

Experiences in Co-operative Research and implementation

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Academic Lab: Social relations and attachment



Main goals of the academic lab

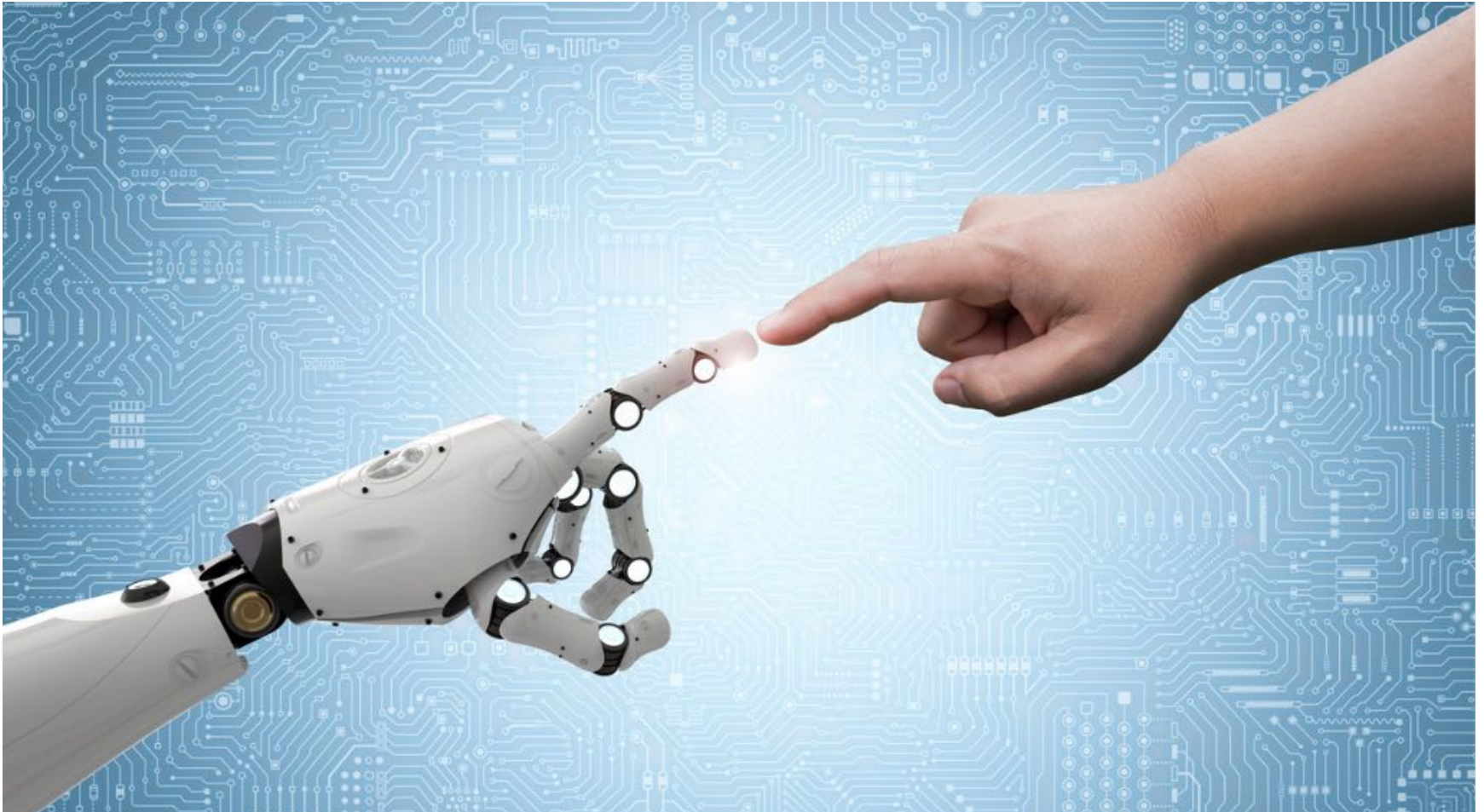
- Help to **develop, stimulate and improve relations** and consequently improve the **quality of life** of persons with a visual and visual and/or intellectual disability.
- **Develop, share and secure knowledge** concerning attachment and social relations.
- **Create a world** where persons with a visual or visual and/or intellectual disability **feel safe and secure and can develop their skills.**



