most frequent marker of major depressive disorder.

Evaluating Screening Instruments for Depressive Symptomatology in Adults With an Intellectual Disability and Autism Spectrum Disorder

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KEYWORDS Autism spectrum disorder; challenging behaviour; intellectual disability; major depressive disorder; problem behaviours; psychiatric disorders

Background: People with intellectual disabilities (ID) and a comorbid autism spectrum disorder (ASD) often display challenging behaviour or even develop psychiatric disorders. In persons with ID, the recognition and the accurate diagnosis of psychiatric disorders, especially major depressive disorder (MDD), can be challenging. **Aims**: The aim of this study was the evaluation of the Reiss and Mini PAS-ADD as screening instruments for MDD. **Methodology**: In an exploratory rather-blinded open trial, a group of adults with mild or moderate ID and ASD were screened for depressive symptomatology with the Reiss and Mini PAS-ADD. Consequently, presence of MDD was confirmed by use of the Diagnostic Manual—Intellectual Disability (DM-ID). **Results**: The Mini-PAS-ADD was the only predictive measure for depression, correctly identifying 66.7% as being depressed, whereas 89.5% of the non-depressive participants were also correctly recognised as such. Neither the Reiss subscales, nor its total score had any significant predictive value. **Conclusion**: Looking at the research group of people with ID, the present study demonstrates that the Mini PAS-ADD can perhaps be used as a primary screening device for the identification of MDD among people with ID and ASD.

POSTERS

The Organisational Environment and Challenging Behaviour in People With Intellectual Disabilities

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KEYWORDS Challenging behaviour; problem behaviours; research

Introduction: This study explored the influences of the organisational environment of disability service organisations on challenging behaviour in people with intellectual disabilities (IDs). An adaption of Bronfenbrenner's socio-ecological theory was used. **Method**: Literature published between 2000 and 2016 was reviewed. We used combinations of the search terms “intellectual disability”, “challenging behaviour”, and “organization”. **Results**: Relevant aspects were identified in the ontosystem (ID and challenging behaviour), microsystem (staff perceptions of residents), mesosystem (staff network), exosystem (policy, performance, working method, leadership, mission statements, power, culture, size and organisational model), macrosystem (de-institutionalisation, disability policy, financing of care, societal structures, and belief systems), and chronosystem (service development). **Conclusions**: The use of a socio-ecological model for people with IDs and challenging behaviour facilitates understanding, evaluation, and management of different aspects affecting the provision of support services for people with IDs and problem behaviours.

Psychiatric Diagnoses in People With Intellectual Disability and a Disharmonious Developmental Profile

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KEYWORDS challenging behaviour; psychiatric disorders

Background: Disharmonious developmental profiles (DDP) are profiles in which the level of cognitive development is remarkably different from the level of emotional development (ED). In people with intellectual disabilities (ID), these profiles are associated with higher rates of behavioural and psychiatric problems. The purpose of this study was to investigate an association between the presence of psychiatric diagnoses and DDP in people with ID. **Methods**: This cross-sectional multicentre study was conducted in 13 different care organizations in the Netherlands. One hundred and seven participants aged ≥ 18 years with a known level of cognitive and emotional development were included. Due to the lack of a clear definition of DDP, its presence was determined by assessing the level of ED regarding the level of cognitive development. The lower the overall level of ED within a certain level of cognitive development, the larger the discrepancy, and the higher the assumption of the presence of DDP. The correlation between the level of ED and the total number of psychiatric diagnoses within each level of cognitive development was described with Spearman’s rho correlation coefficient. **Results**: We found a significant correlation between the overall level of ED and the number of psychiatric diagnoses in participants with mild ($rs = .609$, $p = 0.009$) and moderate ID ($rs = .402$, $p = 0.025$). Conclusion: Lower levels of ED correlate with a higher number of psychiatric diagnoses in people with mild and moderate ID, meaning that the more disharmonious the profile gets, the more psychiatric diagnoses can be found.

The Association Between Challenging Behaviour and Caffeine Intake in People With Intellectual Disabilities: A Study in 13 Residential Settings in the Netherlands

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KEYWORDS challenging behaviour; disruptive behaviors; problem behaviours

Aims: Caffeine overconsumption can cause restlessness, nervousness and insomnia (Chawla et al., 2015). In people with intellectual disabilities (ID) these symptoms are prevalent, and often labelled as challenging behaviour and treated with psychotropic medication. Therefore, we examine associations between caffeine intake, challenging behaviour, and psychotropic medication use in adults with ID. **Methods**: Data was obtained in a cross-sectional study including 303 adults from 13 residential settings. Professional caregivers completed questionnaires about caffeine intake and the Abberant Behaviour Checklist (ABC). The presence of challenging behaviour (yes/no) was categorized by professional caregivers and behavioural therapists. Information about psychotropic medication use was collected from medical files. Associations between caffeine intake, challenging behaviour and psychotropic medication use were studied for the total group and for those with an above average caffeine intake (> 400 mg). **Results**: Daily caffeine intake ranged from 0 to 935 mg (230.3 ± 223.0 mg), and 25.4% of all participants consumed more than 400 mg caffeine per day. Caffeine intake in the total group was significantly associated ($r = 0.180$, $p = 0.002$) with challenging behaviour as reported by the professional caregivers, and remained significant after correction for confounders (benzodiazepines and antipsychotic drugs). In the group with >400mg intake, the association was not significant. No significant association between caffeine intake and psychotropic medication use was found. **Conclusion**: This study shows a small but significant correlation between caffeine intake and challenging behaviour in adults with ID, but not between caffeine intake and psychotropic medication use. The findings of this study do not exclude other injurious effects (Guessous et al., 2014; Peng et al., 2014; Zulli et al., 2016).

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Challenges of Home-Based Service for Children With Developmental Disorders: Challenging Behavior and Parenting Stress

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KEYWORDS challenging behaviour; developmental disorders; family

Aims: Parents of children with developmental disorders (DD) who do not reside in the urban areas of big cities have limited or no access to services aimed to support preschool children and their families. In this paper, we present an innovative social service in the continental counties in Croatia including the home-based service for children with DD, intended to empower the whole family. The aim of the paper is to examine parenting stress and the challenging behavior of preschool children with DD at the beginning and at the end of the 12-month home-based service. **Methods**: The research included 34 parents (couples and single parents) who completed the Child Behavior Checklist (CBCL) and the Parenting Stress Index (PSI). There were 21 children, aged between 2 and 7 years, with DD (cerebral palsy, autism, Down syndrome). **Results**: The results have shown that challenging behaviour in children with autism had decreased by 33%, while challenging behavior in other children had decreased on average by 25%. The level of parenting stress at the end of the service had decreased on average by 8% (mothers and fathers considered jointly). If we consider mothers and fathers separately, the level of stress in mothers decreased by 11% and in fathers by 4%. **Conclusions**: The service has successfully fulfilled its main purpose which was to empower the parents by transferring professional knowledge and skills. The service providers have instructed the parents on how to recognise the child's needs, the causes of challenging behavior and how to resolve it. The parents have also acquired appropriate techniques that enable them to successfully deal with the developmental specificities, which helped to reduce the level of parenting stress.

Benefits of Nursing Care Workshops in a Hospitalization Unit Specialized in Intellectual Disability

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KEYWORDS Disruptive behaviors; Dual Diagnosis; Problem Behaviours; Staff

Introduction: Intellectual disability is usually associated with mental disorders, behaviour problems or both, and individuals are often hospitalized in specialized units.

The Hospitalization Unit Specialized in People with Intellectual Disability (UHEDI) is a unit with a high degree of specialization for 14 persons with intellectual disability and behavior or mental health disorders. The Hospitalization Unit responds to the demand from the community mental health services and focuses on intensive attention and the organization of a comprehensive medium- and long-term care plan.

