Contextual support and quality of life of individuals with intellectual disability and severe and persistent challenging behaviour

Verhaar, L.

Citation

Verhaar, L. (2025, December 10). *Contextual support and quality of life of individuals with intellectual disability and severe and persistent challenging behaviour*. Retrieved from https://hdl.handle.net/1887/4285137

1

CHAPTER 1

Introduction

In the Netherlands, approximately 120.000 people receive long term care and/or treatment because they have an Intellectual Disability (ID) (CBS, 2024a). Approximately 38% (CBS, 2024a, 2024b) of this population is entitled to more intensive, long term support. These individuals, residing in group homes of specialized service organizations, require long-term 24/7 support, due to intensive support needs in multiple areas of life, in particular because of persistent and severe challenging behaviour (CB). The primary aim of this thesis is to evaluate the effects of contextual support on Quality of life (QoL) in care as usual for people with intellectual disabilities and challenging behaviour, living in residential settings. People with ID have significant limitations both in intellectual functioning *and* adaptive behaviour, i.e. in conceptual, social and practical skills. Professional caretakers of individuals with ID shape support by determining where and how to intervene, to enhance quality of life (QoL). An important challenge includes identifying the key aspects for which this person needs support and choosing the appropriate interventions, bearing in mind their capacities, needs and personal preferences, i.e. person-centered practices (Isvan et al., 2023; NQF, 2025).

Challenging behaviour (CB) is behaviour that is considered culturally abnormal and can cause harm to oneself or others or limits the use of access to the community. Challenging behaviour can occur as a reaction to a mismatch between the capacities of an individual and the environment he or she is living in. An extra complication in caring for individuals with ID is therefore understanding an individual's frustrations or desires that may be expressed through challenging behaviour since verbal expression and understanding one's own needs may be hampered. Furthermore, caretakers of people with CB often find themselves in a difficult balancing act: on the one hand, they try to minimize the risk of the adverse consequences of CB (i.e. safety of others or themselves) and on the other hand they strive to ensure a good quality of life with positive and meaningful experiences. This balancing between turning to restrictive measures and focusing on quality of life can create hesitation about the most appropriate intervention strategies in all caretakers involved in the care.

Vignette: Illustration of daily care challenges

Peter is a 34-year-old man with severe intellectual disability (ID) who lives in a group home with six other persons with severe to moderate intellectual disability. The group home is part of a specialized service organization for people with ID, situated in an area with several group homes and facilities which is also connected to the surrounding community. Peter loves to listen to music and also likes to drive around on his bicycle with a caregiver and likes to visit the petting zoo. However, there has been a long period in which all of these activities were not deemed possible. Peter is known to have unpredictable anger outbursts, in these episodes he damages his properties and/or physically harms his caregivers.

It was hard for his caregivers to figure out how to handle this behaviour. At one point, they noticed they were caught up in a pattern of a heightened focus on trying to avoid the outbursts. This resulted in avoiding almost all meaningful activities for Peter, trying to minimize risk by limiting his engagement with the outside world, by restricting his activities and settings he could have been in, which only increased frustration and further fueled the challenging behaviour. Peter's quality of life diminished, and his favorite bike rides and zoo visits were no longer part of his days, he was spending more and more time in his room – sometimes with the door locked. Support staff was trying to get out of this vicious cycle. Within their multidisciplinary team, they were determined to develop and implement a systematic plan, to step by step create opportunities to influence the context around Peter to help regain his quality of life.

A flash forward to today shows Lauren, his caregiver, starting this Sunday with talking to her team: how was Peter's day yesterday, how was his behaviour during dinner and what could have been triggering his behaviour yesterday or today. They are now very well aware of what influences his feelings of distress since they mapped that out carefully and are better able to support him through the day. Peters' caretakers and his father just evaluated the other day how the preceding period of intense support contributed to better being able to 'read' Peter and to communicate with him. They are planning on going out today, since Peter asked about it early this morning. Lauren and her team are aware of the pitfall of going back to the previous tendency of focusing only on avoiding outbursts. They have learned together what kind of conditions and interventions are helpful in supporting Peter during all kinds of activities. As a consequence, there is a large improvement of Peter's quality of life.