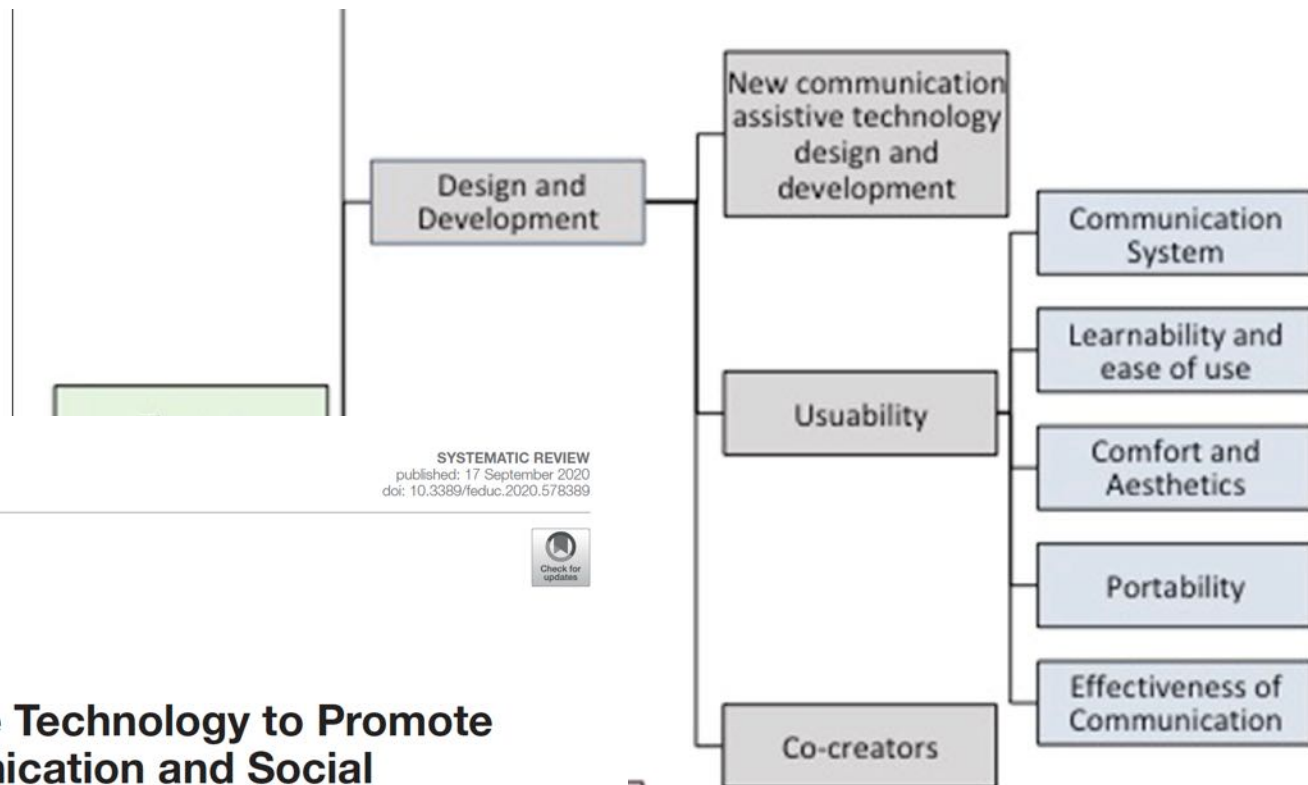
Research focus on:

- Prevention, aimed at developing a secure attachment of the child with parents/guardians
- Identifying and adequately interpreting behavior and stress
- Promoting and improving social relationships
- Restoring disrupted relationships

/here possible we add ICT



Co-creation!