In this presentation, we want to show first results of our study, focusing on the benefit of nursing care workshops aimed at maintaining and/or improving the autonomy of people with ID in their basic daily living activities. **Objectives**: Our objectives are:

- To describe nursing diagnoses of higher prevalence.
- To describe the degree of dependence according to the Barthel scale.
- To describe the workshop design that has been implemented based on the identified needs.

Methodology: The study sample is compiled of 15 patients recruited from the UHEDI of Parc Sanitary Sant Joan de Déu. The Barthel scale and the nursing evaluation instrument based on 11 functional patterns of Majory Gordon were employed to assess the level of autonomy in the basic daily living activities. Demographic data (age and gender) will also be included in the analysis. **Results**: Since we are still in an initial phase of the study, we cannot provide final results, but instead present the most prevalent problems according to NANDA (North American Nursing Diagnosis Association), and the workshops that will be implement, based on the detected needs.

NANDA:

- Constipation
- Deficit of recreational activities
- Deficit in self-care
- Deficit of social skills
- Deficient knowledge

WORKSHOPS:

- Walking activity
- Habits in the dining room
- Hygiene of the environment
- Personal hygiene

We have established three first requirements: 1. each group will have a professional referral nurse, 2. each group will have a maximum of 3 members with similar objectives (NOC) and results on the Barthel scale, 3. each session will last less than 30 minutes. **Conclusions**: We observed willingness of people with ID to participate in the workshops. First observations in the data collection process show an increase of the autonomy of persons with intellectual disabilities. The improvements achieved contribute to a general clinical betterment that will allow the discharge from the Hospitalization Unit and a better community inclusion. We suggest to check in the future that objectives (NOC) and interventions (NIC) of the nursing care plan have been achieved.

The Relationship Between Restrictive Security Measures and Aggression Towards Health Staff in a Residence for People With Intellectual Disability and Mental Health Diagnosis

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KEYWORDS Challenging behaviour; dual diagnosis; intervention; person-centred approach; staff

Introduction: The role of the caregiver (health staff) is very important in a residence specialized for people with intellectual disability and behavioral or mental health disorders. Personal attention, awareness of the staff and specific training are signs of good practice.

The person-centered care model and the philosophy of the liberate care model–with the ultimate objective of no restrictive measures–have been introduced in the last years to the working methodology of the Santa Anna residence, currently the home of 30 individuals.

In this presentation we will show data on isolation from the environment and mechanical restraints as well as the number of incidents of aggression shown by residents. **Objectives**: Our objectives are:

- Analyzing the number of restrictive measures applied to the residents, and the number of incidents of aggression towards staff between 2011 and 2016.
- Establishing a possible relationship between these data. **Methodology**: Data are extracted (1) from the records of restrictive measures reflected in the annual report of the residence, and (2) from the aggression incident reports made by the health personnel. **Conclusions**: We observed a decrease of the mechanical restraints and isolation throughout the years, but increase in aggressions towards health professionals. We conclude that the change of the model regarding the use of restraint decreases the containment in isolation, but therefore increases the time spent in common rooms with consequent altered behavioral states and the possible risk of aggression.

We propose the continuation of the model, further developing the verbal approach and training staff to reduce aggression.

Self-Injurious Behavior in Adults With Autism: A Survey of Residential Care Facilities

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KEYWORDS Autism Spectrum Disorder; challenging behaviour; diagnosis; problem behaviours

Aims: Individuals with autism spectrum disorder and an intellectual disability (ID) have a high risk of developing self-injurious behavior (SIB). Despite this, prevalence research focusing on adults with ASD and ID is sparse. Clinical research on individuals with ID demonstrates that in most cases one or more operant functions of SIB can be identified. Few studies have addressed this factor in individuals with ASD despite preliminary results suggesting that operant functions might differ between both populations. The German AWMF guideline "Intellectual Disabilities" (2014) recommends a multimodal diagnostics and treatment approach to SIB including behavioral interventions based on the operant function. It is yet unknown to what extent these measures are implemented in residential care facilities. **Methods**: We conducted a survey to address these three areas of interest (prevalence, operant function and treatment of SIB). Between October 2016 and January 2017, a total of 63 facilities completed 256 questionnaires about individual residents with SIB. Questionnaires included the SIB scale of the Behavior Problems Inventory (BPI, Rojahn et al. 2001), the Questions about Behavioral Function (QABF, Matson & Vollmer 1995), the Inventar zur funktionellen Erfassung selbstverletzenden Verhaltens (IfES, Bienstein & Nußbeck 2010), and two ad-hoc checklists measuring the impact of SIB on the residents and implemented treatments. **Results and Conclusion**: The study contributes to the existing literature on the prevalence of SIB and provides detailed information about topographies, severity, and frequency of SIB in adult individuals with ASD. It further contributes to the sparse literature on operant functions, and gives a unique insight in treatment strategies implemented within German residential facilities. The data are currently being analyzed, and first results will be presented at the 11th EAMHID congress.

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PSYCHOPHARMACOLOGY

SYMPOSIA

Symposium: Psychotropic Medication Use in People With Intellectual Disabilities

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KEYWORDS challenging behaviour; psychiatric disorders; psychopharmacology

Background and aim of symposium: People with Intellectual Disabilities (ID) use psychotropic medication to manage mental disorders and challenging behaviour. The symposium considers the use of psychotropic medication considering what is effective and the concept of over-use of medication. The purpose of the symposium is to explore the appropriate use of psychotropic medication supported by current evidence and how it could be reduced and managed more effectively and the role of non-pharmacological interventions.

SYMPOSIUM - ABSTRACT 1

An Emotional Developmental Approach to Managing Medication in People With Intellectual Disabilities

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Aims: The emotional developmental level of people with Intellectual Disabilities (ID) is not always taken in to account when considering managing behaviour and mental disorders with psychotropic medication. The aim of the presentation is to compare the assessment of emotional development with the use of psychotropic medication in behaviour management in an in-patient service. **Methods**: The study is set in an in-patient service for people with Intellectual Disability who require in-patient care to manage their behaviour or mental disorders. Medication was assessed at admission and at discharged and compared with the level of emotional development of each person. **Results**: Assessing the level of emotional development helped clinicians to seek appropriate interventions to manage behaviour and mental disorders. Non-pharmacological interventions were used more than previously leading to a reduction in the use of drug therapy by the time of discharge. **Conclusions**: An emotional developmental perspective of behaviour can assist in developing non- pharmacological interventions that lead to a reduction in and more appropriate use of psychotropic medication in ID in-patient services.

SYMPOSIUM - ABSTRACT 2

New and Very New Generation Antipsychotics in Intellectual Developmental Disorders

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Aims: International guidelines advise alternatives to drug therapy as first line interventions in the management of problem behaviour in Intellectual Developmental Disorders (IDD). In spite of the guidelines, almost 60% of prescriptions are still used for this purpose, while consistency with psychiatric diagnosis is often uncertain. Antipsychotics are the most frequently prescribed drugs but the data on their efficacy are controversial. The paper provides a systematic mapping of the literature on the use of New and Very New Generation Antipsychotics (N&VNGA) in adults with IDD. **Methods**: The authors reviewed the international literature on the basis of the following questions: what are the most studied and used N&VNGA in people with IDD? What are the most common outcome measures? What is the level of evidence? **Results**: Risperidone, Clozapine and Olanzapine were the most commonly used compounds. Several empirical studies support the use of

NGA but other publications are more sceptical of the quality of the evidence to date. The most common side effects are weight gain, dyslipidaemia, hyperglycaemia, and QTc prolongation. Some compounds have shown low metabolic effects and have a receptor binding profile which suits the characteristics of this population. **Conclusions**: The scientific community is increasingly evaluating the usefulness of drugs in terms of their effectiveness rather than their efficacy (on target symptoms) and safety, which is related to new patient-oriented outcome measures such as Quality of Life.

