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

Version: Publisher's Version

License: [Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden]

Downloaded from: [https://hdl.handle.net/1887/4285137]

Note: To cite this publication please use the final published version (if applicable).

Contextual Support and Quality of Life of Individuals with Intellectual Disability and Severe and Persistent Challenging Behaviour

Linda Verhaar

Linda Verhaar, MSc.

Contextual Support and Quality of Life of Individuals with Intellectual Disability and Severe and Persistent Challenging Behaviour

Leiden University
Faculty of Social and Behavioral Sciences
Clinical Neurodevelopmental Sciences

The research reported in this dissertation was funded by a consortium of four specialized service organizations in care for individuals with intellectual disabilities and persistent challenging behaviour in the Netherlands (SCORE, Systematic Client Support Result Evaluation), i.e. Ipse de Bruggen, De Hartekamp Groep, Cordaan, and Ons Tweede Thuis.

Design/lay-out
Two paintings by M. de Block
Design cover: L. Verhaar
The cover art is a combination of two paintings made in different phases of life by a woman with intellectual disability and intensive support needs. This artwork reflects quality of life both in flourishing flowers and in art that took another form in more fragile times.

Lay-out: Parntawan Kidtam | www.ridderprint.nl
Print: Ridderprint | www.ridderprint.nl

© Copyright 2025: Linda Verhaar, The Netherlands
All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, by photocopying, recording, or otherwise, without the prior written permission of the author.

Contextual Support and Quality of Life of Individuals with Intellectual Disability and Severe and Persistent Challenging Behaviour

Proefschrift

ter verkrijging van
de graad van doctor aan de Universiteit Leiden,
op gezag van rector magnificus prof.dr.ir. H. Bijl,
volgens besluit van het college voor
promoties te verdedigen op woensdag 10 december 2025
klokke 11.30 uur

door
Linda Verhaar
geboren in 1986

Promotor:
Prof.dr. H. (Hanna) Swaab

Co-promotores:
Dr. Y.M. (Yvette) Dijkxhoorn
Dr.ir. L.M.J. (Leo) de Sonneville

Promotiecommissie:

Prof.dr. L.R.A. (Lenneke) Alink	Wetenschappelijk Directeur Instituut Pedagogische Wetenschappen/voorzitter
Prof.dr. M.V. (Maretha) de Jonge	
Prof.dr. W.G. (Wouter) Staal	
Dr. S. (Sophie) van Rijn	
Prof.dr. P.J.C.M (Petri) Embregts	Tilburg University
Prof.dr. H.C.M. (Robert) Didden	Radboud University

TABLE OF CONTENTS

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.

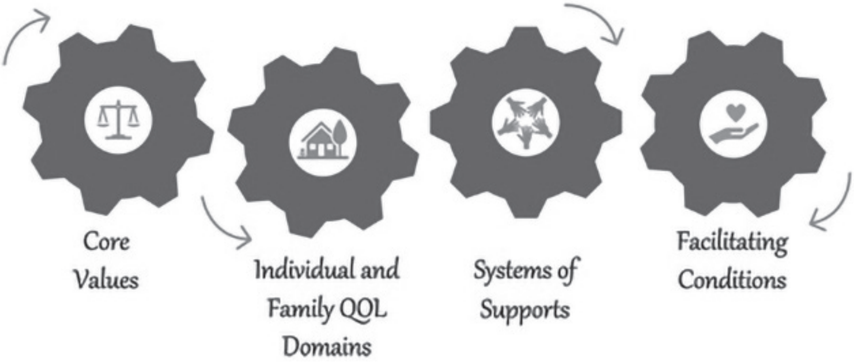
Challenging behaviour

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

CHAPTER 2

The impact of personalized contextual support on quality of life of Dutch persons with intellectual disability and severe challenging behaviour

Published as:
Verhaar, L., Dijkxhoorn, Y. M., de Sonneville, L.M.J., & Swaab, H. (2024). The impact of personalised contextual support on quality of life of Dutch persons with intellectual disability and severe challenging behaviour. *International Journal of Developmental Disabilities*, 1-10. https://doi.org/10.1080/20473869.2024.2428892

ABSTRACT

Individuals with intellectual disability (ID) and severe challenging behaviour (CB) often permanently reside in group homes that offer intensive daily support. In order to assure quality of life, support is individually tailored by shaping the context, based on personal needs. This cross-sectional study investigates whether the appraisal of intensive personalized contextual support is associated with level of quality of life (San Martin Scale), taking into account the impact of challenging behaviour (Developmental Behaviour Checklist-Adults). The support teams (direct caretakers, psychologists, legal representatives) of N=196 people with ID and CB in four service organizations in the Netherlands were asked to appraise the personal fit of the contextual support through structured interview questions. Regression analysis showed that higher appraisal of contextual support was related to higher quality of life. This relationship was stronger if challenging behaviour was less severe. The finding emphasizes the relevance of personalized contextual support in shaping quality of life for individuals with intellectual disability and challenging behaviour.

The Impact of Personalized Contextual Support on Quality of Life of Dutch Persons with Intellectual Disability and Severe Challenging Behaviour

An individual with intellectual disability (ID) typically needs support in multiple domains of daily functioning in order to preserve quality of life (QoL) (Schalock et al., 2021; Shogren et al., 2015). Within the framework of the American Association of Intellectual and Developmental Disabilities (AAIDD), it is proposed that support can buffer the possible adverse outcomes in daily functioning that people with intellectual disability may face and which may result in a lower quality of life (Schalock et al., 2021). Systems of support include a broad range of resources that can be used to contribute to an individual’s wellbeing (Gómez et al., 2021; Verdugo et al., 2024). Professionals participating in this system of support typically base their focus of personal intervention on their assessment of an individuals’ profile of needs according to the five dimensions of human functioning that are defined by the AAIDD model, i.e. (1) intellectual ability, (2) adaptive behaviour, (3) societal participation, (4) health and (5) context, referring to demands and resources of the direct environment (Schalock et al., 2021).

Challenging behaviour is defined as ‘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). The prevalence of challenging behaviour in people with intellectual disability is estimated to be between 2% to 60%, and more severe challenging behaviour is observed in 10-15% of the population (Deb et al., 2022). Individuals with intellectual disability who show severe challenging behaviour are at high risk for problems in daily functioning that may compromise quality of life (Smith et al., 2022). Severe challenging behaviour is known to be highly persistent (Thompson et al., 2022; Totsika & Hastings, 2009). If severe challenging behaviour is present, long term stay (24/7) in specialized intensive support settings is often indicated, since people with intellectual disability and severe challenging behaviour often show intensive support needs (Embregts et al., 2023). If so, all aspects of support should be intensified in order to meet a person’s needs. Guidelines for disentangling challenging behaviour are used to shape support and highlight that a multidisciplinary support team is necessary for indication and implementation (Embregts et al., 2019; NICE, 2015) As part of the method, professional caretakers in a multidisciplinary team regularly have to adapt supportive intervention strategies to what the individual with intellectual disability wants and needs, based on assessment according to the AAIDD domains. All dimensions of the AAIDD model interact and can change, while people with challenging behaviour seem to be especially vulnerable for these changes, which can result in changes in challenging behaviour that may threaten quality of life. For example, physical health status (i.e. illness, pain) may have a direct impact on challenging behaviour (Oliver et al., 2022). The absence of a social network (Bele & Kvalsund, 2016), or lack of engagement in a meaningful occupation, could negatively influence challenging behaviour as well (Ball & Fazil, 2013). Since profound knowledge of a broad range of domains of personal functioning is needed to understand an individuals' support needs, a multidisciplinary support team contributes to an individuals' support plan (ISP), in which the specifics of the contextual support for a given period of time is documented, with the aim of improving an individuals' quality of life in a specific timeframe (Buntinx et al., 2012; Buntinx & Schalock, 2010). This support team is typically composed of direct caretakers, relatives and/or representatives, location management, and other care professionals (such as at least a physician, a psychologist or a pedagogue or specialists regarding specific interventions, such as speech therapist, occupational therapist, psychomotor therapist, physiotherapist). If possible, the support team interacts with the individual with ID during design of the personal support.

With regard to facilitating conditions (Verdugo et al., 2024), since elements within the service organization should not be overlooked as potential causal or maintaining factors in CB, management is involved in the support team. For example, when staff turnover, authentic leadership, or ability to implement working methods are better organized within the service organization, less challenging behaviour is observed (Olivier-Pijpers et al., 2020).

Contextual support in this study is therefore defined as resulting from all efforts of a diversity of 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 the setting of long term care, with the goal of improving quality of life, based on a personal support plan. Interventions are typically focused on training and practice or practical support of professionals such as speech/language therapists, occupational therapists, psychomotor therapists, physiotherapists, or experts in individual psychotherapy. In contextual support the central issue is enhancing daily functioning. After reaching consensus among involved carers, the context of an individual is adjusted to his or her needs, for example by designing one's vocational program, facilitating emotional development, shaping meaningful interactions or adjusting the physical context to one's needs. Contextual support is considered the sum of all these interventions together, derived by consensus within multidisciplinary teams of carers.

The relationship between adequate support and higher quality of life is well established for people with intellectual disability without challenging behaviour (Schalock et al., 2021). For people with severe challenging behaviour however, it is important to enhance our understanding of the relationship between long-term contextual support and quality of life. One might expect that challenging behaviour in itself may result in prioritizing the management of challenging behaviour on the cost of direct focus on quality of life (Morisse & Dosen, 2017).

In this study, the question is addressed whether there is a relationship between success of contextual support, as appraised by the support team and family members, and quality of life for individuals who permanently reside in an intensive support setting in the Netherlands. It is hypothesized that higher satisfaction regarding the organization and provision of contextual support in their service organization correlates positively with quality of life of these individuals with intellectual disability and severe challenging behaviour (Bowring et al., 2019), although the intensity of challenging behaviour may interfere with this relation.

METHOD

Procedure

Data used in this study were collected in the first wave [2017-2018] of a large longitudinal project to evaluate the care for people with intellectual disability and persistent challenging behaviour, living in group homes [*SCORE project*]. Four service organizations for people with intellectual disability participated in this study (Ipse de Bruggen, de Hartekamp Groep, Cordaan and Ons Tweede Thuis). Participants all reside in group homes in residential care facilities, where they receive 24-hour care to support in all areas of living, by a specialized support team. Typically, in intensive support the client-direct caretaker ratio is 4/3:1.

Ethical approval for the study was granted by the ethics committee of the Faculty of Social and Behavioural Sciences, Department of Clinical Neurodevelopmental Sciences, University of Leiden, The Netherlands (ECPW-2015/094), and the ethical committee of the largest participating service organization (Ipse de Bruggen).

Participants

Persons and their support teams were eligible for inclusion when individuals met the following criteria: adults with an intellectual disability, living in residential care facilities in group homes, and having a very intensive support need due to severe challenging behaviour, leaving out those who needed intensive support primarily because of an indication based on multiple (neuromotor/ sensory) disabilities. Severe challenging behaviour in this population implies persistency of challenging behaviour of at least two years.

Candidates eligible for inclusion (*N*=543) and their legal representatives were invited to participate in the study. Legal representatives (and where applicable, the person with ID themselves) were informed about the study by written and online information and asked for informed consent. Seventy percent of the candidates of the four service organizations responded to the invitation (*N*=381) of which *N*=92 (24.4%) declined participation after receiving information and *N*=289 agreed to participate.

N=56 participants dropped out during the course of the study, due to e.g. moving to another service organization, illness or death, logistic problems within the support team, or withdrawal of consent. Participants were only included when results of all questionnaires and interviews were available. This resulted in a further loss of *N=37* participants, due to not returned questionnaires or interview planning difficulties resulting in a total of *N*=196 participants (68% male), mean age 41.95 years (*SD*=14.6, range 18-77).

It is common practice in the Netherlands that within long-term care, family members are included in the core team and are structurally involved in making decisions regarding care for an individual, and thus in designing the contextual support of an individual with ID. Family members often are appointed by court to function as mentor or guardian, which emphasizes their structural involvement in the care process. The validation of their role is grounded in legal and ethical guidelines that mandate their involvement. When referring to “family members” throughout this manuscript, we also mean legal representatives appointed by law, who are often family members, or are appointed when no family is present. Family members are regarded as equal partners in the care process. Their contributions are considered important and valued, ensuring an inclusive approach to decision-making. This equality of opinions is fundamental to our clinical practice as it ensures that all perspectives are considered and respected in the appraisal process.

