

Deaf People with cognitive challenges and their mental health now and in the future

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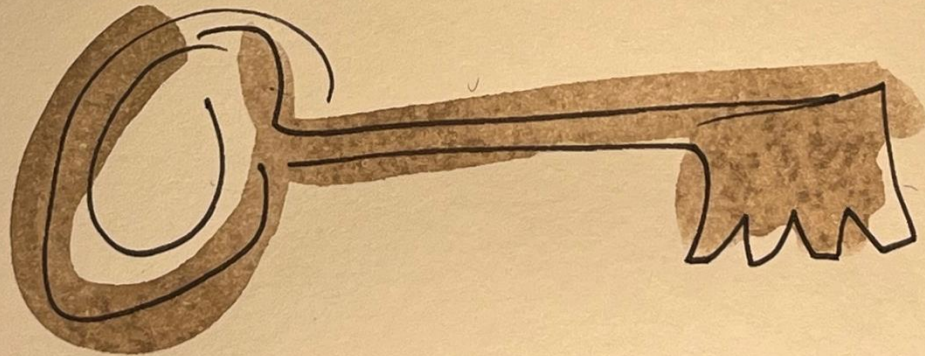




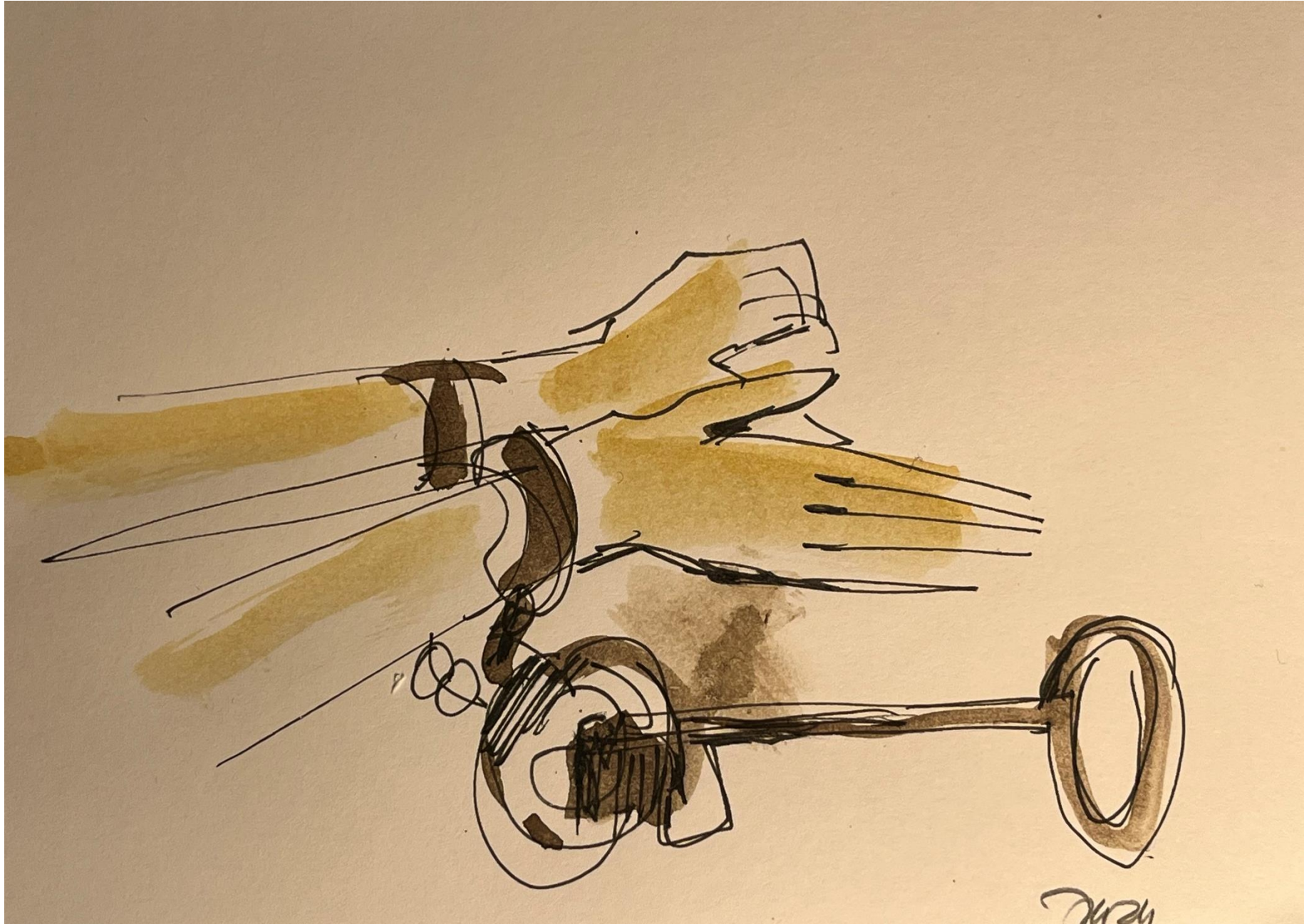


Deaf ~~plus~~

potential
to be
unlocked



ms





Agenda

- I. a. Raising awareness about the high prevalence rates of hearing impairments in people with an intellectual disabilities (ID)
b. Highlighting the specific situations of (prelingually) deaf people with ID;
- II. Addressing the need for multidimensional assessments;
- III. Suggesting how environments can be adapted to the needs of deaf people with ID;
- IV. Indicating how communication abilities of deaf people with ID and their social environment can be improved;
- V. Introducing a therapeutic living community model for deaf people with ID;
- VI. Pointing to important aspects for early intervention and education of children who are deaf and have ID;
- VII. Grounding necessary measures in a human rights foundation



I. Prevalence rates of hearing impairments among people with ID

- In a large epidemiological study in the Netherlands from Splunder et al. (2006) hearing of adults with ID was assessed:
 - 35,8% of the study population had a hearing impairment
 - 47,6% of this group was previously unrecognized
 - 46% of the people with ID had a hearing impairment
- Another study in Austria (Fellinger et al., 2009) helped identify:
 - 46% of the people with ID had a hearing impairment
 - 72,8% of the residents had been previously unrecognised