SYMPOSIUM - ABSTRACT 3

The Overuse of Psychotropic Medication in People With Intellectual Disabilities

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Aims: Evidence indicates that people with Intellectual Disabilities (ID) use medication to manage challenging behaviour and mental disorders. For some it is excessive and not always necessary. The presentation considers the prevalence of psychotropic use in people with ID and how medication could be managed and the role of alternative interventions. **Methods**: A literature review of the current evidence on psychotropic use in people with ID. **Results**: The 'Stopping Overuse of Medication in People with ID' (STOMP) initiative in the UK highlights the excessive use of psychotropic medication among people with ID. Clinical audits have demonstrated the adherence of Psychiatrists to clinical guidelines on prescribing medication. **Conclusions**: People with Intellectual Disabilities use psychotropic medication that may be used to excess. The overuse of medication leads to adverse effects that have impacts on Quality of Life. Reducing medication is beneficial and feasible.

Symposium: Ways to Facilitate Appropriate Psychotropic Drug Use in People With Intellectual Disability (ID)

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KEYWORDS Challenging behaviour; psychiatric disorders; psychopharmacology; quality of life

Aims: In this symposium we will focus on patient-, staff- and setting-related factors associated with psychotropic drug use of people with ID. We will present results of accomplished and ongoing

studies regarding the reasons for antipsychotic drug use for challenging behaviour (CB) (1) and determinants for successful discontinuation (4,5), a study in which ID support professionals are offered training and education in the management of CB (2) as well as a tool to improve their knowledge regarding psychotropic drug use of the individuals (3). In this way, we want to offer clinicians tools to facilitate appropriate psychotropic drug use for individuals with ID. **Background and aim of symposium**: The use of psychotropic drugs of people with ID is high and often for long periods of time. Prescriptions are mostly off-label for psychological or behavioural symptoms in absence of a psychiatric diagnosis. This may be due to diagnostic problems in this population, but also because of environmental factors like lack of knowledge of clinicians and support professionals regarding how to manage CB, setting culture, beliefs and knowledge of clinicians and support professionals towards the effects of psychotropic drug use, and lack of sufficient resources to offer appropriate care to people with ID and CB. Although the off-label use of antipsychotic drugs for behavioural symptoms in absence of a psychotic disorder may be beneficial in the short term, the effectiveness of long-term use in people with ID is unclear. Here, because of increased health risks caused by side-effects, physicians should try to taper off antipsychotics. Behavioural interventions and increasing the knowledge on psychotropic drug use may be effective in reducing CB and long-term off-label use of psychotropic drugs. On the basis of the study results, we aim to discuss policies regarding mental health care and psychotropic drug use of people with ID in an international perspective.

SYMPOSIUM - ABSTRACT 1

Reasons of Physicians Not to Discontinue Off-Label Use of Antipsychotics in People With ID

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Aims: The aim of this study was to investigate the influence of participant- and setting-related factors on decisions of physicians for ongoing off-label antipsychotic drug prescriptions. **Methods**: Participants were residents of six ID service providers, staffed with ID physicians and behavioural scientists. Medical and pharmaceutical records were used to identify antipsychotic drug users, and the duration and reasons for use. Physicians' reasons not to discontinue the off-label use of their patients were categorized as participant- or setting-related. **Results**: Of the 3299 persons 977 used antipsychotics. Prescriptions were in 95% off-label (69% for CB; 25% use for more than one year in cases of transient psychotic symptoms). Overall, physicians decided to discontinue their off-label prescriptions in 51% of cases. Reasons not to discontinue were concerns about symptoms of restlessness, the presence of autism spectrum disorder, previously unsuccessful attempts and objections against discontinuation of legal representatives. There were large differences between the service providers. **Conclusion**: Results show a large variety of physicians' decisions and reasons for ongoing off-label prescriptions, possibly related to setting factors.

SYMPOSIUM - ABSTRACT 2

A Pilot Study Examining the Effectiveness of Behavioural Staff Training Groningen (BSTG) for Individuals With ID and CB

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Aims: The aim of this study was to examine changes in CB and the quality of life of people with ID living in service facilities, and staff-self-efficacy and burnout after BSTG. **Methods**: The participants consisted of 25 staff members working with 11 individuals with ID and CB. A one-group, double pretest-posttest design was used. The effects of BSTG were assessed using structured interviews and questionnaires (see supplementary file [SF]). **Results**: Preliminary results indicated non-significant changes in the measures during the pretest period. After BSTG, CB did not decrease. Taking part in BSTG was associated with improvement in the quality of life; the self-efficacy of staff working with CB improved and scores on burnout measures decreased. **Conclusions**: Preliminary results show positive changes concerning the quality of life of individuals with ID and CB, and staff self-efficacy and burn-out.

SYMPOSIUM - ABSTRACT 3

Online Learning Intervention on Psychotropic Drug Use in People With ID for Direct Support Professionals

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Aims: The aim of this study was to improve the knowledge of ID support professionals in order to facilitate appropriate drug use of people with ID. **Methods**: We developed a tool and used a questionnaire to measure the knowledge (see SF). **Results**: See SF. **Conclusions**: We will demonstrate the tool and present the results of the questionnaire.

SYMPOSIUM - ABSTRACT 4

Discontinuation of Off-Label Used Antipsychotics in People With ID Living in Service Facilities: Results and Determinants

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Aims: The aim of this study was to investigate the results of discontinuation trajectories of off-label long-term antipsychotics used by individuals for more than 6 years, and to identify participant-related and support-professionals-related factors as determinants for successful discontinuation. **Methods**: Antipsychotics were tapered off in a time frame of 14 weeks (a dose reduction of 12.5% every 2 weeks). Data collection took place at baseline, 4, 8, 12, 16, 28, and 40 weeks after the first dose reduction. **Outcomes**: Behaviour (primary), global assessment, autonomic and extrapyramidal symptoms, health-related quality of life, staff-characteristics (details: see SF). **Results**: Preliminary results (71/134 participants analysed at 28 weeks) indicate that at 16 weeks 68 %, and at 28 weeks 49% of participants had completely discontinued their use, and that behaviour had not worsened significantly. **Conclusions**: Results indicate that half of participants succeeded in complete discontinuation. Definite results and results on determinants will be presented.

SYMPOSIUM - ABSTRACT 5

Long-Term Effectiveness of Off-Label Risperidone in Children and Adults With ID: A Double-Blind Placebo-Controlled Discontinuation Study

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Aims: The aim of this study was to investigate the long-term effectiveness of off-label risperidone used by individuals with ID and CB. **Methods**: A double-blind and placebo-controlled discontinuation trial was conducted. For the discontinuation schedule and data collection see study 4. After 8 weeks, a blind follow-up took place and after 18 weeks a natural follow-up. For outcomes see study 4. **Results**: Half way through the study of the 25 participants, 3 had successfully discontinued risperidone, compared to 2 participants who had to quit after the last discontinuation step. There were no differences in behavioural outcomes between the control and the discontinuation group. **Conclusion**: Further results will be presented.