Assistive Technology to Promote Communication and Social Interaction for People With Deafblindness: A Systematic Review

Vernandi Dyzel^{1†}, Rony Oosterom-Calo^{1†}, Mijkje Worm² and Paula S. Sterkenburg^{1,2*}

¹ Faculty of Behavioural and Movement Sciences, VU University Amsterdam, Amsterdam, Netherlands, ² Bartiméus, Zeist, Netherlands

Background: People with deafblindness experience stigmatization, exclusion, and isolation. Due to complex communication challenges, feelings of isolation and exclusion

- Person with disability
- Parents
- Relatives / others

- Professionals (multi-disciplinary)



Expert by experience

Experience and knowledge

Knowledge about organization and implementation

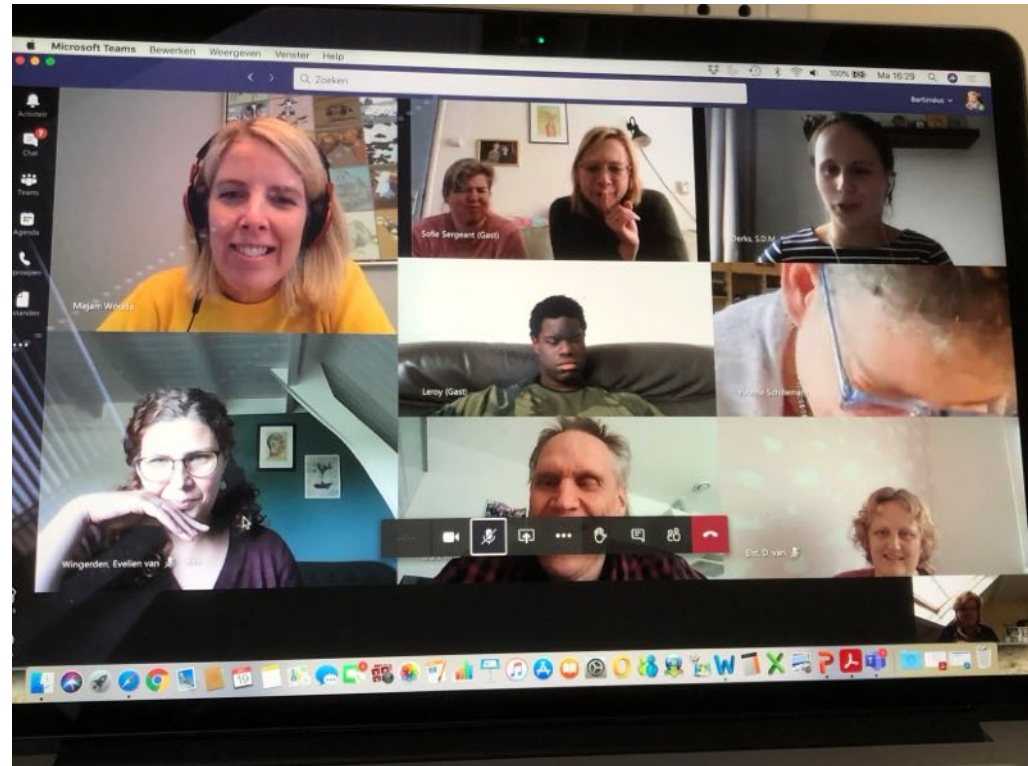
Scientific knowledge

- Managers and coordinators

- Researchers

Each project has other experts by experience!

Also during
the COVIC-19
lockdown!



Collaborations

- Tasks and roles in a research project
- Transparency



Aims:







- Open dialogue between participants in projects.
- Be aware of the different roles in a project.
- Be aware of the different roles in different phases.
- Talk about which role each participant prefers for which task.

Some examples of projects:



... and much more!!

Co-operative Research

GELUID 	
Praten	
Fluisteren	
Neuriën / zingen	
Fluiten	
Lachen	



VU Attune and Stimulate checklist



Stimulate observation of behaviour and stress experienced. Gives advice on how to react in a sensitive and responsive way.