Measures

Quality of Life

The San Martin Scale (SMS) (Verdugo et al., 2014) was used to measure quality of life (QoL). The SMS contains 95 items, providing scores on eight domains, based on the Quality of Life framework by Schalock et al. (2002). The San Martin Scale has a good reliability and validity (construct, convergent and divergent) for persons with an intensive support need and different levels of intellectual abilities (Verdugo et al., 2014), including relatively higher ID-levels which allowed comparisons to be made across different levels of ID (Verdugo et al., 2014, Navas et al., 2023, Traina et al., 2022). Cronbach's alpha ranges from .82 to.93 (domains) and .97 (total score) (Verdugo et al., 2014).

Domains included are Self-Determination, Emotional Well-being, Physical Well-being, Material Well-being, Rights, Personal Development, Social Inclusion, and Interpersonal Relations. The SMS is completed by a caretaker who knows the participant best. Items are statements about the participant's life scored on a 4-point Likert scale, ranging from 'never (1)' to 'always (4)'. Item scores result in eight different quality of life domain scores and a Total QoL Score, all converted to Mean Item Scores (MIS).

Example items are "He/she has the opportunity to deny doing certain activities that are irrelevant to his health (e.g., partake in leisure activities, go to sleep at a certain time, wear the clothes that other choose)" (Self-Determination), "The person is previously informed about changes in the person that provides support (e.g., due to shifts, leaves, vacations, familial situations, etc.)" (Emotional Well Being), "Has adequate hygiene (e.g., teeth, hair, nails, body) and self-presentation (e.g., clothes that are adequate for his age, for the occasion etc.)" (Physical Well-being), "He/she has his own material possessions to entertain himself (e.g., games, magazines, music, television, etc.)" (Material Well-being), "His/her rights are defended and respected (e.g. confidentiality, information about his/her rights as users, etc.)" (Rights), "He/she is provided with new instructions and models to learn new things" (Self Development), "Participates in inclusive activities that interest him/her” (Social Inclusion), “He/she has the opportunity to meet people outside from the support group” (Interpersonal Relationships).

Challenging Behaviour

The Developmental Behaviour Checklist-Adults (DBC-A) is a carer-completed 107-item questionnaire that assesses a comprehensive range of emotional, behavioural and mental health problems in adults with mild, moderate and more severe levels of intellectual disability (Mohr et al., 2005; Mohr et al., 2011; Mohr et al., 2012). Direct caretakers were asked to fill out the questionnaire, rating the answer to each item with ‘never (0)’, ‘sometimes (1)’ or ‘often/frequent (2)’. In this study the total composite score, i.e., a Mean Item Score (MIS) of the DBC-A Total challenging behaviour score, was used as a measure of challenging behaviour (CB), a higher score denoting more CB. The DBC-A is a reliable and internally consistent instrument with Cronbach’s alpha for the total score of α = .95 indicating a high level of internal consistency and for the subscales α ranges from .71 - .91, indicating good to high internal consistency (Mohr et al., 2011).

Individualized Contextual Support Appraisal

To capture the full picture of these individuals’ contextual support, the support team (professionals and family members together) serves as the primary source for mapping a comprehensive overview of an individual’s situation. The support team will be asked through interview questions about the organization of support and their appraisal of the provision of contextual support.

By Delphi approach, first a set of interview questions was constructed. First of all, multiple focus groups within all participating service organizations were organized with representatives of the professional members of support teams (manager, physician, speech therapists, occupational therapist, direct caretakers, psychologist/orthopedagogue, psychomotor therapist) and individuals with ID and their family members themselves about what topics they deemed relevant and distinctive for providing good care specifically for this highly complex group of individuals with ID and severe CB. In other words, what do they consider necessary facilitating conditions for contextual support for this population. We specifically highlight the participation of persons with ID themselves in the focus groups, in order to optimize their connection with issues important to them in their contextual support and to be able to include these issues in our analyses and final interview

The meetings with these focus groups were analysed and resulted in a categorization of relevant elements for providing contextual support: Housing Support, Communication Support, Supporting Positive Relationships, Supporting Self Determination, Physical Health Support, Knowledge Support and Support of Predictability in Daily Routines, each topic containing rich information on conditions that should be present in order to provide good care. This information was – per topic – further structured whether relating to conditions of the micro, meso, exo or macro system (Bronfenbrenner & Morris, 2006), to be able to structurally present them in an interview. Information on each topic was constructed into (Likert-scale) interview questions. Afterwards, a few rounds of consensus meetings regarding the construction and formulation of these items resulted in a final set of interview questions.

A delegation of members of direct support teams (a direct caretaker, their primary psychologist/pedagogue and a family member/representative), well aware of the daily condition and situation, were then interviewed. For every participant, we selected the same roles. For every participant, the interview was held when we could interview these same three roles. The most important direct caretaker fulfilled the role of primary care coordinator. This caretaker is in charge of the planning, coordinating and maintaining oversight of all aspects of daily caretaking. Next to that, we interviewed always the primary psychologist/ pedagogue, who typically acts as a treatment coordinator, overseeing all contextual and therapeutic interventions. Interviewing these two roles plus a family member made sure we interviewed the three people standing closest to this person and collectively representing the best understanding of an individual's needs, preferences and context.

For the interview we used the set of constructed interview questions pertaining to all defined topics of contextual support to jointly appraise the organization and provision of contextual support for each individual. This support team delegation was also asked to discuss each item (total of 82 items) and come to a consensus score, based on the last three months.

We attempted to achieve consensus-based decision-making based on multiple perspectives. We aimed to increase the level of objectivity with this consensus rating approach as it involves multiple persons discussing and reaching an agreement on each criterion, ensuring that the appraisal reflects a collective viewpoint rather than an individual one. However, multiple perspectives are still subjective. This method, however helps to balance personal biases and provides a more comprehensive evaluation of care as usual – which is our aim.

Table 1

Contextual Support Appraisal: domains and examples of interview questions. Rating 1-5 on each question, higher appraisal meaning a higher appraisal from multiple perspectives of the quality of contextual care.

Domain (no. of items)	***Example items (three of each domain)***
Housing Support (14)	- The dynamics within the group home is matching with this individuals' needs - Physical surroundings are adjusted by the support team to the individuals' needs - The support team is able to facilitate distance or proximity, according to this individuals' needs
Communication Support (9)	- All support teams use the same (augmentative and alternative) communication (AAC). - Support team members have access to materials and knowledge of different forms of AAC - Communication in support team between professionals and family/legal representatives is considered adequate
Supporting Positive Relationships(17)	- Professional support team members and legal representatives have a trusting relationship. - Support team members feel safe when working at the group home - Support team members feel supported by management in their daily work
Supporting Self Determination (16)	- The support team is able to create intervention targets in the Individual Support Plan, formed together with the individual (or legal representative) - The topic of self-determination is often discussed with the whole support team. - The support team is able to minimize the use of restrictive measures for this individual
Support of Predictability in Daily Routines (4)	- The support team is able to facilitate this individual with activities matching his or her needs. - The support team can facilitate the individuals' rituals and routines - The support team facilitates a proper onboarding for new members of the support team, regarding providing predictability in daily routines for this individual
Physical Health Support (12)	- The support team provides the individual with healthy food - The support team can easily include a physician in intellectual disability medicine -The service organization has developed policy (vision) regarding the use of medication in individuals with CB
Knowledge Support (12)	- All necessary care-disciplines are involved in care for this individual at the same time and work together. - All involved in care for this individual ask external expertise when necessary - The psychologist of this individual or manager of this group home monitors this support team regularly to foster development

Items could be assigned a score from 1 (totally disagree) to 5 (totally agree) with higher scores denoting higher appraisal of contextual support. Example items can be seen in Table 1. A Mean Item Score for total Contextual Support is computed for each individual, with higher scores indicating higher appraisal of the quality of contextual care for this individual.

Cronbach's alpha for subdomains was calculated and was considered average to good ($.523<\alpha\leq.798$). The total domain composite score was calculated consisting of the average score of all domains together and had a good reliability ($\alpha=.924$). Subdomains correlated $.70<r<.81$ with the total domain composite score (MIS) and since reliability was higher for total MIS, it was decided to limit the analyses to the Total Contextual Appraisal score (MIS).

Statistical Analyses

First, to evaluate if contextual appraisal and Challenging Behaviour are associated with QoL, correlational analyses (Spearman's rho) were calculated between Quality of Life and the potential predictors Challenging Behaviour and Contextual Support Appraisal. Because Contextual Support Appraisal and Challenging Behaviour were correlated ($r=-.185$, $p=.009$), the interaction term of these predictors was added as a predictor and consequently both variables were centered to facilitate the interpretation of the coefficients of the predictors and its interaction.

First, descriptives of Quality of Life, Challenging Behaviour and Appraisal of Contextual Support will be presented. To test the hypothesis that QoL is associated with both challenging behaviour and appraisal of contextual support, a regression analysis was planned. To estimate the contribution of each of the predictors to the amount of explained variance in Quality of Life, a hierarchical regression analysis was performed (method ENTER). Challenging behaviour was added in the first step, level of Contextual Support Appraisal was added in the second step, and the interaction term of the latter two predictors (DBC*Context) was added in the third step. Data were analysed using SPSS statistics version 29 (SPSS, 2023).

RESULTS

Participants descriptives regarding age, Quality of Life, Challenging Behaviour, and Contextual Appraisal are presented in Table 2. Spearman's rho correlations were *r*=-.200 (*p*=.005) for Quality of life (SMS MIS) with Challenging behaviour (DBC-A MIS), *r*=-.371 (*p*<.001) for Quality of life with Contextual Support Appraisal, and *r*=-.185 (*p*=.009) for Contextual Support Appraisal with Challenging behaviour (DBC-A MIS).

Table 2

Descriptives regarding to age, gender, Quality of Life (SMS MIS, scores on scale ranging from 1-4, higher scores denoting higher QoL), Challenging behaviour (CB, DBC-A total MIS, scores on scale ranging from 0-2, higher scores denoting higher CB), Contextual Interview; consensus appraisal score (MIS) of contextual support on a scale 1-5, higher scores denoting higher appraisal of contextual support (N=196).

Gender			**Male (67,9 %)**	
	M	***SD***	**Minimum**	**Maximum**
Age	41.95	14.6	18.03	77.01
Quality of Life	2.87	.31	2.07	3.67
Challenging behaviour	.56	.24	.08	1.50
Contextual Support Appraisal	3.77	.34	2.91	4.62

Relationship Contextual Appraisal with Quality of Life

Hierarchical regression analysis resulted in a significant final model (*F* (3, 192) = 16.232, *p* < .001), predicting 19.7 % of the variance in Quality of Life (see Table 3). Entering Challenging behaviour as predictor in the first step, resulted in 4.8 % of explained variance in QoL (*p*=.002), after adding Contextual Support Appraisal in the second step explained variance increased to 16.2 % (*p*<.001), and after adding the interaction term in the third step, explained variance increased to 19.7 % (*p*=.004), with relatively less Challenging Behaviour and higher Contextual Support Appraisal relating to higher Quality of Life.

Furthermore, the prediction success of the separate domains of QoL (SMS subdomains) was examined. Approximately similar models were obtained for Self Determination and Rights (with 20% explained variance), Social Inclusion and Interpersonal Relationships (with 15% explained variance) and Physical Wellbeing and Material Well-being scored substantially lower (<5% of explained variance).

Table 3

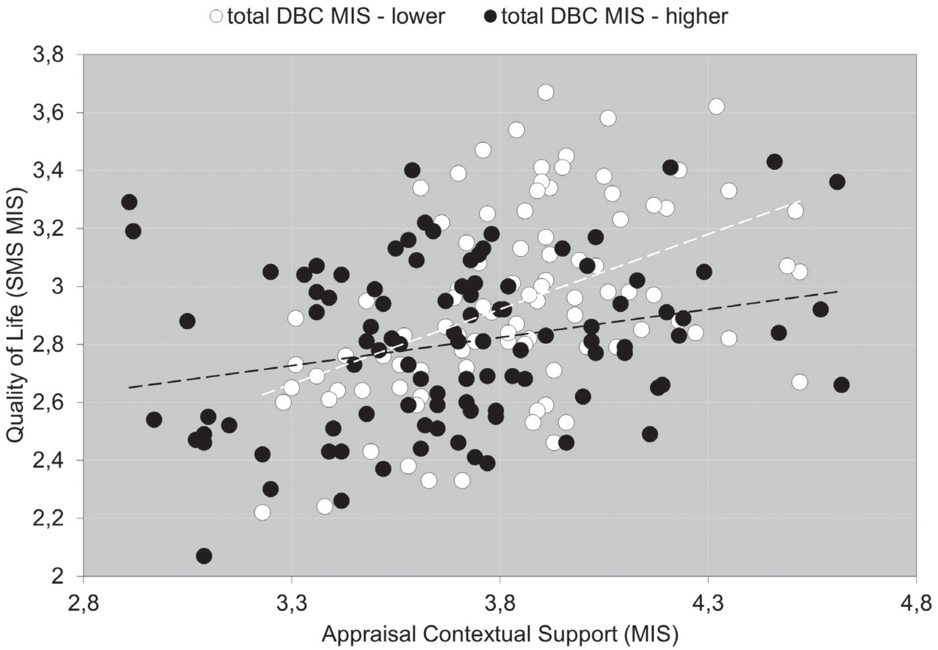
Coefficients in final model

						95% CI	
Predictors	**B**	**Std error**	***β***	***t***	***p***	**lower**	**upper**
(Constant)	1.659	.244		6.794	<.001	1.178	2.141
Challenging Behaviour DBC	-.187	.086	-.143	-2.172	.031	-.358	-.017
Contextual Support Appraisal	.346	.061	.384	5.705	<.001	.227	.466
Interaction DBC*Context	-.658	.229	-.190	-2.876	.004	-1.109	-.207

Figure 1 visualizes the significant interaction between Challenging Behaviour and Contextual Support Appraisal as one of the predictors of level of Quality of Life. This interaction demonstrates that for individuals with relatively lesser levels of challenging behaviour, appraisal is a stronger predictor (21.8% explained variance) of quality of life than for individuals with higher levels of challenging behaviour (6.7% explained variance).