INDIVIDUAL PAPERS

Pregabalin in Intellectual Disabilities

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KEYWORDS Autism spectrum disorder; psychiatric disorders; psychopharmacology

Introduction: Pregabalin is a well-established anti-epileptic drug in the treatment of epilepsy. It is also indicated for the treatment of Generalised Anxiety DIsorder and neuropathic pain. In addition, it has mood modulating properties. In people with Intellectual Disabilities it is used to treat epilepsy. There is little evidence of the use of Pregabalin in managing mental health difficulties in people with Intellectual Disabilities. **Objectives**: To describe the use of Pregabalin in adults with Intellectual Disabilities. **Method**: A descriptive case series of adults with Intellectual Disabilities living in the community under the care of a Community Psychiatrist who are prescribed Pregabalin. Outcomes of treatment were measured using the Health of the Nation Outcome Scale for people with Intellecutal Disabilities (HoNOS-LD). **Results**: Fourteen cases were identified in the community service of adults with Intellectual Disabilities. Twelve were men and two were women. The average age of the sample was 29 years. The range in duration of using Pregabalin was from 3 to 72 months. Thirteen adults had a diagnosis of Autism of which three also had ADHD. The indications for using Pregabalin and numbers were: anxiety (12); lability of mood (2); generalised anxiety disorder (1); epilepsy(1). The daily dose range was from 150 mg to 300 mg. The mean change in HoNOS-LD scores was 32%. **Conclusions**: Pregabalin is a useful treatment in people with Intellectual Disabilities who experience anxiety. It is especially effective among adults with ID and Autism to modulate mood and anxiety symptoms.

Facilitators and Barriers in Implementing and Using Guidelines on Antipsychotic Drugs in People With Intellectual Disabilities

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KEYWORDS Challenging behaviour; policy; problem behaviours; psychopharmacology

Aims: Previous studies showed that guidelines on antipsychotics were insufficiently adhered to in the care of people with intellectual disabilities. Therefore, this study aimed to establish facilitators and barriers in the implementation and use of guidelines and recommendations in prescribing antipsychotics for people with intellectual disabilities in the Netherlands. **Methods**: In-depth interviews with ID physicians, psychiatrists and behavioral therapists were used to evaluate facilitators and barriers in the implementation and use of guidelines. These interviews were based on a questionnaire discussing organizational factors (decision-making process, responsibilities of the main clinician, regulations), caregiver attitudes (involvement, expectations) and facilitating conditions (electronic patient files [EPF], support). **Results**: Organizations that translated guidelines into an organizational

policy had clearer work relations and clarity on who the main clinician was. Clinicians relied on caregivers to signal challenging behavior and adverse effects. However, according to the physicians, they could not always rely on caregivers to have the required knowledge. Facilitation of the use of guidelines was perceived as a barrier: Not all clinicians had the support from nurses for monitoring adverse effects and treatment effects, the EPF systems did not facilitate monitoring, and clinicians were restricted in their time. **Conclusion**: To facilitate the use of guidelines, organizations should translate guidelines according to their own situation, involving physicians and behavioral therapists in this process. There is need for creating more practical and technological support for monitoring adverse effects and treatment effects. Furthermore, caregivers should receive education on antipsychotics to enlarge knowledge and create awareness.

A Pilot Randomised Controlled Trial of Community-Led Anti-Psychotic Drug Reduction for Adults With Learning Disabilities (ANDREA-LD)

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KEYWORDS Challenging behaviour; intervention; outcome; psychopharmacology; research

Aims: There is concern about over-use of anti-psychotics for reasons other than psychosis in adults with intellectual disabilities (ID). There is a lack of strong evidence regarding both the use of anti-psychotics to manage challenging behaviour, and the safety and efficacy of withdrawing patients from them. We assessed the feasibility of conducting a two-arm individually-randomised placebo-controlled trial of gradual anti-psychotic drug reduction compared to treatment as usual. **Methods**: Participants were adults with LD, on risperidone, and without a history of psychosis. We recruited through primary care and community LD teams. Following randomisation, intervention participants went through four stages of blinded reduction (controls maintained starting dose). All participants were followed up at 6 and 9 months. **Results**: In total, 22 participants were randomised from 32 screened (69%). Participants were on a median dose of 1.5 mg of risperidone prior to randomisation (IQR: 1.0 to 2.0 mg), and had at baseline generally low clinical scores on scales measuring aggression, challenging behaviour, and mental health. Thirteen participants progressed through all four stages of the drug reduction (59%), and follow-up data were obtained for 17 (77%). Intervention participants had on average slightly higher scores for aggression, challenging behaviour, mental health, movement disorders, and PRN at follow-up. Reported anti-psychotic side-effects and the dose of anti-psychotic medication was lower for those in the intervention group at follow-up. **Conclusions**: These findings suggest that anti-psychotic drug reduction is possible and safe in this population. However, focused support and alternative interventions may be required.

Prevalence of Metabolic Syndrome Among Adults Prescribed Antipsychotic Drugs in an Irish Community-Based Intellectual Disability Population

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KEYWORDS Psychiatric disorders

Aims: Metabolic syndrome is a serious health condition, increasing morbidity and mortality due to diabetes and cardiovascular disease. Antipsychotic drugs are commonly associated with weight gain and can result in the metabolic syndrome. There has been insufficient research to date examining the prevalence of metabolic syndrome in those with intellectual disabilities (ID) prescribed antipsychotic drugs. This study aims to determine the prevalence of metabolic syndrome in adults prescribed antipsychotic medication, in an Irish urban, community-based ID service. **Methods**: All adults prescribed antipsychotic drugs were identified from an existing mental health database and existing metabolic syndrome monitoring data were obtained from clinical records. Metabolic syndrome was defined by using the criteria of the IDF worldwide consensus guidelines. A total of 195 individuals were identified as being currently prescribed antipsychotic medication as of May 2015. **Results**: Of the 195 cases identified, complete physiological data were available for 130 individuals. Of this sample, 22.3% (n = 29) met the criteria for a metabolic disorder. An additional 6% (n = 8) met the revised criteria which took into consideration medications for risk criteria such as hypertension or hypercholesterolaemia. There was no evidence of gender or age differences in the prevalence of metabolic classification. **Conclusions**: Adults with an ID prescribed antipsychotic drugs are at increased risk of developing metabolic syndrome, leading to increased morbidity and mortality. It is essential for clinicians to prescribe cautiously and to treat modifiable risk factors to reduce the risks in this vulnerable patient group.

Treatment of Addiction in Patients With an Intellectual Disability Using 12-Step Facilitation

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KEYWORDS Abuse; addiction; therapies

Aims: There is need for an effective intervention to treat addiction of intellectually disabled individuals, as they are at risk of developing problems with addiction (Pezzoni and Kouimtsidis, 2015). We adapted a 12-step facilitation to be used in the treatment of patients with intellectual disability. We want to show the efficacy of 12-step facilitation in treating addiction within this group. **Methods**: We made a specialized intervention, developing a version of 12-step facilitation aimed at

intellectually disabled people. This is a naturalistic pilot study running for a period of six months. We use the SumID-Q (Van Der et al., 2011) as an instrument for treatment evaluation. The SumID-Q is relatively new and maps risk factors, the use of chemical entities as well as the consequences of that use, and is tailored to be applied in the group of intellectually disabled individuals. We will apply the SumID-Q at the beginning and end of the trajectory. **Results**: We will show preliminary results of this promising intervention. **Conclusions**: it is possible to adapt 12-step dacilitation for use in the ID population.

References

Pezzoni, V., & Kouimtsidis, C. (2015). Screening for alcohol misuse within people attending a psychiatric intellectual disability community service. *Journal of Intellectual Disability Reseach*, *59*(4), 353–359. doi:10.1111/jir.12168

Van Der, N. J., Kiewik, M., Van Dijk, M., & De Jong, C. (2011). Manual SumID-Q: An instrument to assess substance use in individuals with a mild intellectual disability. Deventer: Tactus [dissertation].