- For parents and caregivers of persons with severe ID

Checklist 'Attune & Stimulate'



- Checklist A&S tested by 32 ROC-students!
- Parent was involved from the start and participated in presentations



Checklist 'Attune & Stimulate'



Expressions of stress of people with severe intellectual disabilities and sensitive caregiving to regulate stress: A qualitative study

Tanja W. M. Doodeman, Carlo Schuengel & Paula S. Sterkenburg

To cite this article: Tanja W. M. Doodeman, Carlo Schuengel & Paula S. Sterkenburg (2022): Expressions of stress of people with severe intellectual disabilities and sensitive caregiving to regulate stress: A qualitative study, *Journal of Intellectual & Developmental Disability*, DOI: [10.3109/13668250.2021.2011171](https://doi.org/10.3109/13668250.2021.2011171)

To link to this article: <https://doi.org/10.3109/13668250.2021.2011171>

Sensitive care-giving



Increasing knowledge on sensitive and responsive caregiving for parents and caregivers through multiple choice questions



Health and Technology (2019) 9:893–901
<https://doi.org/10.1007/s12553-019-00361-0>

ORIGINAL PAPER



Effectiveness of m-learning HiSense APP-ID in enhancing knowledge, empathy, and self-efficacy in caregivers of persons with intellectual disabilities: a randomized controlled trial

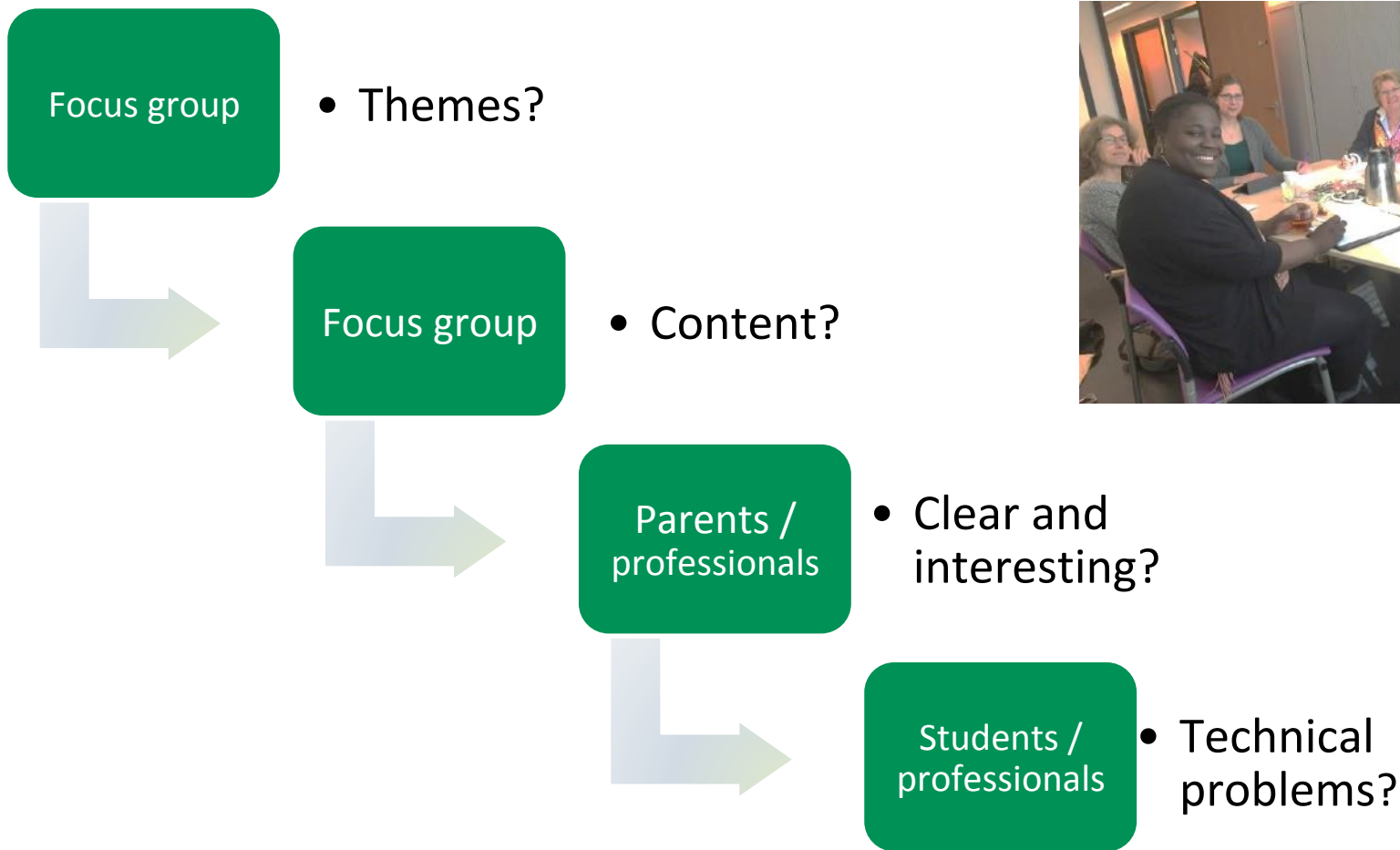
Evelien van Wingerden¹ · Mirjam Wouda² · Paula Sterkenburg^{1,3}