This vignette captures the daily challenges for professionals, showing that determining actions and interventions to improve quality of life can be a complex and multifaceted process. Professionals, together with representatives and the person with ID, are constantly asking themselves how they should intervene. Within a multidisciplinary framework, the emphasis is on identifying the most influential contextual factor through which they can intervene to enhance QoL, while taking into account the individual's abilities, to ensure that the interventions are appropriate. It is recognized that it is often not about one specific intervention but about multiple, integrated contextual interventions where the interaction is more important than the sum of its parts (Knotter, 2019).

The focus of this thesis is therefore to evaluate outcome of contextual interventions for individuals with ID *and* CB, i.e. to evaluate the influence of modifiable contextual factors that can help to enhance QoL. We aim to explore whether approaches that are known to influence QoL in individuals with ID are also effective within this particular group with challenging behaviour. The focus will be on the strategies of personalized support and of supporting communication, that are both known to be effective for the larger population, however, their applicability may vary due to the complexity of the behaviour.

The specialized nature of care for people with ID and CB requires care organizations to also consider various organizational factors and to organize specific knowledge management in order to be able to provide evidence-based person-centered practice, which is scarce for people with persistent and severe CB (Isvan et al., 2023; Kersten, 2024; Lokman et al., 2022; Olivier-Pijpers et al., 2020). This thesis aims to contribute to reducing the gap of knowledge in evidence-based practice.

Quality frameworks exist for the care for people with an intellectual disability – for example the Dutch National Quality Compass for Care for individuals with Intellectual Disabilities (*Kwaliteitskompas Gehandicaptenzorg 2023-2028*, 2023). However, since individuals with ID and CB are specifically at risk for a lower QoL (Smith et al., 2022) it is essential to gain more insight into factors that can contribute to QoL for this group. We aim to specifically evaluate the influence of personalized support, of increased level of support and of strategies for support of communication. The central topic of this thesis therefore is: *Evaluation of contextual factors that are believed to help to shape interventions that improve quality of life for individuals with intellectual disability and severe and persistent challenging behaviour*.

Clinical practice operates in a challenging interplay of negotiating consensus between professional caretakers, family members and the individual involved in deciding the direction of support or intervention to take: Intervention can address a broad range of factors. First, we are interested in whether consensus in personalized support indeed helps to improve quality of life. Second, very often, because of the presence of challenging behaviour, extra funding is requested for these individuals so that extra intensive personal support can be provided. This means more time and resources, but little is known about the effectiveness of this extra intensive support. Furthermore, communication is considered to be an important influential factor in relation to challenging behaviour, but little is known about this relationship in adults with ID who require the most intensive support. Moreover, it is unclear whether strategies to support communication are used for adults with ID and CB in these intensive support settings, and if they are effective for enhancing quality of life.

The following questions will be explored. First we address the question if quality of personalized contextual support, as perceived by the support team, enhances quality of life in adults with ID and severe and persistent CB. Then the question is asked whether extra intensive personal support has a positive effect on quality of life for these individuals? We also explore the association between communication and challenging behaviour in individuals with ID and severe CB? Finally, we explore the contribution of Alternative and Augmentative Communication support to quality of life.