POSTERS

Adherence of Clinicians to Guidelines for the Prescription of Antipsychotic Drugs to People With Intellectual Disabilities

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KEYWORDS Challenging behaviour; policy; problem behaviours; psychopharmacology

Aims: In the Netherlands, antipsychotics are prescribed in various settings, including specialized intellectual disability (ID) care and mental health care. It is not known how guidelines on antipsychotics are adhered to by clinicians in these settings. Therefore, the aim of this study was to compare antipsychotics prescription practice of ID physicians and psychiatrists to existing national and international guidelines. **Methods**: A self-designed checklist was used to review medical records of individuals in specialized ID care and mental health care in the North of the Netherlands. The checklist was based on available national and international guidelines. **Results**: Prescriptions were written for persons with problem behavior in absence of a psychotic disorder or psychotic symptoms in 90% in specialized ID care and 79% in mental health care. In specialized ID care pipamperone (32%) and in mental health care risperidone (49%) was prescribed most often. Only half of the individuals were additionally treated with a psychological or psychosocial intervention. In both settings, treatment effects were measured with a validated scale in only 3%. Adverse effects were monitored more frequently in specialized ID care. The most monitored adverse effect was weight (55%). **Conclusion**: The adherence to guidelines for prescribing antipsychotics to people with intellectual disabilities is insufficient in the Netherlands. Most prescriptions of antipsychotics were for individuals not suffering from psychosis or schizophrenia. Monitoring of treatment effects and adverse effects, and providing non-pharmacological treatments were insufficient. Prescriptions were mostly long-term, although discontinuation was considered in half of the cases.

Health Related Quality of Life (HRQoL) of People With Intellectual Disability (ID) Who Use Off-Label Long-Term Antipsychotics

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KEYWORDS psychopharmacology; quality of life

Aims: The effectiveness of long-term off-label use of antipsychotics for behavioural symptoms in people with ID is unclear. Moreover, because of the risk of adverse-events long-term prescriptions should be avoided. Especially neurological adverse-events like extrapyramidal symptoms (EPS), autonomic symptoms (AS), sedation and affect-flattening may negatively influence HRQoL. Therefore we investigated the presence and severity of EPS and AS, severity of behavioural symptoms and HRQoL in 134 persons in ID living facilities who used long-term antipsychotics for behavioural symptoms. **Methods**: In this study we used baseline data of a discontinuation study. For assessment of EPS we used the Abnormal-Involuntary-Movement-Scale, the Barnes-Akathisa-Rating-Scale and the Unified-Parkinson-Disease-Rating-Scale/motor items; for AS the Scale-Outcomes-Parkinson-Disease/autonomic-symptoms; for behavioural symptoms the Aberrant-Behavior-Checklist (ABC) and Clinical-Global-Impression/scale-Severity (CGI-S); for HRQoL the Personal Outcome Scale/subscales physical- and emotional wellbeing. **Results**: EPS were present in 68% and AS in 74% of persons. Mean scores of EPS, AS, ABC-total, ABC-subscales and CGI-S varied and were highest in those people with more severe ID. Higher ABC/subscale-lethargy was associated with lower POS emotional- and physical wellbeing and higher CGI-S and age were associated with lower POS/emotional-wellbeing. More severe ID and living in larger scale living facilities were associated with higher ABC/subscale-lethargy. **Conclusions**: In people who use off-label long-term antipsychotics those with more severe ID have significantly more symptoms of side-effects and lethargy compared to those less disabled. More severe lethargy is associated with lower HRQoL. Because there is no proof for effectiveness in this indication and the sedative and flattening side-effects discontinuation of antipsychotics is advised.

PSYCHOTHERAPY (PSYCHOLOGICAL AND BEHAVIOURAL THERAPY)

SYMPOSIA

Symposium: Delayed Emotional Development and Its Impact

Name of chair: Pat Frankish

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Pat Frankish Psychology, Kirton Lindsey, UK

KEYWORDS Psychotherapy; training

Background and aim of the Symposium: Dr. Pat Frankish has researched and published data on a model of emotional development that facilitates the understanding and alleviation of challenging behaviour (Frankish 2016). This symposium will explore the use of the model from different angles, in individual work, with people with ID in a group setting, and the wider impact of a whole school initiative.

The symposium will present findings and discussion on the impact of the model and its usefulness for the future, including implications for individual work as well as staff training for a systemic intervention.

Reference

Frankish, P. (2016). *Disability Psychotherapy: An Innovative Approach to Trauma-Informed Care*. London, UK: Karnac.

SYMPOSIUM - ABSTRACT 1

Emotional Support for Children With Intellectual Disabilities in a Specialist School Setting

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Pat Frankish Psychology, Kirton Lindsey, UK

Aims: In line with national drivers to provide strategies for the improvement in meeting mental health needs of children and young people, this project aimed to evaluate a pilot project that is providing an 'Emotional Training Model' programme. This was delivered to multi-disciplinary, multi-agency teams set in two specialist schools for children with Intellectual Disabilities. Alongside the training, ongoing consultation and support was provided to enable key learning to be embedded in the new model of care. **Methods**: The evaluation assesses the impact of the interventions using pre/post intervention data collection. Multi-disciplinary teams and parents involved with the two schools taking part, completed questionnaires capturing experience of stress, burnout, conflict management styles for staff, and satisfaction either with their jobs for the staff team or the service for parents. Observations of some children were completed by the psychology team involved. Demographic data including number of staff absences due to sickness or number of incidents involving the children forms part of the evaluation. **Results**: The impact of the intervention has been an increase in skill level of direct support staff, including teachers, together with more awareness amongst parents and a reduction in distressed behaviour in children. The intervention has been well received and demonstrates the positive effect of a systemic intervention.

SYMPOSIUM - ABSTRACT 2

Further Developments in the Value of Recognising Delayed Emotional Development in People With ID

Pat Frankish

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Pat Frankish Psychology, UK

Aims: To describe a useful model for understanding challenging behaviour and how to address it. The model has clear links with attachment theory and disability psychotherapy. **Methods**: Individuals are assessed as having a discrepancy between their cognitive developmental age and their emotional developmental age. Providing input to improve the emotional development enables an assessment of the model and a measure of improvement in behaviour. Individuals are described as a case series. **Results**: Results so far show an improvement in emotional development and a reduction in challenging behaviour. **Conclusions**: The results are showing that the model is effective and provides a positive way forward for challenging behaviour services.

SYMPOSIUM - ABSTRACT 3

I Can Move Again - A Modern Day Case of Hysterical Paralysis

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This paper describes the use of Disability Psychotherapy to enable a young woman named, Fran, to regain the use of all four limbs that were paralysed. Fran had been referred by a Neurologist in Rehab Medicine, who had exhausted all medical investigations into the cause of her paralysis. The therapy was provided by a Community Based Psychology Service for people with Intellectual Disabilities in Grimsby, North East Lincolnshire, UK. The paper discusses the challenges of providing treatment within a person-led model of care: for example, Fran would not come into sessions without her mother, and would only tolerate monthly sessions. The impact of family dynamics and the neurology of psychosomatic illness on Fran's presentation are explored and the successful outcome of therapy is explained in Fran's own words.

Symposium: Parenting and Early Interventions in Intellectual Disabilities

Name of chair: Paula Sterkenburg

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Vrije Universiteit, Department of Clinical Child and Family Studies, Amsterdam & Bartiméus, Department of Psychotherapy, Doorn, The Netherlands

KEYWORDS attachment; developmental disorders; intervention

Aim of the symposium: To give an overview of early interventions for parents with young children with an intellectual disability and to provide information on planned research as well as results from

two RCT studies on the Video-Feedback Intervention for Positive Parenting developed by Leiden University. **Background and objectives of symposium**: With this symposium we present evidence on the use of early interventions in the care for young children with an intellectual disability. A planned RCT in the UK will be addressed as well as two recently conducted RCTs for parents of children with a visual and intellectual disability as well as parents with an intellectual disability caring for their own young children. Implications of findings for early intervention practice as well as future and ongoing research will be discussed.

