### Challenging behaviour

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# Who are the people who challenge services?:



# Mary

- Loves chocolate
- Has a wicked sense of humour
- Is proud to live in her own home after 40 years of living in hospitals
- Rapid cycling bipolar affective disorder
- Lithium, Valproate, Diazepam, Lorazepam, Olanzapine, Chlorpromazine, Temazepam, Chlormethiazole, Procyclidine
- Is overjoyed to be able to be visited by her family at birthdays and Christmas
- Would be irretrievably traumatised by re-admission to hospital

## David

- Lived with parents all his life
- Stalwart of local community
- Interests in steam trains family trips
- Sudden change in behaviour 'not normal'
- Police 'riot squad'
- Parents cannot cope hospital admission
- Physical symptoms
- Parathyroid tumour
- Fixed but moves to live independently

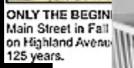
### Evan

- 26 yrs old
- Severe autism
- Self-injury (banging head) since age of 5
- Abused in residential home
- Now in hospital under mental health act
- In isolation
- Evidence of traumatic brain damage (2° to SIB)











# Tethered teenage psychiatric patient shocks Netherlands



Brendan's mother says he is restrained like a "caged animal"



23<sup>rd</sup> January 2011



The pictures show him wearing a harness attached to a metal bracket on the wall by a thick leather strap. He has been confined in this way every single day for three years.

Brandon, who suffers from severe learning difficulties, has been confined to institutions since the age of five.

He used to be allowed home at weekends but staff became increasingly afraid of his moods as he grew older and, since 2007, with the permission of a judge, he has been tethered daily.

Mental health experts in the Netherlands say this is not an isolated case, and there may be as many as 40 patients held in similar circumstances.





#### Children in care far from home 'at risk'

Charities are warning that thousands of children placed in care far from home are more vulnerable to criminality, drug abuse and sexual exploitation.

A third of the 64,000 children in local authority care in England and Wales live outside their local area. The charities say long-distance placements often traumatise children who are already damaged and vulnerable.

Thousands of children are currently being looked after in foster or children's homes hundreds of miles from their local area.

Charities - including Barnardo's, the Who Cares Trust and Voice - say uprooting an already vulnerable child can be highly traumatic. Children in care are often deeply damaged from past abuse, neglect, or growing up with addict parents, the charities say.

**BBC News 26/1/11** 





Six out of 11 care workers who admitted a total of 38 charges of neglect or abuse of patients at a private hospital have been jailed. Five other workers from Winterbourne View near Bristol were given suspended sentences after the acts of abuse were uncovered by BBC Panorama.

- 985,000 people with intellectual disabilities in England (2007 Centre for Disability Research, Lancaster University)
- 132,300 adults with intellectual disability using services. (2008/9)
- 10-15% present challenging behaviour
- "more demanding" challenging behaviour is shown by 64% of people identified as showing challenging behaviour;
- around 50% of people with "more demanding" challenging behaviour live with their families.

- CHALLENGING BEHAVIOUR
  - TASH U.S.
  - Shift focus from individual to carers / environment / professionals
  - Challenge to the system:

Better understanding

More effective responses

Creativity / flexibility

Less punitive / aversive responses

Behaviour diminish – no longer same function

OR

Better able to cope with behaviour

- CHALLENGING BEHAVIOUR corrupted definition
  - -People WITH challenging behaviour (services for ...)
  - -Loss of temporal and situational determinants
  - "Population of people with LD that WILL have challenging behaviour"
  - -Diagnostic label
  - Located within the individual NOT within environment / system
  - -Focus on reduction or elimination of behaviour
  - -Emphasis on specialist services:
    - Segregation, stigma, victims of service deficits

Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and /or the physical safety of the individual or of others and is likely to lead to responses that are restrictive, aversive, or result in exclusion.

- CHALLENGING BEHAVIOUR principles
  - -Socially constructed
  - -Strong shift in emphasis back to system around the individual
  - –Dynamic concept:
    - Impact on other
    - Ability of others to cope with the behaviour
      - -Fear, revulsion, anger, distress
  - Social consequences of isolation, exclusion, stigma, vulnerability, invalidation

### Definition - prevalence

Can be conceptualised within parameters of:

- -No. excluded from local services
- -No. in "out of county" placements
- –No. not receiving day services / employment opportunities / education / respite / home support
- -Service responses involving

Seclusion

Restraint

Locked-doors

Abuse

### Definition - prevalence

### Clinical responses involving:

- Inappropriate prescribing of drug treatments
- Punitive and aversive behavioural interventions
- •Risk avoidance rather than risk management