Figure 1.

Adults with intellectual disability: Relation between quality of life and appraisal of contextual support as a function of level of challenging behaviour (median split of CB around 0.533)



DISCUSSION

As expected, the results of the present study demonstrate a significant relationship between the appraisal from multiple perspectives of the quality of contextual support and the evaluation of a client's quality of life in individuals with intellectual disability and severe challenging behaviour.

In accordance with our hypothesis, higher appraisal representing multiple perspectives of contextual support provided, in relatively less severe challenging behaviour, is associated with higher quality of life, confirming results by Bowring et al. (2019). Our analyses did not show parts of the survey being of more or less relevance in relation to quality of life. Given the individual differences in support needed and the inability to pinpoint a single domain in general where efforts should be intensified, it is all the more important to tailor support plans.

The interaction between appraisal from multiple perspectives of given contextual support and severity of challenging behaviour even further raised explained variance in quality of life. This interaction shows that for individuals with relatively less severe challenging behaviour, explained variance in quality of life amounted to 21.8% in our population, suggesting that contextual support is adequate. For individuals with relatively more severe challenging behaviour however, only 6.7% of variance in quality of life was accounted for by satisfaction of contextual support, suggesting that under those circumstances contextual support, in its current form, is not sufficiently adequate, or reaches its limits. It could be that in working with individuals with severe challenging behaviour, professionals spend more time managing the challenging behaviour itself rather than focus on individualized contextual support to improve quality of life (Tevis, 2020). Severity of challenging behaviour could result in an increased focus on managing disruptive behaviour at the cost of attention for the organization of the necessary contextual support for the wants and needs of an individual, which may compromise quality of life (Morisse & Dosen, 2017).

Studies into the quality of life for people with severe and challenging behaviour are scarce and sample sizes are often small. For example, in a similar but small subgroup, Gur (2018) did not find a correlation between challenging behaviour and quality of life, which was attributed to the limited variance in challenging behaviour and quality of life. The present study showed that contextual support appears to account for a greater portion of the variance in quality of life outcomes compared to challenging behaviour alone, which underscores the relevance of contextual support as an important contributor to the improvement of quality of life.

Limitations of this study are its cross-sectional design, precluding to demonstrate causation or dynamics in changes over time in challenging behaviour and quality of life. Future longitudinal research designs could possibly provide a more comprehensive understanding of the relationship between contextual support and changes in quality of life, more so if including dynamics in contextual support over time. We recognize that various other factors may significantly impact quality of life, including individual characteristics such as the severity of the intellectual disability, adaptive functioning, overall health status, and living conditions (Schalock et al., 2021). The factors could be considered in conjunction with contextual support when evaluating QoL outcomes.

Another caveat, perhaps, is the possible confounding between reported quality of life and satisfaction with the contextual support given, when being judged by the same professional. In this study, we tried to reduce evaluation bias by requiring consensus in the judgement of contextual support among multiple professionals and family members. Post hoc analysis showed a Spearman rank correlation between satisfaction with support given and quality of life of r=.36, which implies that this relation accounts for only 13% of the variance in quality of life.

Recognizing Shogren et al. (2021) recommendation to always include the persons with intellectual disability themselves in evaluation of care, we chose to include them in the construction of our interview. One might consider it a limitation that indirect observation and interviews with significant others were used to assess behaviour and well-being. This method (vs. self-report) could possibly not thoroughly reflect the wants and needs of the individual himself. It is important to state that we carefully checked for each individual that according to direct caregivers, obtaining direct self-reports was considered unfeasible. Proxies are often used as the only available method for collecting data from people with intensive support needs and can be seen as a valid substitute for self-report when the latter is unfeasible (Balboni et al., 2013). It is also considered of significant value since information of significant others is used in daily clinical care as indicators of needs and wants and in designing support strategies (Mumbardó-Adam et al., 2023). Adapting contextual support to an individuals' need is based on the appraisal of professionals and family members involved (Shogren et al., 2020). Inferences are limited to the perceived consensus on contextual support, which reflects decision-making in care as usual.

With respect to clinical implications, this study demonstrates that quality of contextual support plays an important and positive role in the quality of life for individuals with intellectual disability even if there is challenging behaviour and should therefore be considered to be evaluated systematically within this population. When professionals and family members rate the contextual support of an individual as being lower, quality of the contextual support should be reconsidered to remedy this situation, by focusing on contextual elements that contribute to desired outcomes, in line with Shogren et al. (2020). Our study suggests that for individuals with the highest levels of challenging behaviour, the impact of contextual support on quality of life is limited. The quality of contextual support given does not achieve its purpose and perhaps reaches its limits under these circumstances. This poses significant challenges when designing new strategies to optimize support for those individuals that have serious challenging behaviour.

Challenging behaviour is known to be extremely persistent over the years in individuals with intellectual disability and challenging behaviour (Thompson et al., 2022; Totsika & Hastings, 2009). Some behaviour may never diminish, despite all efforts in contextual support, which could explain our results suggesting certain limitations of contextual support. The persistence of severe challenging behaviour may discourage staff in their feeling of being able to influence quality of life through their contextual support. Van den Bogaard et al. (2020) found that staff members are prone to attributing more severe forms of challenging behaviour to the individual, instead of to interactions with others or specific situations. Perhaps in our sample, for the most severe challenging behaviour, this mechanism of attributing to internal causes could come into play, resulting in a problem-oriented approach, with lesser focus on shaping quality of life by providing contextual support. The relationship between contextual support and quality of life might be contingent upon the sense of modifiability.

Challenging behaviour often is an important outcome measure in this population (Bruinsma et al., 2022). However, this study suggests that in those persons with severe levels of challenging behaviour, contextual support was hardly effective. This may be due to focus on reducing challenging behaviour without explicit target on improvement on quality of life. It may therefore be important to focus contextual support on quality of life directly.

This study emphasizes the value of appraisal of significant others and contextual support assessments in evaluating quality of life. Since our study showed the effectiveness of contextual support seems to be less effective when more severe challenging behaviour is present, future research should focus on expanding methods for this group by using contextual support assessment to further tailor the individual support plan. Studies such as by de Kuijper et al. (2023) show promising results when evaluating specific additions of contextual support in highly persistent challenging behaviour when professionals experience difficulties addressing support needs, i.e. when contextual support is considered not sufficient. They found that supporting care providers by consultation of an expert team to address these unmet needs of individuals with challenging behaviour resulted in improvement in behaviour and daily functioning in individuals with challenging behaviour.

In conclusion, the findings of this study highlight the importance of contextual support, especially for shaping the quality of life for individuals with intellectual disability and challenging behaviour. The interplay between challenging behaviour, contextual support and quality of life highlights the need for tailored contextual interventions.

REFERENCES

Balboni, G., Coscarelli, A., Giunti, G., & Schalock, R. L. (2013). The assessment of the quality of life of adults with intellectual disability: the use of self-report and report of others assessment strategies. *Research in Developmental Disabilities*, *34*(11), 4248-4254. https://doi.org/10.1016/j.ridd.2013.09.009

Ball, J., & Fazil, Q. (2013). Does engagement in meaningful occupation reduce challenging behaviour in people with intellectual disabilities? A systematic review of the literature. *Journal of Intellectual Disabilities*, *17*(1), 64-77. https://doi.org/10.1177/1744629512473557

Bele, I. V., & Kvalsund, R. (2016). A longitudinal study of social relationships and networks in the transition to and within adulthood for vulnerable young adults at ages 24, 29 and 34 years: compensation, reinforcement or cumulative disadvantages? *European Journal of Special Needs Education*, *31*(3), 314-329. https://doi.org/10.1080/08856257.2016.1187886

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

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner & W. Damon (Eds.), *Handbook of child psychology*: Vol 1, Theoretical models of human development (6th ed., pp. 793–828). Wiley.

Bruinsma, E., van den Hoofdakker, B. J., Hoekstra, P. J., de Kuijper, G. M., & de Bildt, A. A. (2022). Exploring the association of staff characteristics with staff perceptions of quality of life of individuals with intellectual disabilities and challenging behaviours. *Journal of Applied Research in Intellectual Disabilities*, *35*(5), 1231-1243. https://doi.org/10.1111/jar.13017

Buntinx, W. H. E., Herps, M., & De Ruiter, M. (2012). *Handreiking Ondersteuningsplannen*. Kennisplein Gehandicaptensector, VGN. Retrieved 5 September 2022 from https://www.vgn.nl/system/files/article/file/Handreiking%2B2.%2BOndersteuningsplannen%2B2013.pdf

Buntinx, W. H. E., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(4), 283-294.

de Kuijper, G., Fokkema, T., Jansen, M., Hoekstra, P. J., & de Bildt, A. (2023). Difficulties in addressing diagnostic, treatment and support needs in individuals with intellectual disability and persistent challenging behaviours: A descriptive file study of referrals to an expertise centre. *International Journal of Environmental Research and Public Health*, *20*(14). https://doi.org/10.3390/ijerph20146365

Deb, S., Unwin, G., Cooper, S., & Rojahn, J. (2022). Problem behaviour. In *Textbook of psychiatry for intellectual disability and autism spectrum disorder*. Springer International Publishing.

Embregts, P., Kroezen, M., Mulder, E. J., Van Bussel, C., Van der Nagel, J., Budding, M., Busser, G., De Kuijper, G., Duinkerken-Van Gelderen, P., Haasnoot, M., Helder, A., Lenderink, B., Maes-Festen, D. A. M., Olivier-Pijpers, V., Oud, M., Oude Luttikhuis, I., Schilt, C. J., Smit, T., Van den Heuvel, J., … Wieland, J. (2019). *Multidisciplinaire richtlijn probleemgedrag bij volwassenen met een verstandelijke beperking*. Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten.

Embregts, P. J. C. M., Didden, R., Moonen, X., Leusink, G., & Schuengel, C. (2023). Kenmerken en ondersteuningsbehoeften van mensen met een licht of ernstig verstandelijke beperking en ernstig probleemgedrag en psychische problematiek. *NTZ: Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen*, *49*(3), 11.

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

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

Gur, A. (2018). Challenging behavior, functioning difficulties, and quality of life of adults with intellectual disabilities. *International Journal of Developmental Disabilities*, *64*(1), 45-52. https://doi.org/10.1080/20473869.2016.1221233

Mohr, C., Tonge, B. J., & Einfeld, S. L. (2005). The development of a new measure for the assessment of psychopathology in adults with intellectual disability. *Journal of Intellectual Disability Research*, *49*, 469-480. https://doi.org/10.1111/j.1365-2788.2005.00701.x

Mohr, C., Tonge, B. J., Einfeld, S. L., & Taffe, J. (2011). *Manual for the developmental behaviour checklist for adults (DBC-A). Supplement to the Manual for the Developmental Checklist - DBC-P and DBC-T*. University of New South Wales and Monash University

Mohr, C., Tonge, B. J., Taffe, J., & Einfeld, S. L. (2012). The availability of normative data for the Developmental Behaviour Checklist for Adults. *Journal of Intellectual & Developmental Disability*, *37*(1), 61-64. https://doi.org/10.3109/13668250.2011.649719

Morisse, F., & Dosen, A. (2017). *Schaal voor Emotionele ontwikkeling bij mensen met een verstandelijke beperking-Revised*. Maklu.