SYMPOSIUM - ABSTRACT 1

Evidence for Parent Interventions in Young Children With Intellectual Developmental Disabilities: Application in the EPICC-ID Randomised Controlled Trial

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Aim: Children with intellectual developmental disabilities are four times more likely to develop mental ill-health and challenging behaviours than children without developmental difficulties. However, there is limited research in developing or adapting interventions especially early in life to help children and their families. Service commissioners have yet to provide robust care for this population group. The presentation will summarise the evidence of early interventions in children with intellectual developmental disabilities and focus on a new clinical trial of a parenting intervention in the UK. **Methods**: The talk will provide a narrative account of the literature on early interventions and briefly mention the rationale of a new RCT (Evaluation of a Parenting Intervention for Children with Challenging Behaviour and Intellectual Disabilities, EPICC-ID). The study will be conducted in four areas in England, UK. **Results**: Stepping Stones Triple P (SSTP) will improve challenging behaviour in 258 children aged 3–5 years with moderate to severe intellectual disabilities compared to those in the treatment as usual (N = 258). We shall also carry out a cost effectiveness analysis and a process evaluation hypothesizing that SSTP will reduce health and social care costs and will be acceptable to parents with low drop-out. **Conclusions**: Although parenting interventions for children without intellectual disabilities are well tested and available, many parents of children with ID have either been unable to access them or found that universal parenting groups are unsuitable for their difficulties. We, therefore, anticipate that our findings will contribute to service developments within child mental health services to address this gap.

SYMPOSIUM - ABSTRACT 2

Studying the Effect of Video-Feedback Intervention to Promote Positive Parenting for Parents of Children With A Visual or Visual and Intellectual Disability (VIPP-V): A Randomized Controlled Trial

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KEYWORDS Early Interventions; RCT; Visual impairment; Visual and intellectual disabilities; Video-feedback

Aim: Building secure attachment relationships may be impeded when children have visual or visual and intellectual disabilities. The Video-Feedback Intervention to Promote Positive Parenting developed at Leiden University was adapted for parents of children with a visual or visual and intellectual disability (VIPP-V), to support sensitive parenting. This study examined the effect of VIPP-V on sensitivity, parental stress and self-efficacy. **Methods**: A randomized controlled trial was conducted with parents of children aged 1–5 years with visual or visual-and-intellectual disabilities. The experimental group received seven sessions of VIPP-V while the control group received care as usual (CAU). Parents and their children participated in a pre-, post- and follow-up test (N = 77). Parental sensitivity and quality of parent-child interaction were observer-rated using the National Institute of Child Health and Human Development Scales during a structured play task. Parents self-reported on parental stress and on parenting self-efficacy. **Results**: No effect of VIPP-V was found on parental sensitivity or quality of parent-child interaction. Regarding parenting stress, no main effect on condition was found, but a non-significant trend ($p < .10$) for the two-way interaction effects for parenting stress and condition was present, indicating a decrease in parenting stress for the VIPP-V group from pre-test to post-test, which slightly increased towards follow-up, whereas parenting stress for the CAU group did not change over time. VIPP-V improved parenting self-efficacy, with the advantage for the experimental group increasing from post-test to follow-up. **Conclusions**: The question when and for whom VIPP-V may be beneficial requires further discussion.

SYMPOSIUM - ABSTRACT 3

Possible Predictors of the Quality of Interaction Between Parents With Mild or Borderline Intellectual Disabilities (MID) and Their Young Children

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Aim: To support parents with MID in the interaction with their young children, it is important to know more about indicators which predict success of these kinds of interventions. To determine relevant indicators for such assessments, associations were studied between observed quality of parent-child interaction and potentially explanatory factors: parenting stress, parental adaptive functioning, quality of the home environment, social support and child behaviour problems. **Methods**: Eighty-five parents with MID and their young children participated in home-based pre-test assessments of a video-feedback intervention (VIPP-LD). Harmonious parent-child interaction was rated with the three-bags procedure. Sensitive discipline was measured with a do/don't-task. Parents were interviewed on parenting stress and the informal support network. Parental adaptive functioning, quality of the home environment and child behaviour problems were assessed by the care organisation psychologists. **Results**: Hierarchical stepwise linear regression analyses with four steps indicated that parental adaptive functioning was the only predictor of both harmonious parent child interaction and sensitive discipline during the do-task, but the association was weak. Contrary to expectation, parenting stress did not significantly predict any of the dependent variables, nor did quality of the home environment, the size of the supportive network, and child behaviour problems explain any additional variance. **Conclusions**: Reliable proxy measures for the quality of parental behaviour of parents with ID were not found. Systematic observation of parenting qualities is preferred.

CO-PRODUCTIVE WORKSHOPS

Treatment of Mental Disorders in Children and Adolescents With Mild to Moderate Learning Disability

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KEYWORDS behaviour therapy; developmental disorders; practice; psychiatric disorders; psychopharmacology

Aims: In 2016, the "Handboek Psychiatrie en Lichte Verstandelijke Beperking" (Didden, Troost, Moonen, & Groen, 2016) and the "Leerboek ontwikkelingsstoornissen in de Levensloop" (Staal, Vorstman, & Van Der Gaag, 2016) were released in the Netherlands. The authors discuss different forms of treatment of mental disease in children and adolescents with intellectual disabilities. About 15% of all children have a mild (~IQ between 50–85) or moderate intellectual disability (~IQ between 20–55). Psychiatric disease is more common in youth with intellectual disabilities, but with the right adjustments, good treatment effects are possible. According to many clinicians there is little awareness for psychiatric illness in children and adolescents with intellectual disability, regarding scientific research as well as practical experience. Inspired by these books, some of the authors of the "Handboek Psychiatrie en Lichte Verstandelijke Beperking" (Didden et al., 2016) and their colleagues decided to use their different perspectives, derived from their different disciplines, to work together towards more integrated and adjusted forms of mental health-care for children and adolescents with mild to moderate intellectual disability. Didden et al. (2016) and Staal, Vorstman, & Van Der Gaag (2016): these titles roughly translate as: "handbook mental disorder and mild intellectual disability" and "Textbook Mental disorders across the lifespan" **Brief description of the goals**: We proudly present our practical therapy adjustments and our enthusiasm that comes from cross-disciplinary co-production.

This workshop provides (preferably evidence-based) practical clues in mental health care treatment for children with an intellectual disability, derived from different clinical and scientific perspectives. This concerns rational pharmacological decision-making, including cytochrome-gene-typing as well as modified cognitive behavioral therapy and EMDR to fit children who are less capable of talking about emotional cognitions due to lower verbal skills. Finally, we reveal insights in psychomotor systemic therapy (PMST), especially developed for children with intellectual disability.

We aim to improve practical knowledge and self-reliance of participants by providing perspectives from different disciplines, working in small groups, the use of case-description, discussion, video-material, and participating in role-play. This workshop ends with a final discussion to to facilitate integration of the contents.

From a psychological perspective, different adjustments in individual treatment (CBT and EMDR) will be discussed.

From a systemic perspective, the importance of environment relations will be highlighted.

From a psychomotor perspective, there will be emphasis on the use of non-verbal communication in people with lower verbal skills

From a psychiatric perspective, there will be focus on pharmacological, genetic and somatic issues.