'Instead of responding to the person we typically react to the behaviour'

'Most of what passes as assessment seems to be denial about the

mutuality of our common condition'

Herb Lovett

'Our job is not to fix people, but to design effective environments'

**Rob Horner** 

'Difficult behaviours are messages which can tell us important things

about a person and the quality of his or her life'

David Pitonyak

## Need to understand people better

- 10-15% of people with ID
- 54% of people with SIB have > 1 Ch B
- Men > Women
  - Aggression and property destruction
  - In institutional settings
  - More severe ChB
- Peaks 15-34 then declines

## Need to understand people better

- Association with specific syndromes
  - Lesch-Nyhan, Cornelia de Lange, Prader-Willi, ASD
- Association with mental health problems
- Association with physical illness

# BUT – challenging behaviour does not occur in a vacuum

- Interpersonal dynamic
  - Someone else says "can't stand it"
  - Have to consider the response of the "other"
  - Variation between people
    - •"he's never any problem with me!"

# Challenge is to be accepting and at the same time creative and capable

- find more creative responses and solutions
- overturn traditional or longstanding responses
- adopt counter-intuitive ideas
- question the necessity for the established reputation and practice around the individual

# Challenge is to be accepting and at the same time creative and capable

- take managed risks
- adopt a greater flexibility of roles and responsibilities
- establish creative and unconventional working partnerships between individuals, community supports, voluntary and statutory agencies, professionals.

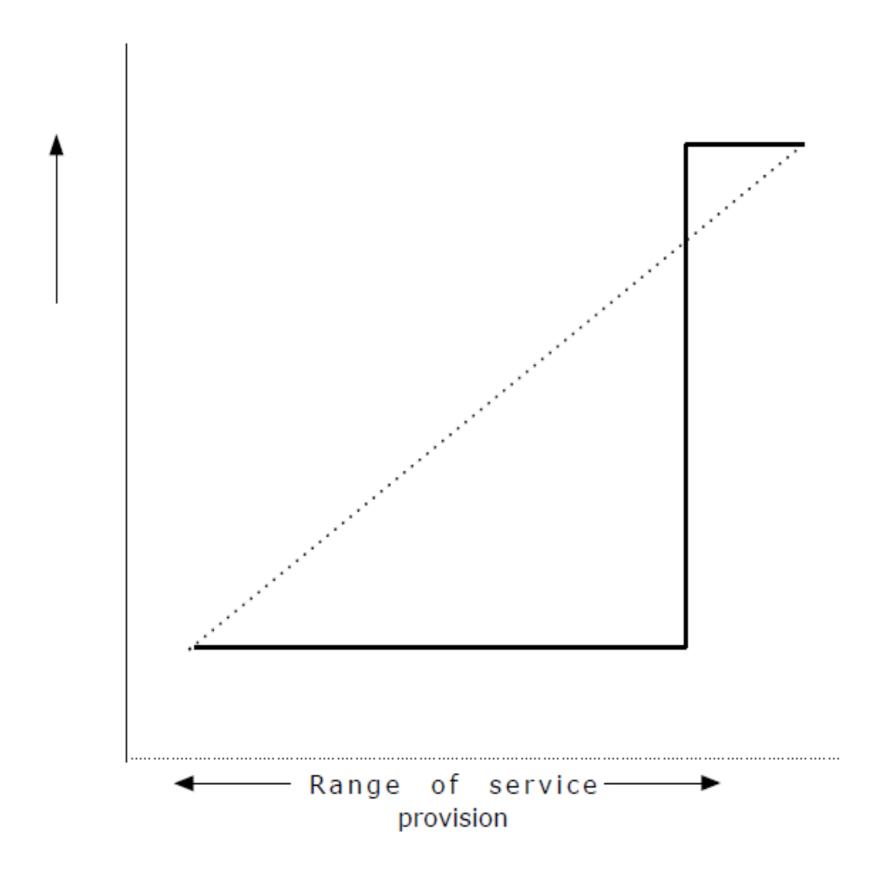


Fig. 3 Need and capability in services for people with learning disabilities.