Mumbardó-Adam, C., Andrés-Gárriz, C., Sanchez-Pedroche, A., & Balboni, G. (2023). Differences in self and proxy assessments of self-determination in young people with intellectual disability: The role of personal and contextual Variables. *Behavioral Sciences*, *13*(2). https://doi.org/10.3390/bs13020156

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/

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. 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., Bonardi, A., Cobranchi, C., Krahn, G., Murray, A., Robinson, A., Havercamp, S. M., & Function, N. R. H. (2021). State of the field: The need for self-report measures of health and quality of life for people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 286-295. https://doi.org/10.1111/jppi.12386

Shogren, K. A., Luckasson, R., & Schalock, R. L. (2015). Using context as an integrative framework to align policy goals, supports, and outcomes in intellectual disability. *Intellectual and Developmental Disabilities*, *53*(5), 367-376. https://doi.org/10.1352/1934-9556-53.5.367

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

SPSS, I. (2023). *IBM SPSS statistics for windows*. In *Armonk, New York, USA: IBM SPSS* (Version 29)

Tevis, K. (2020). *Long-term behavioral health care unbundled: The impact of comorbidity and aggression on caregiver strain and service costs for individuals with intellectual disabilities* The University of Nebraska-Lincoln].

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.

Van den Bogaard, K. J. H. M., Nijman, H. L. I., & Embregts, P. J. C. M. (2020). Attributional styles of support staff working with people with intellectual disabilities exhibiting challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, *33*(3), 465-474. https://doi.org/10.1111/jar.12688

Verdugo, M. A., Gomez, L., Arias, B., Santamaria, M., Navallas, E., Fernandez, S., & Hierro, I. (2014). *San Martin Scale: Assessment of quality of life in persons with significant intellectual and developmental disabilities*. Salamanca: Institute on Community Integration.

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

CHAPTER 3

A three-years follow-up of extra intensive support for individuals with intellectual disability and severe challenging behaviour in the Netherlands

Published as:
Verhaar, L., Dijkxhoorn, Y. M., de Sonneville, L.M.J.., & Swaab, H. (2024).
A three-years follow-up of extra intensive support for individuals
with intellectual disability and severe challenging behaviour in the
Netherlands. *Journal of Intellectual Disabilities*.
https://doi.org/10.1177/17446295241252918

ABSTRACT

Adults with Intellectual Disability who show severe challenging behaviour need intensive individual support. If intensive support proves to be insufficient, extra intensive support can be provided in the Netherlands, which is characterized by more time for individual care. The present study evaluates the impact of extra intensive support over time. Client characteristics of adults receiving intensive support (IS, N=70) or extra intensive support (IS+, N=35) are compared and the impact of provided support on challenging behaviour (Developmental Behaviour Checklist-Adults), adaptive behaviour (Vineland II), and Quality of Life (San Martin Scale) is evaluated over a three years period. Compared to adults receiving intensive support, those receiving extra intensive support initially showed higher intensity of challenging behaviour, higher number of mental health diagnoses and stronger focus on goals to reduce challenging behaviour. Over time, intensity of challenging behaviour decreased in adults receiving extra intensive support, although Quality of Life and adaptive functioning did not improve. Results show that the indications for receiving extra intensive support are clear and that the extra support is effective over time. It is concluded that extra individual support is serving those who need this support.

A three-years follow-up of extra intensive support for individuals with intellectual disability and severe challenging behaviour in the Netherlands

Individuals with intellectual disability show a large etiological heterogeneity (Burack et al., 2021). Due to this variability, individuals with intellectual disability and challenging behaviour (CB) show a wide range of support needs, defined as the range and intensity of supportive interventions necessary to attend to daily essentials, social activities, learning and working (Thompson et al., 2009). In addition to support associated with specific medical and behavioural problems, support needs arise from a combination of an individual's skills, demands and complexity of settings and activities he or she must participate in (Thompson et al., 2009). Besides the evaluation of cognitive functioning (IQ), adaptive behaviour, health, participation, context and their reciprocity, according to the model of human functioning by the American Association of Intellectual and Developmental Disabilities (AAIDD-model) (Schalock et al., 2021), an integrative diagnosis of an individual with intellectual disability should also include an analysis of individual support needs, foremost to optimize the effectiveness of tailor-made support plans, living arrangements and resource allocation.

In the Netherlands, approximately 13% (CBS, 2023) of the population of persons with intellectual disability receiving long-term care is presenting with severe challenging behaviour, needing 24 hour Intensive Support (IS). Support needs are based on diagnostic evaluation, and reflect the individual's personal needs that should be timely and regularly monitored and evaluated (Buntinx & Schalock, 2010b; Schalock et al., 2021). Support is strongly focused on improving quality of life (QoL), which is defined as a set of domains of functioning determining a person's well-being, the outcome being a combination of factors pertaining to physical, emotional and material wellbeing, self-determination, rights, personal development, social inclusion and interpersonal relationships (Schalock et al., 2002).

Challenging behaviour is a well-known risk factor associated with lower QoL (Emerson & Einfeld, 2011; Robertson et al., 2004). Challenging behaviour is defined by Emerson and Einfeld (2011) as behaviour which is culturally abnormal, endangers the physical safety of the person (or others), or limits the use/access to ordinary community facilities. People with intellectual disability are more at risk for challenging behaviour and related restrictive measures (Allen et al., 2009), social exclusion, and lack of autonomy (Griffith et al., 2013), that inevitably and unfavourably influence quality of Life.

Lower levels of cognitive functioning and adaptive behaviour have been linked to more severe challenging behaviour in people with intellectual disability (Bowring et al., 2019; Felce et al., 2009). The presence of challenging behaviour relates to a higher need for behavioural support in general (Seo et al., 2017) and for social support and maintenance of emotional well-being in particular (Lamoureux-Hebert et al., 2010). Bruinsma et al. (2022) found that for support staff higher educational level, friendly behaviour and more self-efficacy, i.e. the feeling of confidence and satisfaction in being able to deal with CB is associated with higher QoL in the individual with intellectual disability and challenging behaviour.

When the level of intensive support does not suffice in meeting a person's support needs, an even higher level of support can be provided in the Netherlands after applying successfully for extraordinary funding. This extraordinary funding enables to provide extra Intensive Support (or IS+). This highest level of support becomes available when the challenging behaviour is not understood, is considered too intense or resistant to current supportive regulation. When it is decided that these individuals are entitled to this additional care, they receive the highest level of intensive support (IS+), through extra financial means. These means are mainly aimed at increasing direct care involvement, by allowing more time to be invested, resulting in a higher client-direct staff ratio, often reaching 1:1 for a significant portion of the day or the whole day. Through an increased staff presence, it is thought that there is more real-time, proactive and therefore effective responsiveness to the individuals' extra intensive support needs due to their challenging behaviour.

In the Netherlands, funding of extra intensive support ultimately aims at regaining QoL within the setting of one's own (group)home, avoiding hospitalization and segregation. Funding is provided by the government and is allocated through a system in which expert clinical judgement is decisive (ZorgverzekeraarsNederland, 2023). These extra resources are received for a certain period of life, as long as deemed necessary, based on repeated clinical judgement. Nationwide, the number of clients for whom this funding has been applied for, has increased enormously in the last few years (Hopman, 2021), due to different factors. Shifting towards more humane support, restrictive measures are no longer viewed as acceptable (Lawrence et al., 2022). The present paper aims to explore efficacy of extra intensive support. Furthermore, since decision criteria for extra intensive support are potentially subjective, this study aims to contribute to improve the assessment framework of allocation of financial resources for extra intensive support and the development of guidelines for clinical evaluation of the effect of extra intensive support .

Outside the Netherlands, this extra intensive support group may be regarded somewhat comparable to 'out-of-area' placements of people with intellectual disability and complex mental health needs in England, and, for example, people with intellectual disability and severe CB residing in small group homes in the USA (Tevis, 2020). As a result of de-institutionalization policies, specialistic settings for complex cases in England are sparsely located. These hospitals are considered essential for highly specialistic care when severe CB is present (Barron et al., 2011; Bonell et al., 2011; Deveau et al., 2015).

Tevis (2020) summarized what factors were most relevant in service costs for people with intellectual disability and severe CB residing in small group homes (1-3 persons, 24/7 care, Nebraska USA). Some of these people receive extra 'exception funding', approved by state officials, in which eligibility criteria are often mostly qualitative, inconsistent and subjective (Tevis, 2020), which situation reflects seemingly similar shortcomings present in the Dutch application system for extra intensive support funding.

Higher support needs are associated with higher costs by the addition of extra staff, and, for example, also staff related costs like extra supervision, training of aggression prevention, and management training. Tevis (2020) found that the combined impact of comorbid mental and physical health problems and aggressive behaviour contributed significantly to higher service costs. More specifically, the frequency and severity of aggressive behaviour contributed more to the rise in costs than the level of cognitive and adaptive dysfunctioning. Management of aggressive behaviour requires more direct support throughout the organization and staff training, but also more indirect support, such as clinical oversight, increased and continuous monitoring (Tevis, 2020).

In the Netherlands, few studies have been conducted regarding the characteristics and efficacy of these extra intensive support. Claes et al. (2009) found that lower adaptive functioning was associated with higher support needs in a general intellectual disability population. Sandjojo et al. (2018) found that self-management training of people with moderate to mild intellectual disability decreased their support needs. To our knowledge, previous studies on clinical characteristics of individuals needing extra intensive support are nonexistent for the Dutch population.

The current study aims to follow-up individuals receiving intensive support or extra intensive support over a three year period in order to explore efficacy of intensive support and extra intensive support. Furthermore, the study intends to identify factors that are instrumental to distinguish between individuals entitled to intensive support and extra intensive support, i.e. level and characteristics of challenging behaviour, adaptive behaviour, quality of life, diagnostic classifications and chosen goals in individual support plans, taking into account relevant previously studied factors, i.e. gender, age and cognitive functioning (Beadle-Brown et al., 2006; Deveau et al., 2015; Knapp et al., 2005; Unwin et al., 2017; Wehmeyer et al., 2009). The extra intensive support group is expected to be characterized by a combination of severe challenging behaviour *and* lower adaptive behaviour *and* lower quality of life, compared to the regular high intensive support group. Further, differences in individual support plans and number of mental health classifications will be explored. In line with Hassiotis et al. (2008), a higher number of mental health diagnoses in the extra intensive support group is expected. Furthermore, it is expected that the focus of goals in Individual Support Plans (ISPs) will be on reducing challenging behaviour since aggression may be more prevalent in the extra intensive support group (Tevis, 2020). Lastly, the development of both groups on measures of challenging behaviour, adaptive behaviour and quality of life will be followed over time.

METHOD

Procedure

Data used in this study were collected during a large longitudinal project, SCORE project. The SCORE project evaluates the effects of regular care of persons with intellectual disability and intensive support need due to persistent and severe challenging behaviour (CB), living in staffed group homes. Care-as-usual was evaluated in four participating Dutch residential disability services for people with an intellectual disability. [Ipse de Bruggen, de Hartekamp Groep, Cordaan and Ons Tweede Thuis].

Persons were eligible for inclusion when they met the following criteria: Adults with intellectual disability, living in staffed group home, needing (regular) intensive support or extra intensive support, due to persistent and severe challenging behaviour (CB), excluding those who needed intensive support primarily because of profound intellectual and multiple additional (neuromotor/sensory) disabilities. The participants were informed about the study by written and digital information. Most participants were unable to give *informed consent* themselves, therefore permission was obtained from legal representatives.

The study has a longitudinal design, collecting survey data in three time waves, starting in 2017 (Time 1, T1), with follow-ups in 2018 (Time 2, T2) and 2020 (Time 3, T3). Ethical approval was granted by the ethics committee of the Faculty of Social and Behavioural Sciences, Department of Clinical Neurodevelopmental Sciences, University of Leiden, The Netherlands (ECPW-2015/094), and the ethical committee of the largest participating residential disability service organisation (Ipse de Bruggen).

Dutch care system

In the Netherlands, participants with intensive support (IS) mainly reside in specialized staffed group homes, where they receive 24 hour care for support in all areas of life, living mainly in group homes varying in size. Extra intensive support (IS+) is available for those already receiving the most intensive regular support, through an independent eligibility process, based on qualitative assessment of psychological reports on a person's functioning, individual support plan, and opinions of staff. In case an individual is eligible for IS+, as argued by the service organization, more financial means become available for the service organization to spend on support specifically for this individual. With these means the individuals can often remain in the same group home, which can be a mix of individuals receiving IS or IS+. Extra intensive support most often involves the availability of more time for individual direct support provided by caretakers, and can also result in environmental adjustments like extra individual facilities to support daily functioning. Typically, in intensive support the client-staff ratio in direct caretaking is 4/3:1, this can go up to 1:1 (or 1:2) for participants who receive IS+. Furthermore, more time for the multidisciplinary support team is available to intensify analysis of individual support needs. The multidisciplinary support team may include professionals like physicians, psychologists/orthopedagogues, occupational therapists.