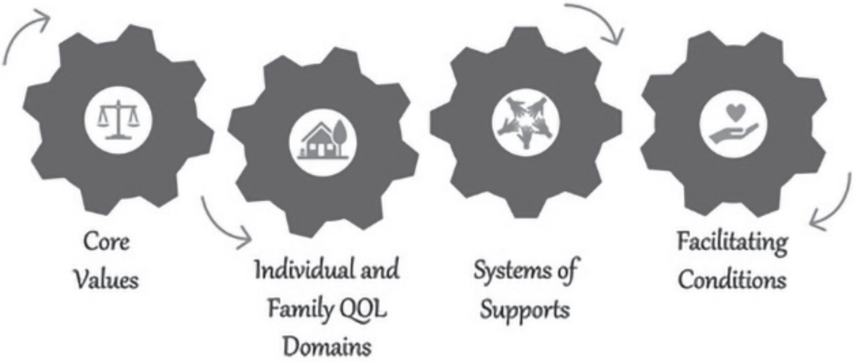
Challenging behaviour

Challenging behaviour is 'culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the persons or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson & Einfeld, 2011, p. 4). Individuals with intellectual disabilities (ID) are at increased risk for challenging behaviour (CB), with prevalence estimates ranging from 2% to 60%, depending on definitions and populations studied (Deb et al., 2022), but with a known consistency over time (Crawford et al., 2019; Thompson et al., 2022; Totsika & Hastings, 2009). More severe challenging behaviour, such as aggression and self-injury, seems to affect a smaller group of the total population of people with ID (10–15%). Challenging behaviour can result in considerable struggles, including social integration difficulties and caregiver stress. More severe challenging behaviour is known to negatively influence quality of life. For example, CB is a large risk factor for involuntary care such as restrictive measures, that staff often sees as unavoidable to cope with challenging behaviour (Spivakovsky et al., 2023) and which can lead to numerous harmful consequences (Allen et al., 2009; Lawrence et al., 2022). Considering the adverse consequences of challenging behaviour and its consequences on quality of life, and the possibility that the care provided does not sufficiently meets the higher level of support that is needed (Friedman, 2021), it is of great importance that professionals that take care of individuals with ID and CB can make well informed decisions to shape the day to day support of individuals with persistent CB in order to improve quality of life.

Factors associated with higher levels of challenging behaviour, such as age, gender, severity of intellectual disability, communication abilities, and co-occurring conditions like autism or ADHD (Bowring et al., 2019) are all more or less unchangeable, which inevitably calls for the investigation of contextual factors that can be influenced to change quality of life. As challenging behaviour is thought to be the result of a mismatch between personal characteristics and the environment (Schalock et al., 2021), professional care is supposed to focus on designing adequate individualized support to lessen the person-environment mismatch. Due to this approach challenging behaviour should diminish and quality of life is expected to improve.

Quality of life

Quality of Life (QoL) is a multidimensional universal concept of overall well-being, composed of core domains that constitute personal wellbeing. It is indicated by physical, emotional and material wellbeing, self-determination, rights, personal development, social inclusion and interpersonal relationships (Schalock et al., 2016; Schalock et al., 2002). Systems of support refer to resources and strategies of support that can buffer possible adverse outcomes on quality of life, targeted support aims at reducing the discrepancy between individual needs and environmental demands by changing relevant contextual factors that may interact with each other (Shogren et al., 2020; Schalock et al., 2021). Support can be offered from different resources, for example one's family network or a professional team. In their Quality of Life Supports Model (QOLSM), Verdugo et al. (2023) integrate the concept of individualized support for people with intellectual disability with the Quality of Life paradigm, see Figure 1. In their four-elements model they visualize a framework which links individual practice to organizational practices and policies. Core values in the QOLSM are linked to quality of life outcomes, and are grounded in the recognition that individuals with intellectual disabilities are full members of society, with equal rights and the need for self-determination. These values guide how support systems are designed and implemented to enhance QoL. Other influential factors in realization of QoL are the facilitating conditions in which support is embedded, like environmental, organisational and systemic factors . These conditions influence both the implementation of support in practice and its impact on meaningful quality of life outcomes (Cavallaro et al., 2025; Gómez et al., 2021; Verdugo et al., 2024).



Note: Quality of Life Supports Model. Reprinted from “A quality of life supports model: Six research-focused steps to evaluate the model and enhance research practices in the field of IDD,” L. E. Gómez,, Schalock, R. L. Schalock, & M. Á. Verdugo (2021). *Research in Developmental Disabilities, 119*, https://doi.org/10.1016/j.ridd.2021.104112.