Received: 5 April 2019 / Accepted: 14 August 2019 / Published online: 10 September 2019
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Hi Sense app: development



Stress: Intelligent Sock & Flower app




Received: 28 February 2018 | Revised: 25 January 2019 | Accepted: 4 February 2019

DOI: 10.1111/jar.12581

ORIGINAL ARTICLE

WILEY | 

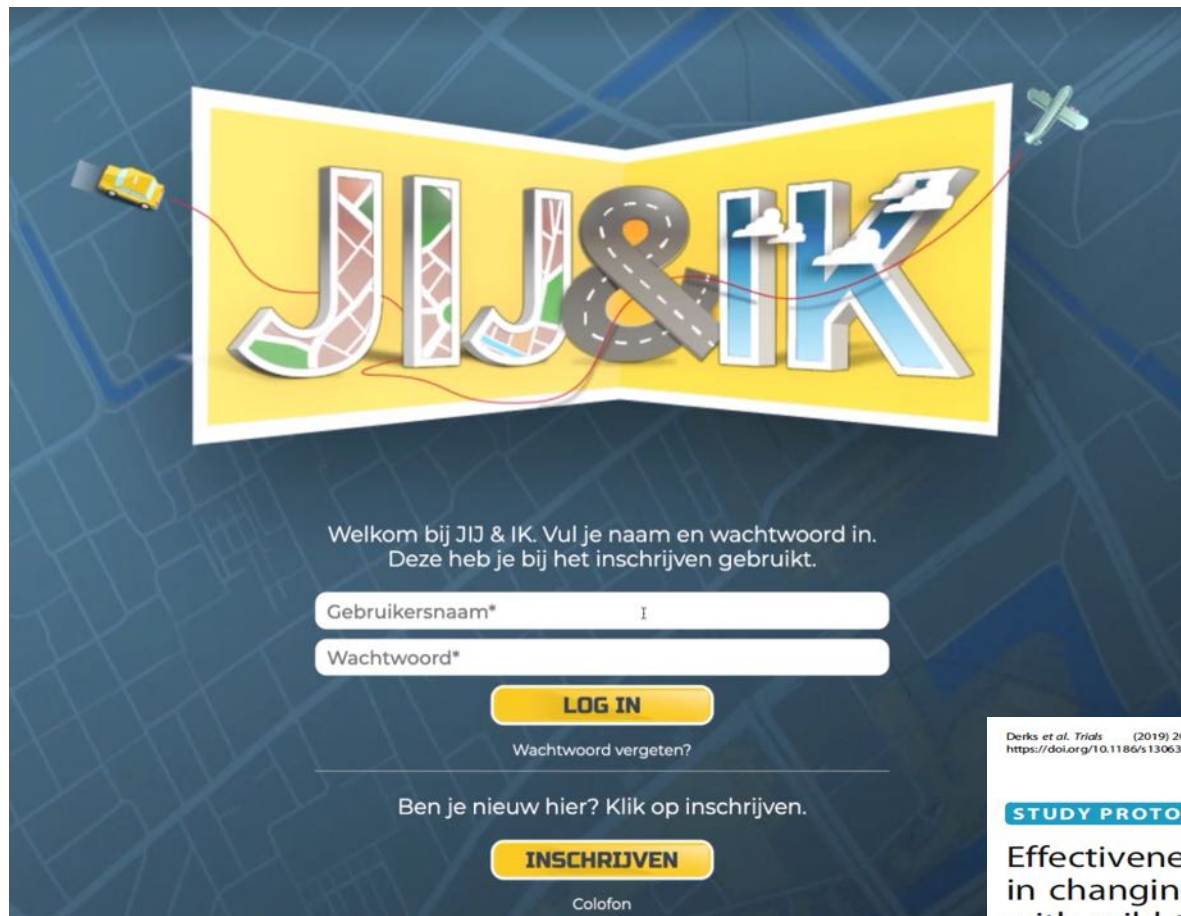
The effects of a bioresponse system on the joint attention behaviour of adults with visual and severe or profound intellectual disabilities and their affective mutuality with their caregivers