Participants

N = 152 participants receiving IS (*N* = 117) or IS+ (*N* = 35) were included at the first time wave. Participants' age ranged from 18.02 years to 76.96 years (*M*=40.23, *SD*=14.22). For reasons of comparison with a group of participants receiving IS+, participants receiving IS were selected by person to person matching on level of cognitive functioning, age and gender. Two matches were selected for each participant with IS+, resulting in a comparison group of *N*=70 participants with IS.

In the longitudinal outcome analyses, 21 participants (8 IS+, 13 IS) were lost at the third time wave. It was analysed with *t*-tests whether these differed from the participants remaining in the study, separately for the IS+ and the IS group. No differences were found for the IS+ group (.845>*p*>.229) nor for the IS group (.849>*p*>.117) on measures of CB, intellectual disability, adaptive behaviour, QoL, gender distribution or age.

Measures

Level of cognitive functioning

For every participant, IQ scores were derived from scores on standardized tests, which were assessed within the last five years, before inclusion in the study, such as the Dutch versions of the Bayley Scales of Infant Development-II-NL (BSID-II-NL)/Bayley-III (Baar et al., 2014), Wechsler Intelligence Scale for Children-III_NL (WISC-III-NL), Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III-NL), Wechsler Adult Intelligence Scale-III-NL (WAIS III-NL) (Kort et al., 2005; Wechsler, 1989; Wechsler, 1991; Wechsler, 2008, 2012), Snijders-Oomen nonverbal-revised (SON-R), Snijders-Oomen nonverbal test 2-8 (Tellegen & Laros, 2011; Tellegen & Laros, 2017). These tests have sufficient reliability and validity. Variation in developmental/IQ tests was due to variation of use in clinical practice. Often in clinical practice among adults with intellectual disability in the Netherlands, intelligence/developmental tests available for a lower chronological age are used (Došen, 2014; Kraijer & Plas, 2014), to accommodate their relatively low level of cognitive functioning.

Participants' own psychologist decided which assessment instrument was best suitable to determine each individuals' profile, based on level of functioning (language use, motor skills etc.) and aim of assessment, in line with clinical guidelines (Embregts et al., 2019). To facilitate comparability and interpretation of scores, all outcomes were converted to cognitive age equivalents in months.

Challenging behaviour: Developmental Behavioural Checklist – Adult (DBC-A)

The DBC-A is a carer-completed 107-item questionnaire that assesses a comprehensive range of emotional, behavioural and mental health problems in adults with mild, moderate and more severe levels of intellectual disability (Mohr et al., 2005; Mohr et al., 2011; Mohr et al., 2012). Professional primary caretakers were asked to fill out the questionnaire, rating the answer to each item with never, sometimes or often/frequent. Six problem domains are distinguished, i.e. Disruptive behaviour, Communication Disturbances and Anxiety, Antisocial behaviour, Self-absorbed behaviour, Depressive and Problems Relating Social, and a Total score. Mean Item Score (MIS) of DBC-A Total problem behaviour was used as a measure of challenging behaviour (CB), i.e. DBC-A total (MIS). A higher score denotes more CB. Domain total scores of CB were also converted to mean item scores for a valid comparison between domains. Equivalent mean scores can either be derived by a large number checked '1' or a low range of items checked '2'. To gain a better understanding of experienced intensity of behaviour, the DBC-A Intensity Index was calculated, i.e. the proportion of the positively checked items that were scored 2, as suggested by Taffe et al. (2008), by first determining the Proportion of Items checked for each participant (DBC-A PIC, total number of checked items/total items of questionnaire items). The sum of items checked 2 per participant was then divided by their PIC, resulting in the DBC-A Intensity Index, representing a measure of intensity of CB. The DBC-A is a reliable and internally consistent instrument with Cronbach's alpha for the total score of $\alpha = .95$ and for the subscales α ranges from .71 - .91 (Mohr et al., 2011).

Adaptive behaviour: Vineland Adaptive Behavior Scales (Vineland II) and Vineland Screener

The Vineland II (Sparrow et al., 2005), administered at the first time wave, is a commonly accepted measure of adaptive skills and has been used extensively in research in subjects with intellectual disability. Data were collected through semi-structured interviews with the professional primary caretaker by certified master students and research assistants who completed training and supervision in Vineland II interviewing. A Dutch translation of the Vineland screener (Sparrow et al., 1993; van Duijn et al., 2009), a questionnaire of 90 items, each rated from 0-2, was used to assess developmental age of individuals with an estimated age between 0 and 12 years. It was administered at the second and third time wave and is a short form of the expanded interview, which covers the same four domains and age equivalents on Communication, Daily living skills, Socialization and Motor skills as in the expanded version. A combination of the four domain scores (composite score), as well as the four domain scores showed good internal consistency and reliability (Cronbach's α >.95, Van Duijn et al., 2009). Since the expanded interview was only administered in the first wave, items corresponding with the screener items were selected from the expanded interview to create comparable total and domain scores of adaptive behaviour over time. A higher developmental adaptive age means more presentation of adaptive behaviour in a person.

Quality of Life: San Martin Scale

A Dutch translation of the San Martin Scale (SMS) (Verdugo et al., 2014) was used to measure quality of life (QoL) and was administered on each time wave. The SMS contains 95-items, based on the QoL framework (Schalock et al., 2002), resulting in eight domains (Self-determination, Emotional Well-being, Physical Well-being, Material Well-being, Rights, Personal Development, Social Inclusion, Interpersonal Relations). Cronbach's alpha ranges from .82 to.93 (domains) and .97 (total score) (Verdugo et al., 2014). The SMS is completed by a staff member with the most knowledge about the participant. Items are statements about the participants life, and proxies have to indicate how often the given statement occurs in the everyday life of this person on a 4-point Likert-scale, ranging from 'never (1)' to 'always (4)'. Item scores result in eight QoL domain scores and a Total QoL Score, all converted to mean item scores.

Individual support plans

The interdisciplinary support team evaluates the individual's support and intervention requirements and this information is formalized into an Individual Support Plan (ISP), documenting the details of the individualized support as agreed upon for a designated period, with an inclusion of the desired goals to be achieved. The ISP of each participant was evaluated and goals were analysed for content and counted through an in-house developed scoring system with multiple scorers, based on criteria for writing support plans (Buntinx et al., 2012). Scorers received training and supervision by an licensed psychologist (Fleiss Kappa interrater reliability of .77). For each participant, goals focused on reducing CB and goals focused on developing new behaviour were counted separately.

Statistical analysis

To test the hypothesis that group differences are present at the first wave, a multivariate analysis (MANOVA) was performed with Group (IS vs. IS+) as between subjects (BS) factor and DBC-A total (MIS) and DBC-A Intensity Index, total Adaptive behaviour score, and total QoL score as dependent variables. Significant group differences will be followed up by repeated measures analysis of variance (RM ANOVAs) with domain as within-subject (WS) factor to see whether possible group differences depended on type of domain. This would be the case when the Group x Domain interaction is significant. Consequently, only interaction effects will be reported.

Differences in distribution of mental health DSM-classifications will be evaluated with Chi-square test. Differences in total number of mental health DSM- classifications will be analysed by a *t*-test for independent samples. To test the hypothesis that the groups differ in aspects of their individual support plan, independent samples *t*-tests were performed comparing groups on number of goals at developing new behaviour and on reducing CB, respectively.

To test the hypothesis that the groups differ in changes over time, RM ANOVAs were performed with BS factor Group, and WS factor Time, for SMS total, DBC-A total (MIS) and DBC-A Intensity Index, and Vineland scores as dependent variables, respectively. For factor Time, SIMPLE contrasts, with T2 vs T1 as first contrast and T3 vs T1 as second contrast were used to assess shorter and longer term development over time, respectively. Significant Group x Time interactions, indicating that changes over time are different for the two groups, will be followed up by RM ANOVAs with BS factor Group (IS vs IS+) and Domain as WS factor, and the *difference* score (T3 minus T1) for each domain as dependent variable, to investigate whether group differences in change over time depend on type of domain.

Data were analysed using SPSS statistics version 28 (IBM, 2022). Significance level was set at $p<0.05$. Effect sizes were calculated using partial eta squared with $\eta_p^2 \sim 0.03$ representing a weak effect, $\eta_p^2 \sim 0.06$ representing a moderate effect and $\eta_p^2 \geq 0.14$ representing a large effect (Cohen, 1992).

RESULTS

Descriptives

The two groups, Intensive Support (IS) and extra Intensive Support (IS+) did not differ in age at assessment [*t*(102)=-1.506, *p*=.135] or in mean cognitive age equivalent [*t*(86)=.093, *p*=.926], or gender distribution, see Table 1.

Table 1

Characteristics for Intensive Support (IS) vs. extra Intensive Support+ (IS+)

	IS (*N*=70)	**IS+ (*N*=35)**
Age at assessment (years) (*M, SD*)	41.67 (13.87)	37.22 (14.67)
Cognitive age equivalent (months)(*M, SD*)	48.37 (36.95)	49.14 (34.38)
Gender (*N* male)	48	24

Table 2

Descriptives Intensive Support (IS) vs. extra Intensive Support (IS+) on measures of Challenging Behaviour, Adaptive behaviour, Quality of life and DSM-classifications. Displayed are Mean Item Scores (MIS) of total and domain scores for DBC-A (range 0-2) and SMS (range 0-4), for Vineland II age equivalents in months

		Intensive Support (IS) M, SD	***Intensive Support+ (IS+) M, SD***
Challenging Behaviour DBC-A	Disruptive	.73 (33)	1.10 (.36)
	Communication Dist./Anxiety	.57 (.28)	.87 (.31)
	Self Absorbed	.55 (.36)	.78 (.39)
	Antisocial	.46 (.31)	.62 (.35)
	Depressive	.41 (.30)	.67 (.36)
	Social Relating	.72 (.41)	.85 (.37)
	Total	.54 (.21)	.78 (.27)
	Intensity Index	.36 (.19)	.48 (.19)
Adaptive behaviour Vineland-II	Communication	40.81 (25.62)	39.73 (25.54)
	Socialization	34.65 (25.18)	28.79 (19.17)
	Daily Living Skills	61.27 (39.60)	54.63 (33.38)
	Motor Skills	49.46 (19.13)	42.60 (23.11)
	Total average	46.28 (26.56)	42.58 (23.11)
QoL SMS	Self Determination	2.72 (.38)	2.60 (.39)
	Rights	2.97 (.36)	3.12 (.38)
	Emotional Wellbeing	2.93 (.44)	3.14 (.42)
	Social Inclusion	2.90 (.41)	2.93 (.45)
	Personal Development	3.33 (.30)	3.20 (.39)
	Interpersonal Relationships	2.57 (.43)	2.72 (.49)
	Material Wellbeing	2.23 (.49)	2.17 (.43)
	Physical wellbeing	2.87 (.40)	2.90 (.42)
	Total	2.82 (.28)	2.85 (.31)

		Intensive Support (IS) M, SD	***Intensive Support+ (IS+) M, SD***
DSM	Presence of mental health classification (other than intellectual disability) *N, %*	42 (60.9%)	28 (82.4%)
	No. of mental health classification (other than intellectual disability)*	1.40 (.73)	1.39 (.57)
	ASD classification %	76%	75%

* NB: only for those participants who received a DSM classification.

Challenging behaviour, adaptive behaviour and quality of life

The MANOVA on group differences resulted in a significant multivariate effect, [$F[4,94)=7.884$, $p<.001$, $\eta_p^2=.251$]. The between-subjects effects were significant for DBC-A total (MIS), $F\ (1,97)=26.454$, $p<.001$, $\eta_p^2=.214$, and the DBC-A Intensity Index, $F\ (1,97)=9.049$, $p=.003$, $\eta_p^2=.085$, but not for adaptive behaviour (Vineland, $p=.383$), and QoL (SMS, $p=.556$). Repeated measures analyses for DBC-A subdomain scores showed a nonsignificant Group*Domain interaction ($p=.077$) indicating that group differences did not depend on type of domain. Post hoc analyses revealed that group differences were significantly higher for IS+ for all subdomains ($.027>p<.001$), except Social Relating ($p=.107$).

Individuals in the IS+ group more often had one or more DSM mental health classification (other than intellectual disability), compared to the IS group, χ_2 (1, $N=103$)=4.828, $p=.028$). When a DSM classification is present, the IS+ group did not differ in total number of DSM mental health classifications from the IS group ($p=.942$), nor did the proportion of Autism Spectrum Disorder classifications ($p=.909$).