The relationship between quality of life and adequate support in one’s individual context is well established for people with intellectual disability without challenging behaviour (Schalock et al., 2021) but little is known about this relation for individuals with additional severe and persistent challenging behaviour.

Outline of this thesis

In the first study, described in Chapter 2, we investigate whether perceived quality of intensive personalized contextual support is related to quality of life for individuals with ID and CB. *Contextual support* is defined as support resulting from all efforts of multiple professionals and other significant persons in the living environment of the individual that may shape context (including interventions) for an individual with intellectual disability and challenging behaviour in a setting of long term care, with the goal of improving quality of life, based on an individual support plan (ISP).

In the Netherlands, people with intellectual disability and high support needs due to challenging behaviour are entitled to live in specialized care settings set up by service organizations for people with intellectual disability. The 24/7 intensive care involves the presence of a multidisciplinary support team, including for example specialists regarding specific interventions, such as speech-language, occupational, and psychomotor therapists, physiotherapists, direct caretakers and relatives and/or representatives and at least a psychologist and ID-physician for each individual. Interviews, through Delphi-method, were held with relevant stakeholders to develop an instrument for the assessment of the given contextual support to answer the question whether the appraisal of contextual support by members of the multidisciplinary team and family members of an individual relates to quality of life.

In Chapter 3, the focus is on a specific subgroup of people living in residential settings, namely those who, due to challenging behaviour, present with extra intensive support needs of such intensity and frequency that extra allocation of staff and resources is needed. If the request for extra funding is granted, this funding enables to provide extra intensive personal support. This highest level of support is allocated when the challenging behaviour is not understood, or is considered too intense or resistant to regular support . These extra means are mainly aimed at increasing direct care involvement by allowing more time to be invested through a higher client-direct staff ratio. In regular intensive support, staff ratios are typically 1:3/4, but with this extra allocation reach ratios of 1:1 for a significant portion of the day or the whole day.

The effectiveness of this extra intensive support is hardly studied. In Chapter 3 we aim to answer the question whether extra intensive support helps to improve quality of life, to diminish challenging behaviour, and to improve adaptive functioning in individuals with very severe challenging behaviour.

In Chapters 4 and 5, we will evaluate the relevance of the ability to communicate and to support communication in individuals with challenging behaviour. Individuals with ID have more difficulties in communication (Oliver et al., 2022; Schalock et al., 2021), and the severity of communication difficulties is known to be related to higher levels of challenging behaviour (Bowring et al., 2019; Oliver et al., 2022). The ‘unmet needs’ framework (Cohen-Mansfield, 2013) states that challenging behaviour might be an attempt to communicate ‘a need’ or a distressed emotion. Challenging behaviour may therefore be seen as a last resort of expression when the individual cannot communicate in any other way (NICE, 2015). Following this ‘unmet needs framework’, difficulties in communication (understanding or expressing) are important to examine in relation to challenging behaviour, not only to better understand the function of CB, but also to evaluate whether communication might be an important focus of intervention (Oliver et al., 2022). In Chapter 4 we focus on receptive and expressive communication of individuals with ID and severe CB. This study aims to determine the relative contribution of different aspects of communication to different forms of challenging behaviour.

In Chapter 5 we focus on the evaluation of the contribution of Alternative and Augmentative Communication on adaptive communication, quality of life and challenging behaviour for adults with ID and challenging behaviour in 24/7 intensive support care. Alternative and Augmentative Communication (AAC) is an umbrella term for "support designed to maximize one's communication potential" (Andzik & Chung, 2022, p. 182), in which aided AAC (use of equipment, i.e. pictures, cards, communication boards, electronic communication devices) and unaided AAC (i.e. gestures, sign language) are included.

Chapter 6 summarizes the results of our studies and discusses the impact of our findings.