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INDIVIDUAL PAPERS

AutCom – Evaluation of a Multimodal Group Training Program Supporting Adults With Autism and Intellectual Disability

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KEYWORDS autism spectrum disorder; body-mind connection; education; therapies

Aims: Even though autism spectrum disorder (ASD) is a lifelong condition frequently co-occurring with intellectual disability (ID), there is a lack of structured treatment concepts supporting adults with ID and ASD. The Autism Competence Group (AutCom) is a newly developed, mixed-gender group training to foster social, emotional and executive skills. AutCom combines an educational approach with musical and bodily interventions. Setting and course were structured considering ASD-typical features. This study aims to evaluate the program's efficacy and appropriateness. **Methods**: A group of 6 adults completed the program including 16 sessions, conducted by a music therapist and a psychology student. A control group matched for gender and IQ was selected from the waiting list, receiving treatment as usual. Efficacy was assessed by a pre-post-comparison of self-reports and external assessments. Outcome variables were measured by established scales: social responsiveness (SRS), challenging behavior (ABC, MOAS), quality of life (POS), appropriateness (ZUF); social, emotional and executive skills were measured with a self-developed questionnaire. **Results**: In the self-assessment, competences increased in all domains. The external assessment showed higher improvements on most scales for the treatment group compared to the control group. All participants showed high ZUF-scores, indicating appropriateness and broad acceptance of the program. **Conclusions**: AutCom is a promising approach fostering social and emotional skills and was highly accepted by the participants. The combination of musical and bodily interventions, and educational principles showed to be very suitable for adults with ID and ASD.

Behaviour Analysis: From Controlling to Understanding the Challenging Behaviour

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KEYWORDS Behaviour therapy; challenging behaviour; self determination

Aims: The significance of behaviour and factors affecting it has been studied in order to select the right type of non-pharmacological intervention as part of our new legislation to promote the self-determination of intellectually disabled clients. **Methods**: The used method, behaviour analysis examines causal relations between behaviour and environment1,2. According to this method challenging behaviour is a consequence of person’s interactive relationship with the environment, not just a result of personal characteristics as originally described by B. F. Skinner1,2. This behaviour analysis has been applied at our institute to promote self-determination of intellectually disabled clients. A typical case is introduced as an example of its benefits in our everyday clinical routine. **Results**: In this case the use of behaviour analysis helped us to understand why the client wanted to stay isolated in her own room and eventually (through positive reinforcing and skills training) led to her increased, independent attendance to daily activities. **Conclusion**: Being encouraged by our positive clinical experience the behaviour analysis is used more frequently and systematically than in the past to minimise the control measures of our intellectually disabled clients.

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Who Am I? A Life Story Intervention for People With Intellectual Disabilities and Psychiatric Problems

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KEYWORDS person-centred approach; psychiatric disorders; research; therapies; wellbeing

Aim: Despite the high prevalence of psychiatric problems among people with intellectual disabilities (ID) there is a profound lack of effective treatments for this group in double jeopardy. This is worrying because there is a risk of aggravation of the problems, possibly even leading to chronicity. We therefore introduce a new innovative intervention especially designed for people with ID and psychiatric problems. The intervention is based on narrative and life review therapy, and pays attention to the unique and personal perspective of people with ID. The intervention consists of training and a manual for therapists as well as a structured workbook with exercises for participants. **Method**: Four studies were conducted to evaluate the intervention. A first pre-and post-follow-up design assessed changes in psychiatric problems with 27 participants, a second pre-post design with 20 participants also assessed changes in positive functioning, and a third study included a follow-up as well as a control group which assessed changes in psychiatric problems among 60 participants. A qualitative evaluation was carried out with 37 participants. **Results**: The three quantitative studies show large changes in psychiatric problems, in particular regarding depression, and an increase in mental well-being, mastery, and life satisfaction. All participants were positive in their explicit evaluations of the therapy and the personal learning points. They now cope better with difficult experiences and are more empowered by strengthening their identities and social relations. Conclusion: The intervention is promising for the treatment of people with ID and psychiatric problems.

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Can Thoughts Predict Symptoms of Depression and Anxiety in Adults With Low Ability

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KEYWORDS psychotherapy

Aims: Beck's cognitive models of anxiety and depression have extensive empirical support and underpin cognitive behavioural therapies in the general population. Few studies have investigated of the viability of cognitive models with adults who have low ability including Intellectual disability (ID). Only one has tested Beck's key concept of cognitive content-specificity for anxiety and depression but ability was not measured or co-varied and Beck's assessment paradigm was not replicated. **Methods**: Adults (68) attending day support services who were unselected for mental health problems were interviewed using the modified Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI-II) symptoms measures. The cognitions checklist—depression (CCL-D) and cognitions checklist—anxiety (CCL-A) measured type and frequency of thoughts. Receptive language ability was assessed on the PPVT-4 with standard scores ranging from 20–95 and a mean of 62.25. **Results**: Hierarchical regression showed that depressive cognitions but not ability, predicted symptoms of depression. However, ability predicted a greater proportion of anxiety symptoms than did anxious cognitions. **Conclusions**: This is the first study to investigate cognitive content-specificity using Beck's assessment paradigm and to co-vary ability in a sample with ID. The substantial variance in symptoms predicted by depressive cognitions in an unselected sample of adults adds support for the use of cognitive behavioural therapy for depression amongst adults with low ability including ID. Further theoretical research should be undertaken in whole populations to test the impact of ability on the foundations of cognitive behavioural therapies.

Rehabilitation and Technology: An Integrated Tailored Approach to ASD - Prospectives of Interventions From Traditional Therapy to Virtual Reality and Parent Training

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KEYWORDS Autism spectrum disorder; rehabilitation; research; technology

Aims: The aim of the present study is to show the results of our research concerning touchless motion-based software in the rehabilitation treatment of children with autism spectrum disorder (ASD) and the importance of their parents' active participation. **Methods**: The work that we present analyzes the results of a study of specific software introduced in a rehabilitative program for children with ASD in five different age groups, stressing the importance of working with parents in order to support engagement in the individualized rehabilitative program. **Results**: Patients can learn intuitively to perform their physical therapy proposal with motion-based touchless software and with a high motivational level. This approach can guarantee a significant and task-oriented working time. A computerized system is therefore customizable, moving from a general rehabilitation model to a tailored treatment approach. Moreover, a computerized system allows working in pairs or in small groups, thus promoting socialization. The indirect work from parents, structured in parent training sessions, allows for a further chance of successful treatment, supporting the possibility of further development of skills outside the rehabilitation setting. **Conclusions**: This type of method permits continuous and renewable calibration, which can transversally follow the life cycle, taking into account the specific needs of that moment as well as monitoring rehabilitation for each user. In addition, it can help to provide data for research. Comparing clinical needs with parents' perceptions allows the therapist to reach better goals and better quality of life for the entire family.

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Nine, Autistic and in a Straitjacket - How to Get Rid of It?

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KEYWORDS autism spectrum disorder; dual diagnosis; ethics & human rights; psychotherapy

Aims: This case study enters the heart of therapy and shows how relationships are created with simple reflections and interventions, step-by-step. The aim is to sensibilize therapists for working with dual-diagnosis patients in all its complexity. **Method**: Starting from an observation of the developmental status of this patient, a continuous reflection and experimentation by playing with him allows to get into contact and helps him to discover the environment without being disturbed by his anxiety and anxiousness, which lead to violent behavior. During the first meeting with this boy and the caretakers, he was pinned to a chair with a straitjacket without sleeves. He is not allowed to walk freely because he would destroy everything and harm others. A rigorous examination of the child's situation in a personal way, in a familiar and institutional context makes us understand his particular body language without speaking and gives us tools to structure the therapy. We will follow the therapist in his thinking and working with the child and all persons involved in this process. **Result**: We succeed in creating a relationship in a way that helps the boy being less anxious and we are able to support and even discover his environment without violence in his behavior. **Conclusion**: Even in cases of extremely difficult and complex pathologies we can expect positive outcomes from therapy.