Individual support plans

Table 3 summarizes ISP outcomes. On number of goals targeted at development of new behaviour, groups did not differ significantly ($p=.612$), but the IS+ group showed a significantly higher number of goals targeted at reducing challenging behaviour [$t(96)=2.237$, $p=.028$, $d=2.969$].

Table 3

Individual support plans for Intensive Support (IS) vs. Intensive Support+ (IS+)

	IS	*IS+*
No. of goals targeted at development of new behaviour	1.19 (.20)	1.36 (.29)
No. of goals targeted at reducing CB	3.31 (.37)	4.73 (.52)

Outcome of longitudinal follow-up

Challenging behaviour

For DBC-A total (MIS), main effect of Time was not significant (*p*=.384). Also the interaction Time*Group was not significant for contrast 1 (p=.115) and contrast 2 (p=.06). For DBC-A Intensity Index, the main effect Time was not significant (p=.06), but the Time*Group interaction was significant [*F*(2,70)=4.204, *p*=.019, η_p^2=.107], accompanied by a nonsignificant first contrast (*p*=.06) and a significant second contrast (*p*=.005, η_p^2=.105), indicating that decrease in intensity over time was only present in the IS+ group (see Figure 1). Repeated measures analyses for DBC subdomain scores show a nonsignificant Group*Domain interaction (*p*=.20) which indicates that group differences for contrast 2 did not depend on type of domain (Figure 2.)

Figure 1

Challenging behaviour over time as a function of Group with DBC-A total score (MIS) (± SEM)(left graph) and DBC-A (Intensity Index) (± SEM)(right graph)

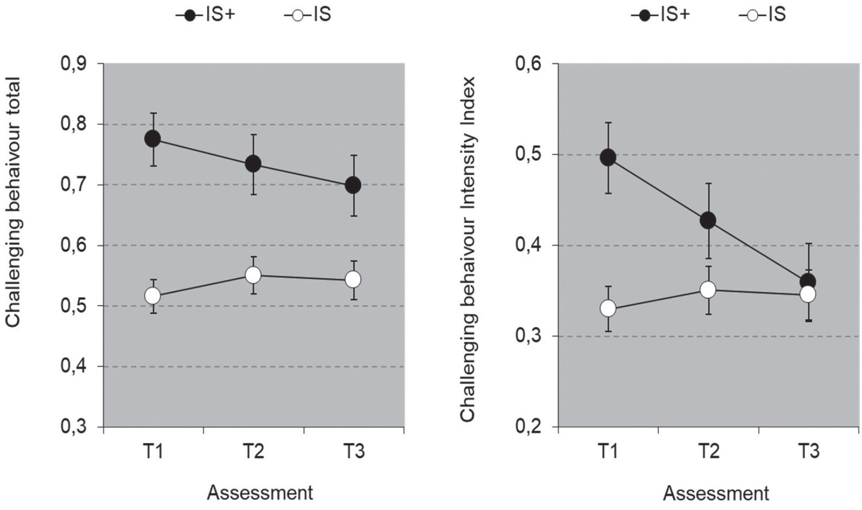
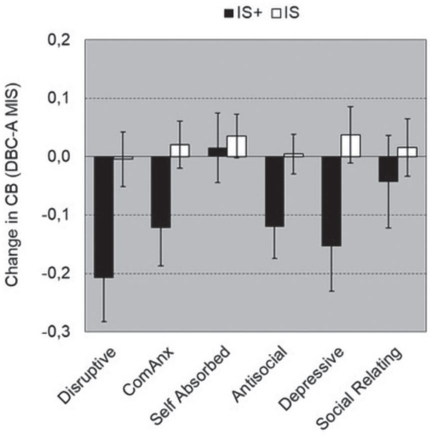


Figure 2

Change over time (T3 vs. T1) ± SEM in challenging behaviour total score (MIS) as a function of Challenging Behaviour domain and Group. Negative change in CB means decrease in CB over time.

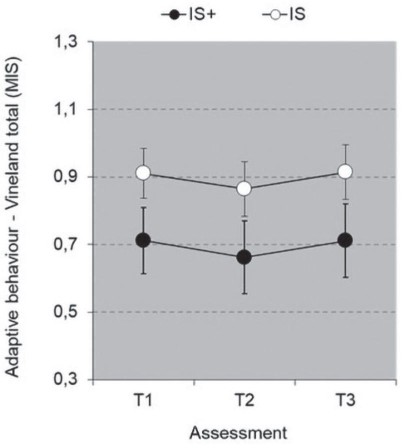


Adaptive Behaviour

Total adaptive behaviour shows a significant main effect for Time [*F*(2,112)=3.851, *p*=.024, η_p^2=.064], further specified by a significant first contrast (T1 vs. T2), [F(1,56)=5.197, *p*=.026, η_p^2=.085], reflecting a decrease in level of adaptive behaviour at T2, and a nonsignificant second contrast (T1 vs. T3), (*p*=.94), reflecting that at T3 adaptive behaviour recovered to the level at T1 (see Figure 3). The Group*Time interaction, overall and per contrast, was not significant (.91<*p*<.99). The main effect of Group was not significant (*p*=.123).

Figure 3

Overall Adaptive Behaviour (± SEM) Score (MIS) over time as a function of Group



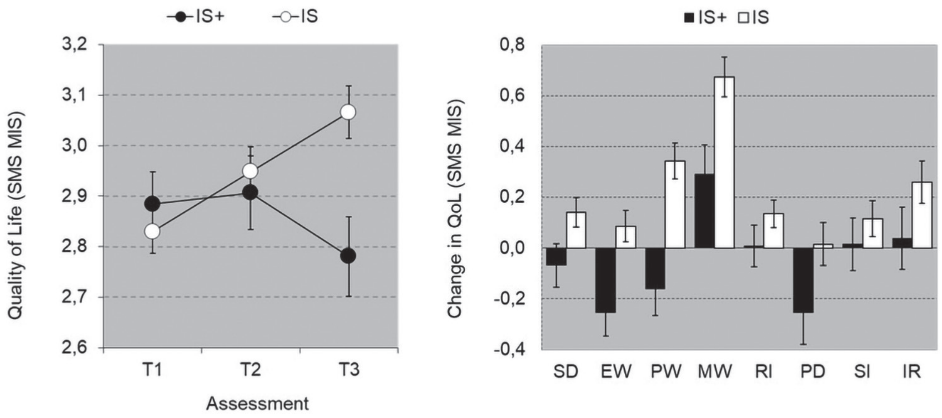
Quality of life

Total Quality of Life (SMS, Figure 3) shows a nonsignificant main effect for Time ($p=.196$), but a significant Time*Group Interaction [$F(2,62)=6.177$, $p=.004$, $\eta_p^2=.166$], accompanied by a nonsignificant first contrast ($p=.248$), and a significant second contrast [$F(1,63)=12.394$, $p<.001$, $\eta_p^2=.164$], which is accounted for by an increase over time in QoL for the IS group (see Fig. 2a). Post hoc RM analyses for T3 vs. T1 confirmed a significant increase in QoL over time for the IS group [$F(1,55)=23.245$, $p<.001$, $\eta_p^2=.297$] but not for the IS+ group ($p=.540$).

Repeated measures analyses for SMS subdomain difference scores (T3 vs. T1) show no significant Group*Domain interaction ($p=.091$) which indicates that group differences in changes over time (T3 vs. T1) did not depend on type of domain (Figure 2.). Visual inspection of differences scores per domains suggests that only SMS domain Material Wellbeing showed an improvement over time for the IS+ group. Post-hoc RM-analysis for this domain confirmed this suggestion [$F(1,24)=4.208$, $p=.051$, $\eta_p^2=.149$].

Figure 4

Overall Quality of Life (San Martin Scale Mean Item Score ± SE) over time as a function of Group (left graph) and changes in Quality of Life (± SE) as a function of Quality of Life domain and Group (right graph). Domains right graph: Self Determination (SD), Emotional Wellbeing (EW), Physical Wellbeing (PW), Material Wellbeing (MW), Rights (RI), Personal Development (PD), Social Inclusion (SI), Interpersonal Relationships (IR)



DISCUSSION

This study aimed to explore the efficacy of the provided support over a period of three years and explored factors that help to decide which persons with intellectual disability and severe challenging behaviour should be entitled to receive extra intensive support. A group of individuals who received extra intensive support (IS+) were compared with a group of individuals who received intensive support (IS) as usual.

Efficacy of treatment

A strength of the study is its longitudinal design, providing valuable insights in potential treatment-related changes in behaviour, adaptive functioning and quality of life over three years' time of individuals receiving intensive or extra intensive support. There were no significant changes in total level of challenging behaviour over time for both the intensive support and the extra intensive support group. However, intensity of challenging behaviour was found to decrease in the extra intensive support group.

Adaptive behaviour did not improve over time for both groups. Quality of life improved in the intensive support group but not in the extra intensive support group, which could have been due to the different focus of care. In the extra intensive support group, focus was mostly on management of challenging behaviour, i.e. an emphasis on managing problematic behaviour rather than on improving development, particularly for individuals who receive extra intensive support. This is in line with for example Unwin et al. (2017) who found an overreliance on medication and contact time with psychiatrists, and relatively less attention for help by clinical psychologists, physiotherapists, and community nurses for the management of challenging behaviour. Extra intensive support is mostly used to implement a higher staff-individual ratio. Bruinsma et al. (2022) found that more staff members working per person with intellectual disability (higher staff-individual ratio) was related with lower quality of life scores in persons with intellectual disability and challenging behaviour, especially for social inclusion and self-determination. In line with our findings, it is therefore conceivable that that the intensity of being continuously monitored in very complex care (individual staff ratio 1:1 or even 1:2) could be experienced as more restrictive, which could affect quality of life negatively. Another explanation of the extra intensive support group not improving in quality of life might be that in cases of severe challenging behaviour, a longer time period is needed to improve quality of life.

Improvement in challenging behaviour in the extra intensive support group over time was associated with more intensive individual care, but the professional's ability to create a different environment or support setting through higher availability of financial means might also be an important contributor. It is known that not only physical, but also organizational aspects of the onto-, micro-, meso-, exo- and macrosystem may be of influence on the incidence of challenging behaviour (Bronfenbrenner & Morris, 2006; Olivier-Pijpers et al., 2018; Olivier-Pijpers et al., 2020). For example, the relevance of direct physical environment as earlier addressed by Roos et al. (2022), but also factors such as grouping of residents can be of influence on challenging behaviour (Olivier-Pijpers et al., 2020). Furthermore, factors within staff are important to consider, since individuals with extra intensive support are highly dependent upon them (Embregts et al., 2023; Wissink, 2015). For example as staff turnover or staff's sense of safety (Olivier-Pijpers et al., 2020). In future research on the effects of extra intensive support for a group with specific needs, it could be important to analyse the contribution of environmental and organizational factors to incidence and severity of challenging behaviour and quality of life in addition to more intensive individual support.

Differences between groups receiving IS or IS+ at time of inclusion

As expected, the individuals with extra intensive support showed higher levels of challenging behaviour, and their challenging behaviour is experienced as more severe. Both groups showed a similar profile of challenging behaviour, i.e. differences between groups could not be pinpointed to one or more specific domains of challenging behaviour. Furthermore, individuals with extra intensive support showed a higher number of co-morbid mental health classifications and a stronger focus on goals in ISPs to reduce challenging behaviour than on goals to develop new behaviour.

The finding that challenging behaviour is initially higher in the extra intensive support group is partly in line with the findings of Tevis (2020), who argues that intensity and frequency of aggression against others and self is the most important factor associated with direct (more staff) and indirect needs, such as additional training to maintain safety, supervision and clinical overview.

Our results indicate that not only level of disruptive behaviour, but also levels of other forms of challenging behaviour, including internalizing challenging behaviour, were higher in the IS+ group.

Regarding adaptive behaviour, no initial differences were found between the groups, and this result was independent of type of adaptive behaviour. Level of adaptive behaviour does not seem to differentiate in support needs in our group which is in line with the results of Buntinx et al. (2010a). For quality of life, also no initial differences were found between groups.