REFERENCES

Allen, D., Lowe, K., Brophy, S., & Moore, K. (2009). Predictors of restrictive reactive strategy use in people with challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, *22*(2), 159-168. https://doi.org/10.1111/j.1468-3148.2008.00484.x

Andzik, N. R., & Chung, Y. C. (2022). Augmentative and alternative communication for adults with complex communication needs: a review of single-case research. *Communication Disorders Quarterly*, *43*(3), 12.

Bowring, D. L., Painter, J., & Hastings, R. P. (2019). Prevalence of challenging behaviour in adults with intellectual disabilities, correlates, and association with mental health. *Current Developmental Disorders Reports*, *6*(4), 173-181. https://doi.org/10.1007/s40474-019-00175-9

Cavallaro, R., Carollo, A., Balboni, G., Gómez, L. E., Dimitriou, D., & Esposito, G. (2025). Beyond disability: A scientometric review of quality of life in developmental disabilities. *Research in Developmental Disabilities*, *158*. https://doi.org/https://doi.org/10.1016/j.ridd.2025.104919

CBS. (2024a). *Personen met indicatie naar gebruik Wlz-zorg; indicatie, leveringsvorm, zzp [Indicatie grondslag: Totaal personen, Periode: 2022]*. Centraal Bureau voor de Statistiek. Retrieved November 21 from https://www.cbs.nl/nl-nl/cijfers/detail/84529NED?q=vg6%20vg7

CBS. (2024b). *Personen met indicatie naar gebruik Wlz-zorg; indicatie, leveringsvorm, zzp [leveringsvorm zorg: totaal leveringsvorm zorg, periode 2022]*. Centraal Bureau voor de Statistiek. Retrieved November 21 from https://www.cbs.nl/nl-nl/cijfers/detail/84529NED

Cohen-Mansfield, J. (2013). Nonpharmacologic treatment of behavioral disorders in dementia. *Current Treatment Options in Neurology*, *15*, 765-785.

Crawford, H., Karakatsani, E., Singla, G., & Oliver, C. (2019). The persistence of self-injurious and aggressive behavior in males with Fragile X Syndrome over 8 years: A longitudinal study of prevalence and predictive risk markers. *Journal of Autism and Developmental Disorders*, *49*(7), 2913-2922. https://doi.org/10.1007/s10803-019-04002-3

Deb, S., Unwin, G., Cooper, S., & Rojahn, J. (2022). Problem behaviours. In: Bertelli, M.O., Deb, S., Munir, K., Hassiotis, A., Salvador-Carulla, L. (eds) *Textbook of Psychiatry for Intellectual Disability and Autism Spectrum Disorder* (pp. 145-185). Springer, Cham.

Emerson, E., & Einfeld, S. L. (2011). *Challenging behaviour*. Cambridge University Press.

Friedman, C. (2021). The impact of human service provider quality on the personal outcomes of people with intellectual and developmental disabilities. *Frontiers in Rehabilitation Sciences*, *2*, 780168. https://doi.org/10.3389/fresc.2021.780168

Gómez, L. E., Schalock, R. L., & Verdugo, M. A. (2021). A new paradigm in the field of intellectual and developmental disabilities: Characteristics and evaluation. *Psicothema*, *33*(1), 28-35. https://doi.org/10.7334/psicothema2020.385

Isvan, N., Bonardi, A., & Hiersteiner, D. (2023). Effects of person-centred planning and practices on the health and well-being of adults with intellectual and developmental disabilities: a multilevel analysis of linked administrative and survey data. *Journal of Intellectual & Developmental Disability*, *67*(12), 1249-1269. https://doi.org/10.1111/jir.13015

Kersten, M. C. O. (2024). *Making knowledge work: Factors, strategies and leadership to improve sharing and application of knowledge in the care and support for people with intellectual disabilities*. Tilburg, Tilburg University.

Knotter, M. H. (2019). *The whole is more: A contextual perspective on attitudes and reactions of staff towards aggressive behaviour of clients with ID in residential institutions*. Amsterdam, Universiteit van Amsterdam.