 - 90,9% of those who were profoundly deaf were the most likely to have been previously known to be deaf by their caregivers
 - 21 % with dual sensory impairment



**About half of the population with ID have hearing impairments
which often remain undetected**

Ia. Prevalence rates of Intellectual Disabilities in people who are prelingually deaf

One out of five individuals who is prelingually deaf has also intellectual disabilities

- In the Metropolitan Atlanta registry, a co-occurrence rate of 23% for ID and 10% with cerebral palsy was found (Centers for Disease Control and Prevention, 2017; Van Naarden Braun et al., 2015).
- A similar rate (22%) of cognitive disabilities were reported by the Gallaudet Research Institute (2008).



Ib. Today's adult population who is prelingually deaf and has ID

- Most likely they experienced severe communication gaps in their early years of life (language deprivation syndrome)
- In many cases hearing loss was detected late in life, hearing technology was hardly efficient and signed communication was not available in the family



Ib. Today's adult population who is prelingually deaf and has ID

- Many of them have no access to sign language and live quite isolated in hearing and speaking environments either with their relatives or in institutions for people with ID
- Miscommunication is frequently the reason for challenging behaviour in this vulnerable population

The interplay between deafness, cognitive abilities, access to specific education based on meeting communication needs and societal attitudes contribute to a large heterogeneity of developmental profiles.