Limitations

It is virtually impossible to account for all potentially influential factors in this highly complex group. For example, variables representing more complex medical needs were not included and therefore possible interference of severity of medical conditions cannot be evaluated. Indeed, excluding people with mostly medical needs, only people with intellectual disability for whom challenging behaviour was the most important support need were selected. Furthermore, by matching the intensive support and extra intensive support groups on gender, age and cognitive functioning, variability due to this matching might have been missed. Since severe challenging behaviour is known to occur more often in the lower range of cognitive functioning, the group on this end of this spectrum might be relatively overrepresented in the intensive support sample. Another limitation is the absence of medication data in this study, as medication could influence level of behaviour. Pharmacological interventions in adults with intellectual disability are often administered, especially when challenging behaviour is present for the regulation of behaviour. Their potential influences could be diverse (Bowring et al., 2017; Groves et al., 2023).

Unavoidably, the last time wave was partly affected by covid measures, which complicates the interpretation of its results. In most qualitative studies it is hypothesized that people with an intellectual disability and high support needs display more anxiety, distress, or challenging behaviour during quarantine periods, because of their already increased vulnerability, accompanied by sudden changes in daily routine and social interaction (Buonaguro & Bertelli, 2021; Doody & Keenan, 2021). Consequently, in our study an increase in challenging behaviour was expected instead of the observed decrease. It is therefore possible that the improvement in challenging behaviour in the extra intensive support group is an underestimation.

Due to the level of intellectual disability, self-evaluation was not feasible. Therefore, proxy assessment by primary staff was used to complete the questionnaires regarding challenging behaviour, adaptive functioning and quality of life, probably increasing likelihood of reporting socially desirable answers or underestimation of quality of life of adults with intellectual disability, compared with self-reports, especially on more subjective aspects as emotional/psychological domains (Koch et al., 2015). The use of multiple-proxy assessment may help to increase reliability. Future research can be improved by using structured observations in addition to questionnaires, to serve the ecological validity of findings.

In order to strengthen the generalizability of our conclusions, four residential disability service organizations were involved. These organizations offered similar type of group home living, and are highly specialized in care for people with intellectual disability and (severe) challenging behaviour. Therefore, one should not generalize the results in these highly specialized and organized organizations to smaller organizations with less specialization.

Clinical implications

This research contributes to knowledge to correctly and responsibly allocate funding to enable extra intensive support, and its effectiveness over time. It appears that those individuals with more severe challenging behaviour and more mental health problems are the ones receiving extra intensive support, i.e. serving those who need this support most. Following the results of this study it is furthermore recommended to develop allocation policies for extra intensive support. An objective assessment framework of measures of challenging behaviour, adaptive behaviour and quality of life, also over time, should be implemented as an important and valuable addition to qualitative descriptions as evaluation method. Measures such as the Supports Intensity Scale (Thompson et al., 2004) show promising results in identifying those in need of extra intensive support - for example (Wehmeyer et al., 2009).

Results of this study indicate the efficacy of extra intensive support, focused on reducing challenging behaviour as an initial intervention. Diminishing challenging behaviour to restore stability can be a primary emphasis in clinical practice. However, once this goal has been achieved, renewed emphasis should be placed on the restoration of quality of life. Our results indicate that reducing challenging behaviour by extra intensive support does not necessarily coincides with an enhancement in quality of life.

The evaluation whether individuals with intellectual disability and severe challenging behaviour are entitled to extra intensive support, is currently mainly oriented on client characteristics (onto-system), but should shift towards a more integrated approach of understanding the complexity of challenging behaviour, taking into account contextual factors as well. The presence of challenging behaviour should be seen as a starting point in this evaluation, recognizing the interactive interplay of different factors of individual functioning, as outlined by Embregts et al. (2023). This paper moreover adds a heightened emphasis on systematic, longitudinal monitoring, especially within clinical practice.

In conclusion, this study demonstrated the effectiveness of extra intensive support in a three years follow-up. Furthermore, it was shown that extra intensive support treatment was indeed offered to participants presenting with the most severe level of challenging behaviour in combination with more mental health classifications. Differences in challenging behaviour between groups could not be pinpointed to specific domains of challenging behaviour. In addition, extra intensive support was also characterized by a higher number of support plan goals. The results suggest that the governmental funding policies and systems of service provision in the country are effectively meeting the needs of those requiring this extra high level of support. Furthermore, more intensive support resulted in a reduction in level of challenging behaviour over three years' time, underscoring the effectiveness of the implemented extra care.

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

Baar, A. L. V., Steenis, L. J. P., Verhoeven, M., & Hessen, D. J. (2014). *Bayley-III-NL Bayley Scales of Infant and Toddler Development – Third Edition – NL*. Universiteit Utrecht.

Barron, D. A., Hassiotis, A., & Paschos, D. (2011). Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality. *Journal of Intellectual Disability Research*, *55*, 832-843. https://doi.org/10.1111/j.1365-2788.2011.01405.x

Beadle-Brown, J., Mansell, J., Whelton, B., Hutchinson, A., & Skidmore, C. (2006). Too Far to Go: Out-of-Area Placements for People with Intellectual Disabilities. *Tizard Learning Disability Review*, *11*(1), 24-+. https://doi.org/10.1108/13595474200600005

Bonell, S., Ali, A., Hall, I., Chinn, D., & Patkas, I. (2011). People with Intellectual Disabilities in Out-of-Area Specialist Hospitals: What Do Families Think? *Journal of Applied Research in Intellectual Disabilities*, *24*(5), 389-397. https://doi.org/10.1111/j.1468-3148.2010.00623.x

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

Bowring, D. L., Totsika, V., Hastings, R. P., Toogood, S., & McMahon, M. (2017). Prevalence of psychotropic medication use and association with challenging behaviour in adults with an intellectual disability. A total population study. *Journal of Intellectual Disability Research*, *61*(6), 604-617. https://doi.org/10.1111/jir.12359

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner & W. Damon (Eds.), *Handbook of child psychology:* Vol 1, Theoretical models of human development (6th ed., pp. 793–828). Wiley.

Bruinsma, E., van den Hoofdakker, B. J., Hoekstra, P. J., de Kuijper, G. M., & de Bildt, A. A. (2022). Exploring the association of staff characteristics with staff perceptions of quality of life of individuals with intellectual disabilities and challenging behaviours. *Journal of Applied Research in Intellectual Disabilities*, *35*(5), 1231-1243. https://doi.org/10.1111/jar.13017

Buntinx, W. H. E., Herps, M., & De Ruiter, M. (2012). *Handreiking Ondersteuningsplannen*. Kennisplein Gehandicaptensector, VGN. Retrieved 5 September 2022 from https://www.vgn.nl/system/files/article/file/Handreiking%2B2.%2BOndersteuningsplannen%2B2013.pdf

Buntinx, W. H. E., Maes, B., Claes, C., & Curfs, P. (2010a). De Nederlandstalige versie van de supports intensity scale: psychometrische eigenschappen en toepassingen. *NTZ*, *36*(1), 4-27.

Buntinx, W. H. E., & Schalock, R. L. (2010b). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(4), 283-294. https://doi.org/10.1111/j.1741-1130.2010.00278.x

Buonaguro, E. F., & Bertelli, M. O. (2021). COVID-19 and intellectual disability/autism spectrum disorder with high and very high support needs: issues of physical and mental vulnerability. *Advances in Mental Health and Intellectual Disabilities*, *15*(1), 8-19. https://doi.org/10.1108/Amhid-07-2020-0016

Burack, J. A., Evans, D. W., Russo, N., Napoleon, J. S., Goldman, K. J., & Iarocci, G. (2021). Developmental Perspectives on the Study of Persons with Intellectual Disability. *Annual Review of Clinical Psychology, Vol 17, 2021*, *17*, 339-363. https://doi.org/10.1146/annurev-clinpsy-081219-090532

CBS. (2023, 27 January 2023). *Personen met indicatie naar gebruik Wlz-zorg; indicatie, leveringsvorm, zzp*. Centraal Bureau voor de Statistiek. Retrieved 13 March 2023 from https://opendata.cbs.nl/#/CBS/nl/dataset/84529NED/table?searchKeywords=verstandelijke%20beperkingen

Claes, C., Van Hove, G., van Loon, J., Vandevelde, S., & Schalock, R. L. (2009). Evaluating the inter-respondent (consumer vs. staff) reliability and construct validity (SIS vs. Vineland) of the Supports Intensity Scale on a Dutch sample. *Journal of Intellectual Disability Research*, *53*, 329-338. https://doi.org/10.1111/j.1365-2788.2008.01149.x

Cohen, J. (1992). Quantitative methods in psychology: A power primer. *Psychological bulletin*, *112*, 1155-1159.

Deveau, R., McGill, P., & Poynter, J. (2015). Characteristics of the most expensive residential placements for adults with learning disabilities in South East England: a follow-up survey. *Tizard Learning Disability Review*, *20*(2), 97-102. https://doi.org/10.1108/Tldr-01-2015-0003

Doody, O., & Keenan, P. M. (2021). The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: a scoping review. *Annals of Medicine*, *53*(1), 786-804. https://doi.org/10.1080/07853890.2021.1922743

Došen, A. (2014). *Psychische stoornissen, probleemgedrag en verstandelijke beperking*. Koninklijke Van Gorcum.

Embregts, P., Kroezen, M., Mulder, E., Van Bussel, C., Van der Nagel, J., Budding, M., Busser, G., De Kuijper, G., Duinkerken-Van Gelderen, P., Haasnoot, M., A, H., B, L., DAM, M.-F., V, O.-P., M, O., I, O. L., CJ, S., T, S., J, V. d. H.,...J, W. (2019). *Multidisciplinaire richtlijn probleemgedrag bij volwassenen met een verstandelijke beperking*. Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten.

Embregts, P. J. C. M., Didden, R., Moonen, X., Leusink, G., & Schuengel, C. (2023). Kenmerken en ondersteuningsbehoeften van mensen met een licht of ernstig verstandelijke beperking en ernstig probleemgedrag en psychische problematiek. *NTZ: Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen*, *49*(3), 11.

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

Felce, D., Kerr, M., & Hastings, R. P. (2009). A general practice-based study of the relationship between indicators of mental illness and challenging behaviour among adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *53*, 243-254. https://doi.org/10.1111/j.1365-2788.2008.01131.x

Griffith, G. M., Hutchinson, L., & Hastings, R. P. (2013). “I’m not a patient, I’m a person”: The Experiences of Individuals With Intellectual Disabilities and Challenging Behavior-A Thematic Synthesis of Qualitative Studies. *Clinical Psychology-Science and Practice*, *20*(4), 469-488. https://doi.org/10.1111/cpsp.12053

Groves, L., Jones, C., Welham, A., Hamilton, A., Liew, A., & Richards, C. (2023). Non-pharmacological and pharmacological interventions for the reduction or prevention of topographies of behaviours that challenge in people with intellectual disabilities: a systematic review and meta-analysis of randomised controlled trials. *Lancet Psychiatry*, *10*(9), 682-692. https://doi.org/10.1016/S2215-0366(23)00197-9

Hassiotis, A., Strydom, A., Hall, I., Ali, A., Lawrence-Smith, G., Meltzer, H., Head, J., & Bebbington, P. (2008). Psychiatric morbidity and social functioning among adults with borderline intelligence living in private households. *Journal of Intellectual Disability Research*, *52*, 95-106. https://doi.org/10.1111/j.1365-2788.2007.01001.x

Hopman, F. (2021). *Van Meerzorg naar passende zorg: bouwstenen voor een toekomstbestendige langdurige zorg* (2021016866). Zorginstituut Nederland.

Knapp, M., Comas-Herrera, A., Astin, J., Beecham, J., & Pendaries, C. (2005). Intellectual disability, challenging behaviour and cost in care accommodation: what are the links? *Health & Social Care in the Community*, *13*(4), 297-306. https://doi.org/DOI 10.1111/j.1365-2524.2005.00539.x

Koch, A. D., Vogel, A., Becker, T., Salize, H. J., Voss, E., Werner, A., Arnold, K., & Schutzwohl, M. (2015). Proxy and self-reported Quality of Life in adults with intellectual disabilities: Impact of psychiatric symptoms, problem behaviour, psychotropic medication and unmet needs. *Research in Developmental Disabilities*, *45-46*, 136-146. https://doi.org/10.1016/j.ridd.2015.07.022

Kort, W., Schittekatte, M., Bosmans, M., Compaan, E., Dekker, P., Vermeir, G., & Verhaeghe, P. (2005). *WISC-III NL: handleiding en verantwoording*. In: Pearson.

Kraijer, D., & Plas, J. (2014). *Handboek psychodiagnostiek en beperkte begaafdheid* (4 ed.). Pearson Education Benelux B.V.