Kyra Frederiks^{1,2}  | Paula Sterkenburg^{2,3} | Emilia Barakova¹ | Loe Feijs¹



Sense - a biofeedback system to support the interaction between parents and their child with the Prader-Willi syndrome: a pilot study

'You & I' Stress regulation

Welkom bij JIJ & IK. Vul je naam en wachtwoord in.
Deze heb je bij het inschrijven gebruikt.

Gebruikersnaam*

Wachtwoord*

LOG IN

[Wachtwoord vergeten?](#)

Ben je nieuw hier? Klik op inschrijven.

INSCHRIJVEN

Colofon

Stimulate
mentalizing and
stress regulation
through a game
'You & I' for
adults with ID (IQ
50-85)

Derks et al. *Trials* (2019) 20:500
<https://doi.org/10.1186/s13063-019-3608-9>

Trials

STUDY PROTOCOL

Open Access

Effectiveness of the serious game 'You & I' in changing mentalizing abilities of adults with mild to borderline intellectual disabilities: a parallel superiority randomized controlled trial





Suzanne Derks¹, Suze van Wijngaarden², Mirjam Wouda³, Carlo Schuengel¹ and Paula S. Sterkenburg^{1,4*}

Serious Game 'jij & ik'




Mark and Yvonne are involved as co-researchers in the research of the Serious Game 'You & I'.

The Involvement matrix

Center of Excellence for Rehabilitation Medicine Utrecht




Vereniging van mensen met een lichamelijke handicap

An explanation of the five roles can be found on the next page
Please read the practical guide before using the Involvement Matrix

ROLE IN PROJECT/RESEARCH


	Listener <i>Is given information</i>	Co-thinker <i>Is asked to give opinion</i>	Advisor <i>Gives (un)solicited advice</i>	Partner <i>Works as an equal partner</i>	Decision-maker <i>Takes initiative, (final) decision</i>
STAGE OF PROJECT/RESEARCH	Preparation				
	Execution				
	Implementation				

www.participatiematrix.nl



ACADEMISCHE WERKPLAATS

Bartiméus:

VU  VRIJE UNIVERSITEIT AMSTERDAM

An explanation of the five roles can be found on the next page
Please read the practical guide before using the Involvement Matrix