II. Addressing the need for multidimensional assessments

Focus on:

- the preferred mode of communication
- level of cognitive functioning and adaptive skills in various domains
- level of language abilities (signs)
- social communication abilities
- physical health (vision, mobility,...)
- mental state

Assessment tools: Developmental profile

Cognition	Adaptive Behaviour	Language Expressive	Language Receptive	Social Communication	Social & Emotional Development
SON 6-40 Son 24-7 Hawie Lei....	VINELAND 2 VINELAND 3	Language Expressive Language level Proxy (Goldstein & Bebko 2003) KBB	REYNELL adapted for sign language CDI Proxy	Social communication questionnaire (eg. QSC-ID)	SEO SEED
Motoric Development Barthel Index	Social Network	Auditory Functioning OAE Audiometry (eg. Behavioural audiometry)	Visual Functioning (eg. Teller Acuity Cards)		Physical & Mental Health Disorders ADOS

Adaptive behaviours and intellectual functioning

Int J Environ Res Public Health. 2022 Aug 11;19(16):9919. doi: 10.3390/ijerph19169919

Intellectual Disability Profiles, Quality of Life and Maladaptive Behavior in Deaf Adults: An Exploratory Study

Johanna Eisinger¹, Magdalena Dall¹, Jason Fogler^{1 2 3}, Daniel Holzinger^{1 4 5}, Johannes Fellinger^{1 4 6}

Affiliations + expand

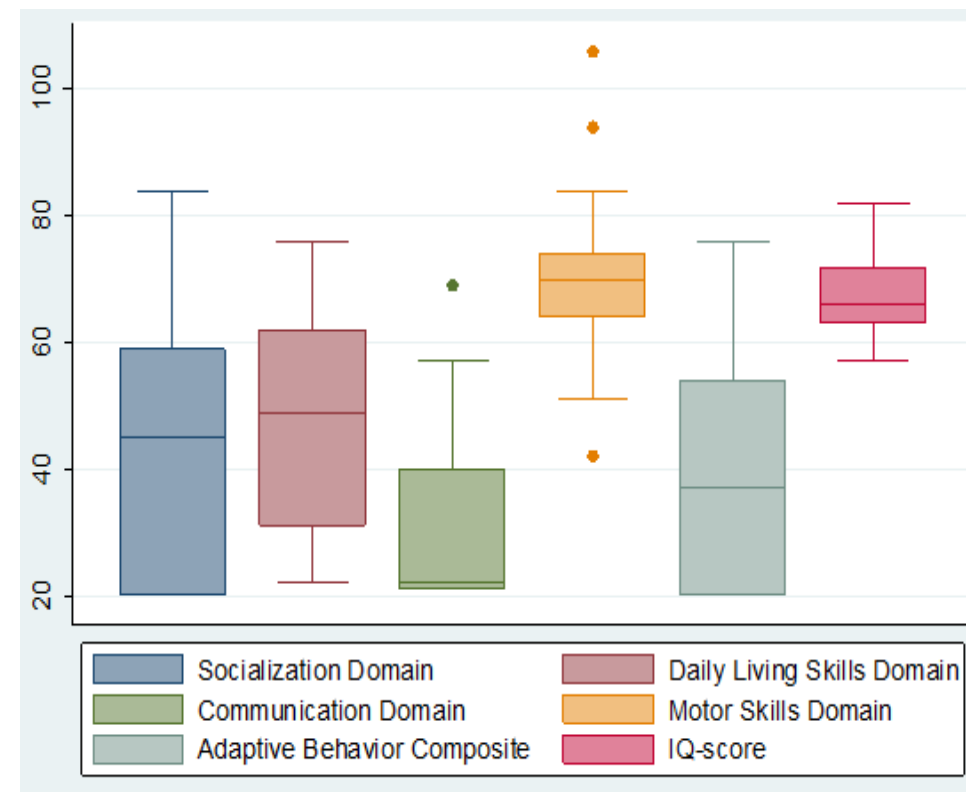
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Abstract

Individuals who are prelingually deaf and have intellectual disabilities experience great challenges in their language, cognitive and social development, leading to heterogeneous profiles of intellectual and adaptive functioning. The present study describes these profiles, paying particular attention to domain discrepancies, and explores their associations with quality of life and maladaptive behavior. Twenty-nine adults with prelingual deafness (31% female) and mild intellectual functioning deficits (mean IQ = 67.3, SD = 6.5) were administered the Vineland Adaptive Behavior Scales-II (VABS-II) and an adapted sign language version of a quality of life scale (EUROHIS-QOL 8). Intellectual disability domain discrepancies were characterized as at least one standard deviation difference between the social domain and IQ and the practical domain and IQ, and a significant difference, according to the VABS-II manual, between the social and practical domains. Domain discrepancies were found between intellectual functioning and both the practical (58.6%) and social domain (65.5%). A discrepancy between intellectual and social functioning was significantly associated with a higher level of internalizing maladaptive behavior ($T = 1.89$, $p < 0.05$). The heterogeneous profiles highlight the importance of comprehensive assessments for adequate service provision.