, capability of service to respond; ......, individual demand on service

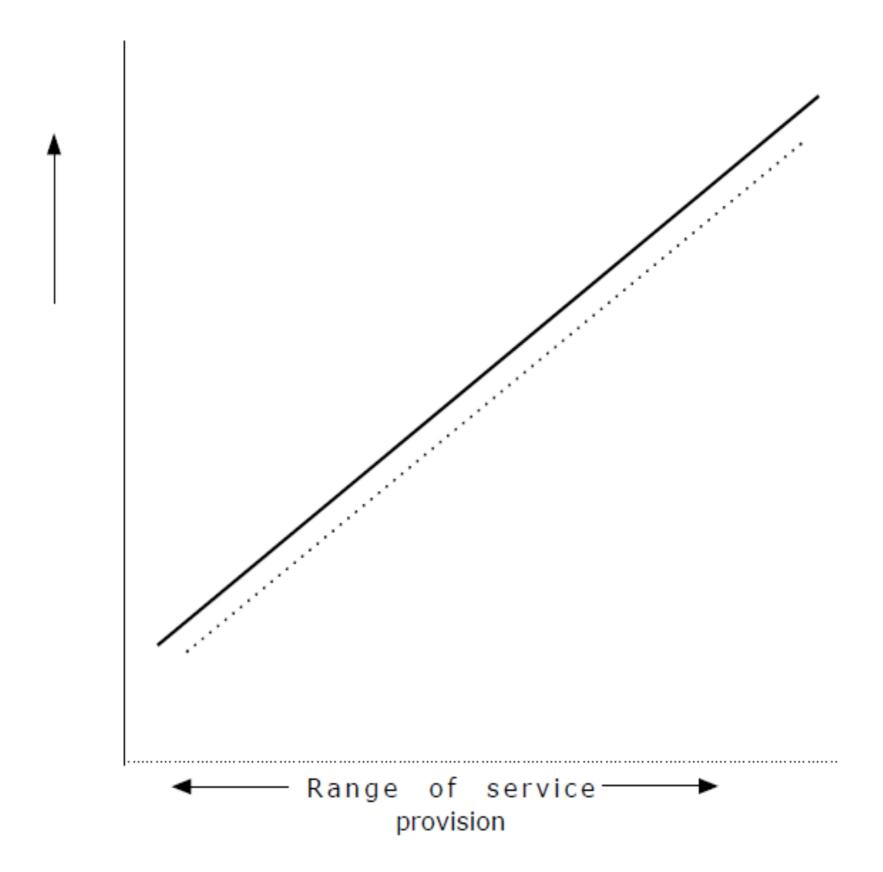


Fig. 4 Aim for capability to parallel need. ——— , capability of service to respond; ....., individual demand on service.

# Violations of rights

- ChB major predictor of abuse
- Inappropriate use of medication
- Use of restrictive and punitive interventions
- Social exclusion
- Deprivation
- Neglect







# 'Challenging behaviour – a unified approach'

Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices

College Report CR144 June 2007

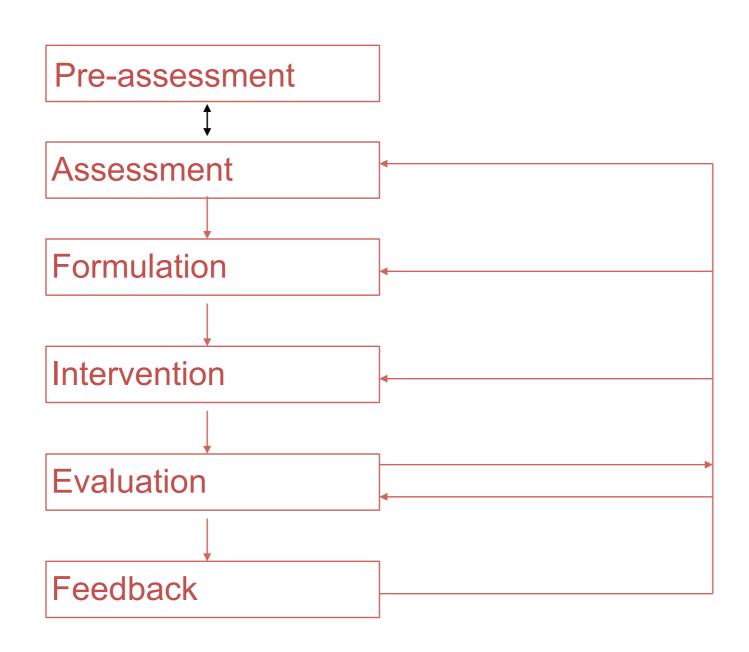
# Why a united approach?