Integration Model for Self-Management

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KEYWORDS dual diagnosis; education; prevention

The Fibbe SCL (Fibbe Child Study Centre) integration model is a three-dimensional approach for children with intellectual disabilities. The integration model is easy in use and addresses all elements which are relevant in realizing individual, behavioural self-management in the learning environment. The integration model consists of three dimensions: 1) school, 2) classroom, and 3) student/child. Only when paying attention to all three dimensions, the optimum result is obtained. The school is preeminently the best learning environment for students/children. Following a close dialog with the parents, the outcome can also be copied to the situation at home. The following elements are addressed in the three dimensions:

(1) School: school-environment, rules and protocols, daily routine (including the corresponding skills) and resources.
(2) Classroom: the supportive student's/child's learning cycle —behaviour of the student/child, (self)-recognition, (self)-assessment, asking for help.
(3) Student/child: know yourself; and for the teacher/mentor: know your student/child.

Fibbe Child Study Centre uses the integration model for all individuals. As the variety of individuals and their problems is huge, the way elements are addressed in-depth differs a lot. However, as a routine, all elements are checked to make sure the optimum result and the greatest extent of behavioural self-management in an effective learning environment is obtained. The integration model in itself is not evidence-based. The model should be seen as a kind of pre-project phase. The project comprises all activities/elements (evidence-based) for realizing the individual self-management. In the pre-project planning phase, using the integration model, all elements which need attention and follow-up are identified. In other words: the behavioural points of attention are presented in a constructive three-dimensional (school, classroom and student) manner.

Psychoactive Medications and Contextual Behavioral Sciences: Moving From Biological Data to a Human Interaction Frame

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KEYWORDS behaviour therapy; challenging behaviour; neurodevelopmental disorders; psychiatric disorders; psychopharmacology

Aims: The prevalence of psychiatric disorders and prescribed psychoactive drugs in subjects with neurodevelopmental disorders (NDD) is reported in literature as being very high. Often, there is no reported link between diagnosis and prescription. The limitations in this area could be decoded within a conceptual, methodological and practical perspective. On the one hand, we know that challenging behaviors are still the main driver for the use of medications, frequently in the form of multiple substance prescription with sedative scopes, even if data on the efficacy of this approach are extremely poor and discouraging. On the other hand, the screening and assessment tools known and used by clinicians substantially lack in validity and reliability when applied to persons with NDD. **Methods**: There are two kinds of resources that we can consider and try to merge in order to obtain better results and improve the clinicians' competences in the field of NDD. The first is the improvement and the dissemination of the evidence-based guidelines (e.g. AAIDD) for prescriptions in NDD population. The second are the procedures and protocols for the differential diagnosis, assessment and treatment of behavior problems. The latter point refers to the field of behaviour modification and applied behavior analysis, which has brought a remarkable body of evidence in the last 30 years. The presentation will give a summary of the literature in these fields (narrative review) and will try to point out practical implications and concerns. **Results**: Data show that medical doctors and psychologist working with persons with NDD should consider these specific evidences and guidelines, and try to combine information. Literature demonstrates how our clinical activity must be driven by an accurate knowledge of biological reactions (including side effects and peculiar responses often existing in NDD populations as well as efficacy

outcomes), and of the contextual variables influencing the individual responses (e.g. learning history, functioning, relational environment, life opportunities and activities). **Conclusions**: Through the integration of biological knowledge and behavioral sciences we can improve differential psychiatric diagnosis, and promote more effective and valid drug prescription patterns. This appears to imperative for considering the person with NDD in a mindful perspective, and to promote their quality of life, respecting their needs, wishes and values.

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POSTERS

The Usefulness of Group Cognitive Remediation in Young Adults With Mild to Moderate Intellectual Disability: A Pilot Study

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KEYWORDS challenging behaviour; cognition; neurodevelopmental disorders; training

Aims: Can we manage challenging behavior in individuals with intellectual disabilities with cognitive training? Cognitive training on working memory to improve fluid intelligence in individuals with intellectual disabilities is a challenging exercise. Studies suggested that even small proficiency in working memory would improve cognitive performances in individuals with intellectual disability. Thus, the aim of the current pilot study is to examine the usefulness of group cognitive remediation related to specific challenging behavior in young adults with mild to moderate intellectual disability. **Methods**: Five female participants with mild to moderate intellectual disability were recruited from an inpatient setting. Fifteen group sessions were conducted, consisting of one-hour sessions twice a week over a period of eight weeks. Cognitive training consist of (1) verbal and writing fluency, (2) short term and working memory exercises, (3) interactive games related to turn-taking, and (4) group role-play practice for generalization

of cognitive skills to manage specific challenging behavior(s). Outcome measures will be evaluated with the participants' self-report for every session, staff quantitative rating on DAS Behavior Problem Scales, and a questionnaire on challenging behavior. **Results**: It was expected that scores on the DAS Behavior Problem Scales and challenging behaviors in general would improve. The possible influence of individual variables and contextual variables will be discussed. **Conclusions**: Long-stay inpatient individuals with intellectual disability may benefit from intensive group cognitive training related to specific challenging behavior. Further research is required to examine long-term effects and to generalize the skills for other challenging behavior.

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Medical Hypnosis to Manage Distress Related to Blood Tests in Children With Down Syndrome

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KEYWORDS intervention; practice; stress

Aim: Medical hypnosis has received much support as a technique for effectively decreasing pain and anxiety levels in children having blood samples taken. The present study investigates the effect of hypnosis with respect to reducing emotional distress caused by venipuncture in children with Down syndrome. Hypnosis is a non-pharmacologic intervention, without any known specific side effects, depicted in narrative reviews and reported in meta-analysis as being beneficial in reducing distress related to medical procedures. **Methods**: The study sample included 10 participants with Down syndrome, 7 boys and 3 girls, aged from 6 to 17 years, mean age: 12.5 (SD = 4.15). We used the Stanford Hypnotic Scale for Children, Modified Form (SHCS; Morgan and Hilgard, 1979) a widely used and accepted measure of children's hypnotic susceptibility. The Modified Form of the SHCS, initially aimed for administration in young children (4 to 8 years), was adapted for our sample of children with Down syndrome. The sample presented problems with relaxing or keep their eyes closed. **Results**: Findings show that the children had the capacity to respond to suggestions under hypnosis; both motor and cognitive. The experience with the creative modifications of the induction technique in order to suit a child's special needs will be outlined. Children with Down syndrome show specific patterns. **Conclusions**: The differences between the hypnotic pattern of children with Down syndrome and children from the general population have to be considered. Even if children with Down syndrome might be less receptive to hypnosis than children from the general population, it should not hinder them from benefiting from hypnosis.

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SPORT, EXERCISE, AND BODY-MIND LINK

POSTER

Mental Health and Physical Activity: The Applicability of a Sports-Related Basic Needs Model in People With Intellectual Disabilities

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KEYWORDS autonomy; self determination; sport & exercise; wellbeing

Aims: According to the basic needs theory, as part of self-determination theory, three basic psychological needs of human beings are considered: autonomy, competence, and relatedness. The satisfaction of these needs has been shown to effect well-being and vitality (Ryan & Deci, 2000). In several studies, the basic needs model was validated in a sports context. Satisfaction of basic needs, influenced by sport coaches' support of autonomy in the sports environment, leads to greater subjective vitality and improved satisfaction with life in athletes without an intellectual disability (ID) (Adie, Duda, & Ntoumanis, 2008; López-Walle, Balaguer, Castillo, & Tristán, 2012; Reinboth & Duda, 2006). The aim of the present study is to test this model in a German-speaking population of people with ID participating at the Special Olympics World Winter Games. **Methods**: Athletes (N = 180) at the Special Olympics World Winter Games of March 2017 took part in structured interviews, conducted on an individual level. **Results**: The model will be analyzed by structural equational techniques and it is assumed to fit the data. This would indicate that coach autonomy support impacts basic needs, improving vitality and satisfaction with life in athletes with ID. **Conclusion**: The findings related to the interaction between sport and well-being will be discussed in the context of mental and physical health in this population.

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