Keywords: adaptive behavior; deaf; domain discrepancy; intellectual disability; intellectual functioning; maladaptive behavior; quality of life.



n=29 with mild borderline IQ deficits

Challenges in mental state examinations

- Misinterpreting the intensity of visual communication as a correlate for agitation
- Misreading language dysfluency as a thought disorder
- Poor common knowledge mainly due to lack of access to information: not to be seen as a correlate of the level of intelligence

III. Adapting environments to the needs of deaf people with ID

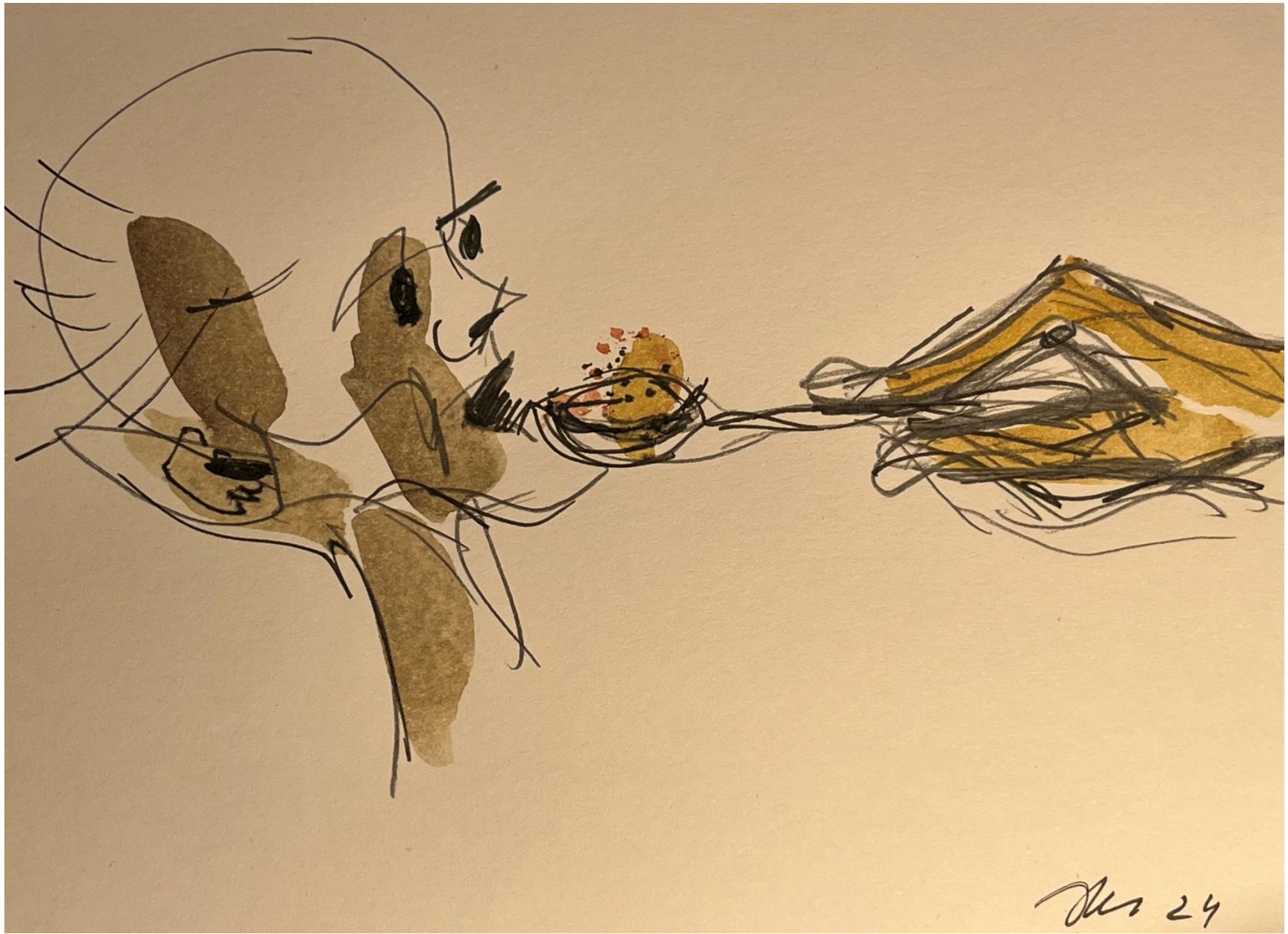
- Announcement strategies and structured schedules