- Traditional models (medical & psychological)
- Emphasise differences
- But many commonalities
- The point at which we most often have to work together
- Differences between professions often exploited or made worse by professional and organisational systems
- Best outcomes are when an interdisciplinary approach is taken (including families and carers)
- Outcome Joint Report "Challenging Behaviour: A unified approach"

## Positive Behavioural Support

• '...characterised by educational, proactive, and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments. It blends best practices in behavioural technology, educational methods, and ecological systems change with person-centered values in order to achieve outcomes that are meaningful to the individual and to his or her family'

### Model for assessment and intervention



#### **ASSESSMENT / DIAGNOSIS / FORMULATION**

Emphasis on detailed assessment of:

- The behaviour
- -The person
- -Underlying medical and organic factors (including medical examination and investigations)
- -Psychological and psychiatric factors
- -Social and environmental factors

#### **ASSESSMENT / DIAGNOSIS /FORMULATION**

- To collect enough information to lead to a coherent diagnosis and formulation
- To lead to an intervention plan which fits the person and their environment
- To establish a baseline that enables subsequent evaluation of effectiveness

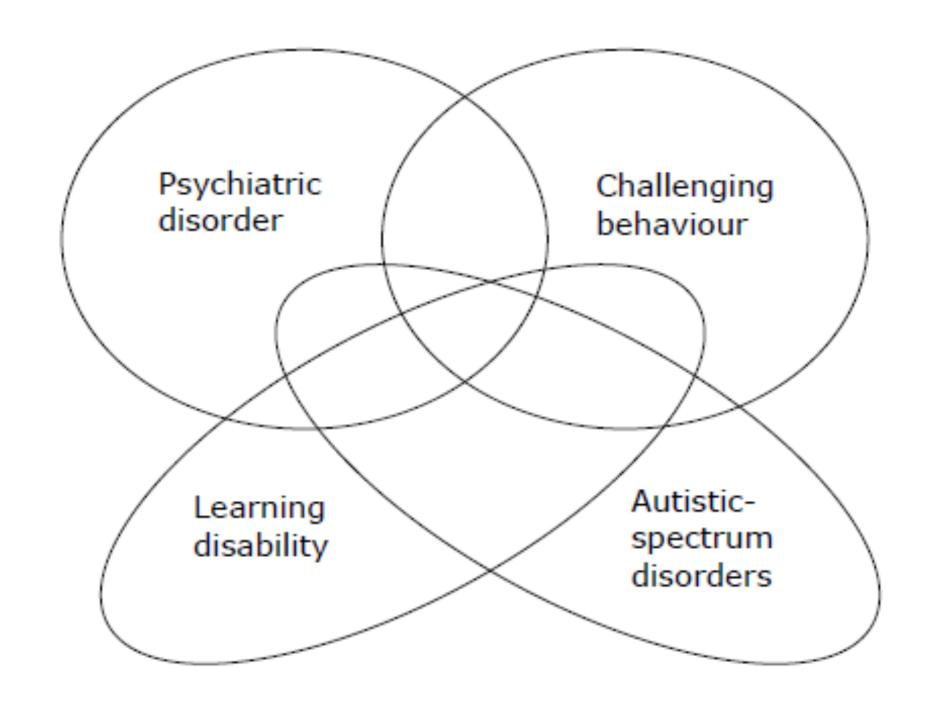
#### **ASSESSMENT / DIAGNOSIS / FORMULATION**

Focus of assessment should be determined by:

- the degree of physical harm to the person and others
- the risk of loss of access to opportunities for development and participation
- the levels of distress being experienced by the person and others
- the capacity and motivation for change in the person and in their environment

#### **ASSESSMENT / DIAGNOSIS / FORMULATION**

We take the view that a functional assessment and diagnosis are both integral features of the assessment of challenging behaviours that should be carried out by all clinicians, either individually or in collaboration.



#### Behaviour:

as the symptomatic presentation of a psychiatric disorder

as a secondary feature of a psychiatric disorder: as a motivational basis for the expression of previously established behavioural patterns

Emerson et al 1999

4<sup>th</sup> association:

latrogenic effects of treatment:

akathisia

neuroleptics

anxiety

- SSRIs

disinhibition

benzodiazepines

'Psychiatric diagnosis' should always be considered

Assessment not solely the province of psychiatrists – collaborative working

Psychiatric disorder should not be <u>assumed</u> simply because of changes in behaviour

Range of 'psychiatric treatments should always be considered

Do not treat 'behaviour' with drugs – clear rationale essential for what is being treated (DATABID guidelines)

### All interventions should be:

- delivered as part of a comprehensive, multidisciplinary plan of assessment, formulation, diagnosis and management
- Should be clearly communicated to: individual family / carers other professionals
- Evaluated

### **Current service challenges**

- Overuse of medication
- Trauma informed support and interventions
- Shaping "the market"

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