Kwaliteitskompas Gehandicaptenzorg 2023-2028. (2023). Vereniging Gehandicaptenzorg Nederland. Retrieved October 24 from https://www.vgn.nl/system/files/2023-08/kwaliteitskompas-GHZ_augustus2023_DEF.pdf

Lawrence, D., Bagshaw, R., Stubbings, D., & Watt, A. (2022). Restrictive practices in adult secure mental health services: A scoping review. *International Journal of Forensic Mental Health*, *21*(1), 68-88. https://doi.org/10.1080/14999013.2021.1887978

Lokman, S., van Oorsouw, W., Didden, R., & Embregts, P. (2022). Setting up a new team of support staff for people with mild intellectual disability or borderline intellectual functioning and severe challenging behaviour: A concept mapping study. *Journal of Applied Research in Intellectual Disabilities*, *35*(6), 1348-1359. https://doi.org/10.1111/jar.13023

NICE. (2015). *Challenging behaviour and learning disabilities: Prevention and interventions for people with learning disabilities whose behaviour challenges (NICE guideline 11)*. London: National Institute for Health and Care Excellence (NICE) Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK305019/

NQF. (2025). *Person centered planning and practice - Final report*. National Quality Forum. Retrieved March 7 from http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx

Oliver, C., Ellis, K., Agar, G., Bissell, S., Chung, J. C. Y., Crawford, H., Pearson, E., Wade, K., Waite, J., & Allen, D. (2022). Distress and challenging behavior in people with profound or severe intellectual disability and complex needs: Assessment of causes and evaluation of intervention outcomes. In *Contemporary Issues in Evaluating Treatment Outcomes in Neurodevelopmental Disorders* (pp. 109-189). Academic Press Inc.

Olivier-Pijpers, V. C., Cramm, J. M., & Nieboer, A. P. (2020). Cross-sectional investigation of relationships between the organisational environment and challenging behaviours in support services for residents with intellectual disabilities. *Heliyon*, *6*(8), e04751. https://doi.org/10.1016/j.heliyon.2020.e04751

Schalock, R., Verdugo, M. A., Gomez, L., & Reinders, H. S. (2016). Moving us toward a theory of individual quality of life. *American journal on intellectual and developmental disabilities*, *121*(1), 1-12.

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). *Intellectual disability: Definition, diagnosis, classification, and systems of supports* (12 ed.). American Association on Intellectual and Developmental Disabilities.

Schalock, R. L., Verdugo, M., & Braddock, D. L. (2002). *Handbook on quality of life for human service practitioners*. American Association on Mental Retardation.

Shogren, K. A., Luckasson, R., & Schalock, R. L. (2020). Using a multidimensional model to analyze context and enhance personal outcomes. *Intellectual and Developmental Disabilities*, *58*(2), 95-110. https://doi.org/10.1352/1934-9556-58.2.95

Smith, J., Baksh, R. A., Hassiotis, A., Sheehan, R., Ke, C. C., Wong, T. L. B., Strydom, A., & Investigators, P. (2022). Aggressive challenging behavior in adults with intellectual disability: An electronic register-based cohort study of clinical outcome and service use. *European Psychiatry*, *65*(1). https://doi.org/10.1192/j.eurpsy.2022.2336

Spivakovsky, C., Steele, L., & Wadiwel, D. (2023). *Restrictive practices: A pathway to elimination*. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Thompson, T. J., Walker, M. W., LeBoeuf, J. B., Simeonsson, R. J., & Karakul, E. (2022). Chronicity of challenging behaviors in persons with severe/profound intellectual disabilities who received active treatment during a 20-Year period. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(2), 162-170. https://doi.org/10.1111/jppi.12395

Totsika, V., & Hastings, R. P. (2009). Persistent challenging behaviour in people with an intellectual disability. *Current Opinion in Psychiatry*, *22*(5), 437-441.

Verdugo, M. A., Schalock, R. L., & Gómez, L. E. (2024). The Quality of Life Supports Model as a major component in applying the quality of life paradigm. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1). https://doi.org/10.1111/jppi.12468