III. Adapting environments to the needs of deaf people with ID

- Acoustical and visually accessible design of the environment





IV. Improving communication abilities and social interaction of deaf people with ID



IV. Improving communication abilities and social interaction of deaf people with ID

✓ Interaction style which fosters the development of communicative abilities:

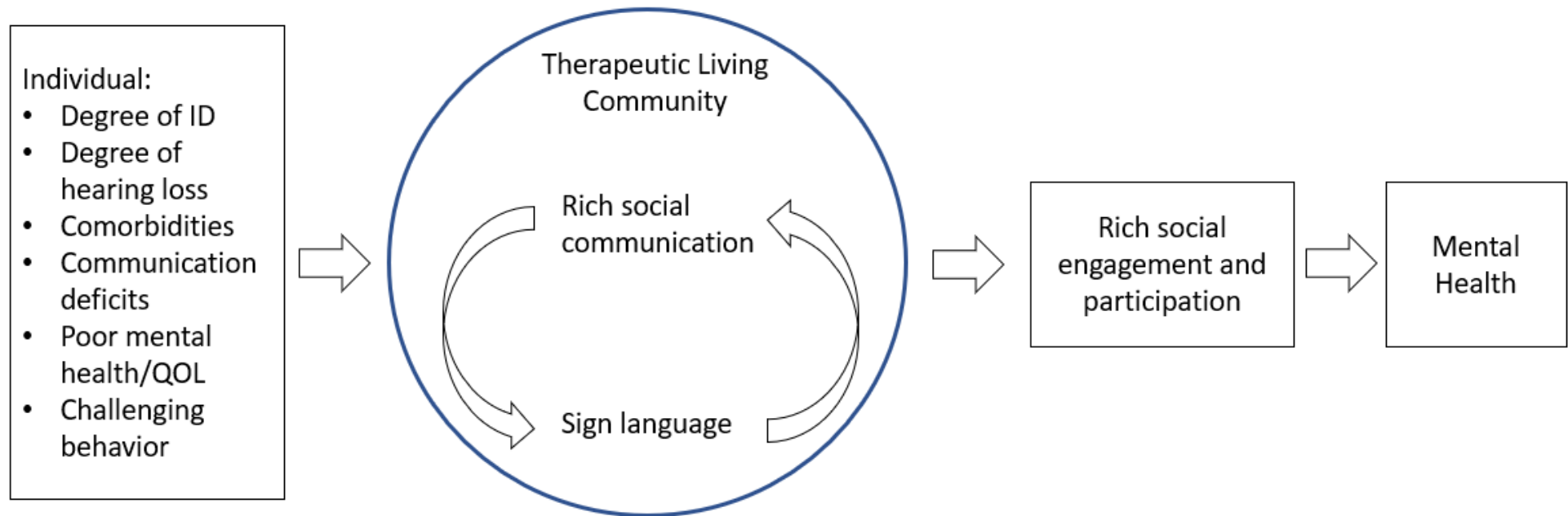
- Develop high sensitivity towards the person who is deaf and has ID by giving enough opportunity to initiate and actively engage in communication
- Respond to the signals when interacting with someone to improve reciprocity and not dominate the conversation by giving them enough time to process the information and to respond.