ROLE IN PROJECT/RESEARCH

INVOLVEMENT MATRIX

Listener

Is given information

Co-thinker

Is asked to give opinion

Advisor

Gives (un)solicited advice

Partner

Works as an equal partner

Decision-maker

Takes initiative, (final) decision



Listener



Co-thinker



Advisor

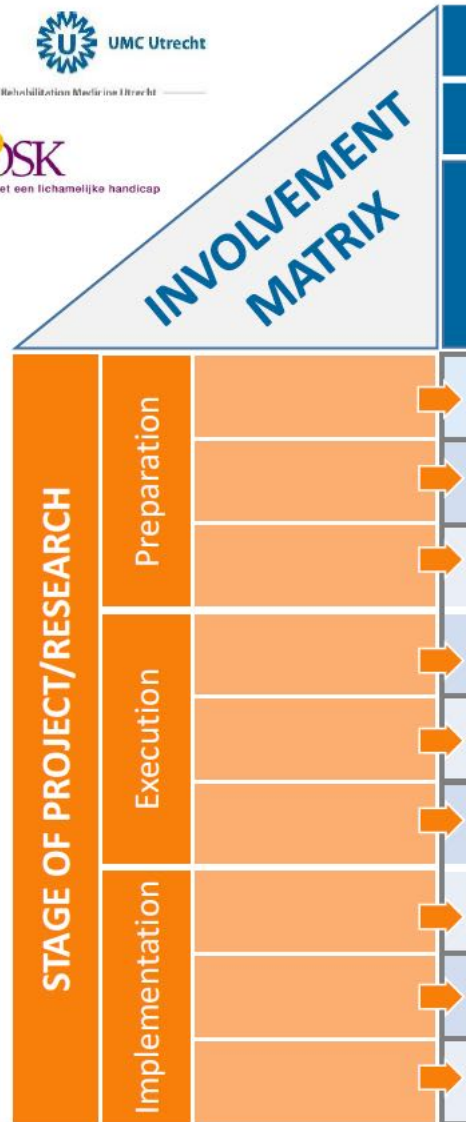


Partner



Decision-maker

INVOLVEMENT MATRIX



Using the participation matrix!



Listener



Co-thinker






Advisor



Partner



Decision-maker

	Listener	Co-thinker	Advisor	Partner	Decision-maker
 Mark	X				
Suze(anne)	X	X	X	X	X
Paula*		X	X	X	X
					
					

- Scientist Practitioner

Execution

INVOLVEMENT MATRIX



Listener



Co-thinker



Advisor



Partner



Decision-maker

	Listener	Co-thinker	Advisor	Partner	Decision-maker
Mark: 1		X	X	X	
Mark: 2	X	X	X	X	X
Mark: 3	X	X		X	
Mark: 4	X	X		X	
Suze(anne)		X	X	X	X
Paula	X	X	X	X	X

1 = Development of intervention; 2 = Data collection;
 3 = Data analyses; 4 = Publications

Implementation

INVOLVEMENT MATRIX



Listener



Co-thinker



Advisor



Partner



Decision-maker

	Listener	Co-thinker	Advisor	Partner	Decision-maker
Mark		X	X	X	X
Suzanne		X	X	X	X
Paula		X	X		X

Implementation: presentations, implementation plan

How do you work together in your team? What do you want to improve?



Listener



Co-thinker






Advisor



Partner



Decision-maker

	Listener	Co-thinker	Advisor	Partner	Decision-maker
					
					
					

Lessens from the past

Start 2016

- We all learn from each other.
- We learn how to collaborate.
- We learn how to participate also in the preparation phase.
- We learn how to be partners.
- We learn how to share the role of decision maker.



Acknowledgements

- www.participatiematrix.nl
- Grand: ZonMW-Gewoon Bijzonder
- Researchers and co-researchers in the research lab: Vrije Universiteit Amsterdam, Ons Tweede Thuis, Bartiméus

Follow our research via:

www.socialerelatiesenict.nl

Thank you!



B:

About co-creation see:

Embregts, P., Moonen, van Putten, & Sterkenburg, P.S. (2021). De waarde van ervaringskennis: *Ervaringen vanuit verschillende Academische Werkplaatsen Verstandelijke Beperkingen*. Tijdschrift voor artsen voor verstandelijk gehandicapten, 39(3), 181-186.

https://nvavg.nl/wp-content/uploads/2021/09/Website_Magazine_NVAVG_NR_3-1.pdf