V. Introducing a therapeutic living community model for deaf people with ID (Lebenswelt)

Conceptual Model

Linking Social Communication and Mental Health



Fellinger J., Dall M., & Holzinger D. (2021). Therapeutic Living Communities for Adults who are Deaf and have Intellectual Disabilities: Development of a Conceptual Model Linking Social Communication and Mental Health. *International Journal of Developmental disabilities*. In press

Lebenswelt – Therapeutic Communities

- Deaf people with ID and other disabilities (deaf-blind) living together in three therapeutic communities based on constant use of sign language and other modes of visual and alternative communication
- Focus on communicative and social development
- Support by professional staff (25% deaf staff)
- Located in the centres of villages
 - *Residential living*
 - *Working facilities*
 - *Therapeutic programs*
- Goal: to increase **Quality of Life & Self-Determination** by improving communication and social skills



Lebenswelt: Achieving the mission

Ensuring and promoting:

- ✓ *Sufficient possibilities to establish social relationships*
- ✓ *An atmosphere of unconditional acceptance, forgiveness and trust*
- ✓ *The social inclusion of the living community in the social life and structure of a village*
- ✓ *Meaningful work*
- ✓ *Availability of visual language (residents and staff members use signed language)*
- ✓ *Recruitment of staff members who are deaf themselves*
- ✓ *Further training of staff members in the social use of language and nonverbal signals (project diaLOG)*

EMPIRICAL MANUSCRIPT

Development of Deaf Adults with Intellectual Disability in a Therapeutic Living Community

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Abstract

People with intellectual disabilities who are deaf face obstacles participating in social environments that do not take into account their need for accessible visual communication. In the present case series, we describe the development of the adaptive skills profiles of eight participants in a fully inclusive therapeutic living community, designed specifically for people with developmental disabilities who are deaf and focused on supporting communication, social relationships, conflict resolution, and work satisfaction. Adaptive skills ratings collected at enrollment and twelve years later suggest increases in social awareness and community living, whereas personal care and homemaking showed relatively little change.

Results

- Positive effects in the individuals' development of social communication, social relationships, and well-being has been observed.
- The outcomes suggest an increase in social awareness and community living abilities



Is it feasible to assess self-reported quality of life in individuals who are deaf and have intellectual disabilities?

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Abstract

Purpose There is consensus that Quality of Life (QOL) should be obtained through self-reports from people with intellectual Disability (ID). Thus far, there have been no attempts to collect self-reported QOL from people who are deaf and have ID.

Methods Based on an established short measure for QOL (EUROHIS-QOL), an adapted easy-to-understand sign language interview was developed and applied in a population ($n=61$) with severe-to-profound hearing loss and mild-to-profound ID. Self-reports were conducted at two time points (t_1 and t_2), 6 months apart. The Stark QOL, an established picture-based questionnaire, was also obtained at t_2 and three Proxy ratings of QOL (from caregivers) were conducted for each participant at t_1 .

Results Self-reported QOL was successfully administered at both time points for 44 individuals with mild and moderate ID (IQ reference age between 3.3 and 11.8 years).

The self-reports showed sufficient test–retest reliability and significant correlations with the Stark QOL. As anticipated, self-reported QOL was higher than proxy-reported QOL. Test–retest reliability and internal consistency were good for self-reported QOL.

Conclusion Reliable and valid self-reports of QOL can be obtained from deaf adults with mild-moderate ID using standard inventories adapted to the linguistic and cognitive level of these individuals.

Results

- high quality of life scores; self-rated quality of life was even higher than the proxy ratings

› [Int J Environ Res Public Health](#). 2022 Aug 11;19(16):9919. doi: 10.3390/ijerph19169919 .

Intellectual Disability Profiles, Quality of Life and Maladaptive Behavior in Deaf Adults: An Exploratory Study

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Abstract

Individuals who are prelingually deaf and have intellectual disabilities experience great challenges in their language, cognitive and social development, leading to heterogeneous profiles of intellectual and adaptive functioning. The present study describes these profiles, paying particular attention to domain discrepancies, and explores their associations with quality of life and maladaptive behavior. Twenty-nine adults with prelingual deafness (31% female) and mild intellectual functioning deficits (mean IQ = 67.3, SD = 6.5) were administered the Vineland Adaptive Behavior Scales-II (VABS-II) and an adapted sign language version of a quality of life scale (EUROHIS-QOL 8). Intellectual disability domain discrepancies were characterized as at least one standard deviation difference between the social domain and IQ and the practical domain and IQ, and a significant difference, according to the VABS-II manual, between the social and practical domains. Domain discrepancies were found between intellectual functioning and both the practical (58.6%) and social domain (65.5%). A discrepancy between intellectual and social functioning was significantly associated with a higher level of internalizing maladaptive behavior ($T = 1.89$, $p < 0.05$). The heterogeneous profiles highlight the importance of comprehensive assessments for adequate service provision.

Keywords: adaptive behavior; deaf; domain discrepancy; intellectual disability; intellectual functioning; maladaptive behavior; quality of life.

Results

- A discrepancy between intellectual and social functioning was significantly associated with more internalizing maladaptive behavior

Exploring spirituality and quality of life in individuals who are deaf and have intellectual disabilities

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Abstract

Purpose: While positive contributions of religion and spirituality (R/S) to quality of life (QOL) are confirmed by a growing body of evidence, only limited research has involved people with intellectual disabilities and so far, no studies included prelingually deaf individuals with intellectual disabilities. This study explores the role of R/S in people with intellectual disabilities and deafness living in three therapeutic living communities specifically adapted to their needs.

Methods: Forty-one individuals (mean age: 46.93 years, 43.9% female) with prelingual deafness and mild to moderate intellectual disability participated in structured sign language interviews adapted to their cognitive-developmental level, regarding their QOL, individual spirituality and participation in spiritual practices in the community. Participants' QOL was assessed with an established short measure for QOL (EUROHIS-QOL) adapted to easy-to-understand sign language. With 21 participants, qualitative interviews were conducted. In addition, proxy ratings from caregivers were obtained.

Results: The participants' ratings of their individual spirituality ($r = 0.334$; $p = 0.03$) and spiritual practices-in-community ($r = 0.514$; $p = 0.00$) correlated positively with their self-reported QOL. Qualitative findings illustrate the importance of R/S and give insights into R/S concepts and practices.

Conclusions: Personal spirituality and participating in spiritual practices are positively related to self-reported quality of life in deaf individuals with intellectual disability (ID). As a consequence, access to spiritual and religious services should be included in comprehensive programs and society at large.

Keywords: Deaf; Intellectual disability; Quality of life; Spirituality and religion.

Results

- Ratings of individual spirituality and spiritual practices-in-community correlated positively with self-reported QOL

Communicative deficits associated with maladaptive behavior in individuals with deafness and special needs

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Abstract

Background: At least one in three individuals who are prelingually deaf has special needs, most commonly due to intellectual disabilities. The scant literature on challenging behavior in this population, however, suggests high rates of prevalence and an important need to better understand the contributing factors.

Aim: We sought to analyze the prevalence of maladaptive behavior and its association with intellectual functioning, adaptive skills, language skills, and social communication in a population of adults with deafness and special needs.

Methods: Participants were 61 individuals from three therapeutic living communities established for people with deafness and special needs. The participants had a mean age of 54.7 years, 64% were male. Intellectual functioning was measured with two versions of the Snijders-Oomen Non-verbal Intelligence Scale. The Vineland-II Scales were used to assess adaptive and maladaptive behavior. Language skills were measured with instruments specifically adapted for this population, including the Reynell Developmental Language Comprehension Scale, the comprehension scale of the Child Development Inventory, and the Profile of Multiple Language Proficiencies. Due to high correlations between instruments, a composite language score was used. A specific questionnaire to measure social communication in adults with intellectual disabilities was also utilized.


Results: The mean nonverbal developmental reference age was 6.5 years, whereas the equivalent for the language measures was about 3.5 years. The prevalence rate of elevated maladaptive behavior was 41% (v -scale score ≥ 18) and 18% of the participants had a clinically significant score (v -scale score ≥ 21). Regression analyses showed that only language and social communication skills were significantly associated with maladaptive behavior, while intellectual functioning and adaptive skills were not.

Conclusion: These findings emphasize the importance of the constant promotion of communicative skills, as those people with better language and social communication skills demonstrate lower levels of maladaptive behavior.

Keywords: deaf; intellectual disabilities; language skills; maladaptive behavior; social communication.

Results

- 59% of the participants had an elevated or highly elevated maladaptive behaviour
- Language and social communication were significantly associated with maladaptive behaviour, while cognition and adaptive behaviour was not

> [J Deaf Stud Deaf Educ.](#) 2021 Sep 15;26(4):556-559. doi: [10.1093/deafed/enab019](#) .

Deaf Residents With Intellectual Disabilities During the First Covid-19 Associated Lockdown

Julia Salzner ¹, Magdalena Dall ², Christoph Weber ^{2 3}, Daniel Holzinger ^{1 2 4}, Johannes Fellinger ^{1 2 5}

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PMID: [34185050](#)  PMCID: [PMC8344832](#)  DOI: [10.1093/deafed/enab019](#) 

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Abstract

Two indicators for stress (mood and aggressive behavior) were evaluated in order to investigate the effect of the restrictions taken against the spread of the coronavirus on people who are deaf and hard of hearing (DHH) and have intellectual disabilities (ID). In three therapeutic living communities, specifically designed for the visual communication needs of people who are DHH and have ID, the mood of the residents is routinely assessed by staff members and every aggressive incident is recorded with the Staff Observation of Aggressions Scale-Revised (SOAS-R). For the 38 residents who were present 8 weeks before the first lockdown (t1) and the following 8 weeks (t2), mood ratings and ratings of aggressive behavior were compared between the two time periods. In contrast to our hypothesis the mood ratings of the residents had a slight significant improvement, whereas the incidents and severity of aggressive behavior did not change significantly. These results suggest that with proper communicative support, individuals who are DHH and have ID can cope effectively with significant restrictions imposed by a pandemic-caused lockdown.

Results

- During the first lockdown, the mood slightly increased while the incidents and severity of aggressive behaviour did not change significantly
- There was a lot of effort to keep up communication and information during this time

VI. Early intervention and education of children who are deaf and have ID

- Opportunities of the new-born hearing screening
- Provision of a medical home
- Family-centred early intervention for deaf children with ID: audiology support and different communication options and opportunities (early planning within the family), including signs, should be made available to the child and the family
- Transition planning includes engagement and contribution of other deaf peers, supporting groups and networks, professionals, education and vocational training systems, local communities and authorities

VII. Grounding necessary measures in a human rights foundation

- Deaf people with ID: particularly vulnerable and at risk of being ‘unheard’, marginalised and excluded from enjoying their rights
- Right to **Communication** is both a basic need and a basic right of all human beings: deeply rooted in the established right to freedom of expression (Article 19, UDHR; Article 19, ICCPR)
- Article 21 of the UNCRPD evokes:
 - freedom of expression and opinion as well as access to information for people with disabilities
 - freedom to seek, receive and impart information and ideas on an equal basis with others and through **all forms of communication** of their choice
 - recognition and promotion of the use of sign languages
- Article 19 of the UNCRPD calls on state parties to take effective and appropriate measures to guarantee the full enjoyment of the right of being included and participating in the community by persons with disabilities.



WORLD FEDERATION
OF THE DEAF

Position Paper on the Social Inclusion of Deaf People with Intellectual Disabilities

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Inclusion
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May 2023

It is an obligation for public stakeholders to promote with concrete actions:

- access for deaf people with ID to big enough networks of people who can communicate with them
- meaningful engagement and social inclusion of the deaf people with ID within the deaf community and the mainstream society
- inclusion of an entire community that is based on the use of sign language in the general society









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