Lamoureux-Hebert, M., Morin, D., & Crocker, A. (2010). Support needs of individuals with mild and moderate intellectual disabilities and challenging Behaviors. *Journal of Mental Health Research in Intellectual Disabilities*, *3*(2), 67-84. https://doi.org/10.1080/19315861003650558

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

Mohr, C., Tonge, B. J., & Einfeld, S. L. (2005). The development of a new measure for the assessment of psychopathology in adults with intellectual disability. *Journal of Intellectual Disability Research*, *49*, 469-480. https://doi.org/10.1111/j.1365-2788.2005.00701.x

Mohr, C., Tonge, B. J., Einfeld, S. L., & Taffe, J. (2011). *Manual for the developmental behaviour checklist for adults (DBC-A). Supplement to the Manual for the Developmental Checklist - DBC-P and DBC-T*. University of New South Wales and Monash University.

Mohr, C., Tonge, B. J., Taffe, J., & Einfeld, S. L. (2012). The availability of normative data for the Developmental Behaviour Checklist for Adults. *Journal of Intellectual & Developmental Disability*, *37*(1), 61-64. https://doi.org/10.3109/13668250.2011.649719

Olivier-Pijpers, V. C., Cramm, J. M., Buntinx, W. H. E., & Nieboer, A. P. (2018). Organisational environment and challenging behaviour in services for people with intellectual disabilities: A review of the literature. *Alter-European Journal of Disability Research*, *12*(4), 238-253. https://doi.org/10.1016/j.alter.2018.06.004

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

Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D., Meek, A., Carr, D., Lowe, K., Knapp, M., & Hallam, A. (2004). Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. *American Journal on Mental Retardation*, *109*(4), 332-344.

Roos, J., Koppen, G., Vollmer, T. C., Van Schijndel-Speet, M., & Dijkxhoorn, Y. (2022). Unlimited surrounding: A scoping review on the impact of the built environment on health, behavior, and quality of life of individuals with intellectual disabilities in long-term care. *Herd-Health Environments Research & Design Journal*, *15*(3), 295-314.

Sandjojo, J., Zedlitz, A. M., Gebhardt, W. A., Hoekman, J., Dusseldorp, E., den Haan, J. A., & Evers, A. W. (2018). Training staff to promote self-management in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *31*(5), 840-850.

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 Washington, DC.

Seo, H., Shogren, K. A., Wehmeyer, M. L., Little, T. D., & Palmer, S. B. (2017). The impact of medical/behavioral support needs on the supports needed by adolescents with intellectual disability to participate in community life. *Ajidd-American Journal on Intellectual and Developmental Disabilities*, *122*(2), 173-191. https://doi.org/10.1352/1944-7558-122.2.173

Sparrow, S., Carter, A., & Cicchetti, D. (1993). Vineland Screener: Overview, reliability, validity, administration, and scoring. *New Haven, CT: Yale University Child Study Center*.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland adaptive behavior scales Vineland-II: Survey forms manual*. Pearson Minneapolis, MN.

Taffe, J. R., Tonge, B. J., Gray, K. M., & Einfeld, S. L. (2008). Extracting more information from behaviour checklists by using components of mean based scores. *International Journal of Methods in Psychiatric Research*, *17*(4), 232-240. https://doi.org/10.1002/mpr.260

Tellegen, P., & Laros, J. (2011). *SON-R 6-40 Snijders-Oomen Niet-verbale intelligentie test*. Amsterdam: Hogrefe.

Tellegen, P., & Laros, J. A. (2017). *SON-R niet-verbale intelligentietest*. Amsterdam: Hogrefe.

Tevis, K. (2020). *Long-term behavioral health care unbundled: The impact of comorbidity and aggression on caregiver strain and service costs for individuals with intellectual disabilities* The University of Nebraska-Lincoln].

Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., & Wehmeyer, M. L. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, *47*(2), 135-146. https://doi.org/10.1352/1934-9556-47.2.135

Thompson, J. R., Bryant, B., Campbell, E., Craig, E., Hughes, C., & Rotholtz, D. (2004). *Support intensity scale*. Washington DC: American Association on Mental Retardation.

Unwin, G., Deb, S., & Deb, T. (2017). An exploration of costs of community-based specialist health service provision for the management of aggressive behaviour in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *30*(2), 316-325. https://doi.org/10.1111/jar.12241

van Duijn, G., Dijkxhoorn, Y., Noens, I., Scholte, E., & van Berckelaer-Onnes, I. (2009). Vineland Screener 0-12 years research version (NL). Constructing a screening instrument to assess adaptive behaviour. *International Journal of Methods in Psychiatric Research*, *18*(2), 110-117. https://doi.org/10.1002/mpr.282

Verdugo, M. A., Gomez, L., Arias, B., Santamaria, M., Navallas, E., Fernandez, S., & Hierro, I. (2014). *San Martin Scale: Assessment of quality of life in persons with significant intellectual and developmental disabilities*. Salamanca: Institute on Community Integration.

Wechsler, D. (1989). Wechsler preschool and primary scale of intelligence--revised. *Journal of School Psychology*.

Wechsler, D. (1991). *Wechsler intelligence scale for children–Third Edition*. *San Antonio, TX: The Psychological Corporation*.

Wechsler, D. (2008). *Wechsler adult intelligence scale* (3rd ed.). The Pscychological Corporation.

Wechsler, D. (2012). *WAIS-IV-NL: Wechsler Adult Intelligence Scale: Nederlandse bewerking*. Pearson Assessment and Information BV.

Wehmeyer, M., Chapman, T. E., Little, T. D., Thompson, J. R., Schalock, R., & Tasse, M. J. (2009). Efficacy of the Supports Intensity Scale (SIS) to Predict Extraordinary Support Needs. *Ajidd-American Journal on Intellectual and Developmental Disabilities*, *114*(1), 3-14. https://doi.org/10.1352/2009.114:3-14

Wissink, J. (2015). *Floreren: Zoektocht naar goed leven voor mensen met een ernstige verstandelijke beperking en ernstige gedragsproblemen*. Amsterdam: Vrije Universiteit.

ZorgverzekeraarsNederland. (2023). *Voorschrift zorgtoewijzing 2023*. Zorgverzekeraars Nederland (ZN). Retrieved February 6 2023 from https://www.zn.nl/app/uploads/2023/04/Voorschrift_Zorgtoewijzing_2023_ZONDER-wijzigingen_december_versie_241122.pdf

4

CHAPTER 4

Adults with intellectual disability in long-term, intensive support care: the relationship between communication and challenging behaviour

ABSTRACT

Background Deficits in communication are a well-known risk factor for developing challenging behaviour (CB), especially in persons with intellectual disability. The objective of this study was to gain more insight into the relative contribution of different aspects of communication to different forms of CB in individuals with ID who receive intensive support due to their severe challenging behaviour.

Methods Cross-sectional study of 169 adults with ID and persistent challenging behaviour, residing in long-term high-support care were included. Level of cognitive functioning (CF) was estimated on the basis of cognitive assessment, resulting in 80 adults with a level of cognitive functioning (CF) below 48 months, and 89 adults with a level of CF at or above 48 months. Participants were assessed for adaptive behaviour with the Vineland-II Adaptive Behavior Scales, differentiating between expressive communication and receptive communication (comprehension). Challenging behaviour was measured with the Developmental Behavioural Checklist-Adults.

Results For all participants, regarding subdomains of CB, the strongest relationship was observed between receptive comprehension and internalizing problems such as self-absorbed behaviour, anxiety and problems in interactive behaviour. Less receptive comprehension and being male was associated with higher risk for overall challenging behaviour in persons with relatively higher cognitive functioning.

Conclusions More difficulties in comprehension of communication seem to result in more social withdrawal (self absorbed behaviour and less interaction) and more anxiety in persons across the whole range of ID. This underlines the importance of supporting communication abilities in people with ID.

Adults with intellectual disability in long-term, intensive support care: the relationship between communication and challenging behaviour

A substantial amount of individuals with intellectual disability (ID) need lifelong care, offered by specialized service organizations. This support by service organizations can vary in intensity. When severe and persistent challenging behaviour (CB) is present, the highest level of intensive support is needed, supporting all areas of daily life. Challenging behaviour is defined as behaviour which is culturally abnormal, endangers the physical safety of the person (or others), and/or limits the use/access to ordinary community facilities (Emerson, 2001). People with ID living in these specialized residential care settings show a higher prevalence of challenging behaviour, i.e. 50-80% versus 10-18% in the total population with ID (Bowring et al., 2019). Challenging behaviour can result in multiple negative outcomes for the individual (lower quality of life, risk of self-harm, seclusion/separation), or for their support team (risk of harm, distress). In order to mitigate the impact of challenging behaviour by support and intervention, it is necessary to understand its mechanisms.

Intellectual disability is characterized by significant limitations in cognitive functioning and adaptive behaviour (Schalock et al., 2021). When personal competencies do not meet contextual demands of the environment, this person needs specific support to be able to function in that given context. Targeted contextual support, aimed at reducing the discrepancy between individual support needs and contextual demands is a major component of care to promote individual growth and wellbeing (Schalock et al., 2021). For people with ID and severe challenging behaviour, their living environment often is a high support specialized care setting (CBS, 2023), which therefore in itself is the foremost instrument of support.

Challenging behaviour is viewed as resulting from the interaction between a person's psychosocial or biological vulnerabilities, maintaining processes (i.e. functions of challenging behaviour for *that* individual, including carers' behaviour as a contributing factor) and impact factors (impact of challenging behaviour as a cyclical relationship with more risk factors, i.e. social exclusion) (Hastings et al., 2013). For example, psychosocial factors that are consistently associated with higher levels of challenging behaviour are an individuals' limited understanding of communication or being non verbal, severity of intellectual disability, but also having no daytime activity or living in an institutional setting (Bowring et al., 2019).

According to van den Akker et al. (2021) underlying mechanisms for challenging behaviour should be seen as multifactorial. For aggressive behaviour, multiple behavioural, psychiatric and psychosocial factors interact. The causes of challenging behaviour, they argue, are specific for a person in its particular context and intervention targets should be formulated following functional assessments of the individual to optimize support. This means that it is necessary to further identify mechanisms in severe challenging behaviour and develop support and interventions targeted at these factors. An important priority of staff in specialized settings should be to tailor their interactions based on an individuals' specific needs. Positive and meaningful interactions between staff and persons with ID contribute to a higher quality of life. For persons with persistent challenging behaviour, these interactions are even more complicated and a mismatch between a staff members' communication skills and a person's ability to communicate can worsen the challenging behaviour (Simons et al., 2021).

Communication – as an important part of adaptive functioning - is often affected in people with ID (Schalock et al., 2021). Communication abilities can be distinguished in expressive, receptive and written communication (Sparrow et al., 1984). Expressive communication refers to spoken language, for example, to express one's needs to others. Expressive communication is not limited to verbal language, it also involves the ability to express intentions by gestures, eye gaze, and facial expressions. Receptive communication is the ability to understand the communication of others, to comprehend interaction and intention. The use of written language refers to the ability to integrate both into writing or reading.

The relationship between communication difficulties and challenging behaviour is well established for typically developing children. Receptive and expressive communication difficulties predict challenging behaviour in children, more than other aspects of risk status, like low socio-economic status or age (Chow & Wehby, 2018). Adaptive behaviour, including the ability to communicate, similarly is a well-known predictor for challenging behaviour in people with ID, with lower levels of communicative functioning associated with more challenging behaviour (Bowring et al., 2019; Felce & Kerr, 2013). Studies that focus on the relation between communication difficulties and challenging behaviour often reduced the concept of communication difficulties to, for example, speech present or not present, or 'limited understanding', i.e. not taking severity of communication deficits, or type of communication difficulties, into account. This approach precludes to study eventual differential effect of various types of communication difficulties and their interaction with challenging behaviour and the impact of severity of these difficulties (Bowring et al., 2019; Bowring et al., 2017; Smith et al., 2020). Therefore, this study will fill this gap by evaluating severity and type of communication difficulties in relation to severity and type of challenging behaviour in persons with ID and persistent challenging behaviour. The outcome may help to determine focus on individual and contextual support needs on the basis of assessed communication profiles. We hypothesize that for people with more severe ID, more serious communication difficulties are associated with more severe challenging behaviour.

METHOD

Procedure

Data in this study were collected in the first measurement period [2017-2018] of the longitudinal SCORE study. This study evaluates the regular care of people with ID and persistent challenging behaviour and intensive support needs, living in group homes in four service organisations specialized in care for persons with ID (Ipse de Bruggen, de Hartekamp Groep, Cordaan and Ons Tweede Thuis).

Ethical approval for the study was granted by the ethics committee of the Faculty of Social and Behavioural Sciences, Department of Clinical Neurodevelopmental Sciences, University of Leiden, The Netherlands (ECPW-2015/094), and the ethical committee of the largest participating service organization (Ipse de Bruggen).

Participants

Persons were eligible for inclusion when individuals met the following criteria: Adults with intellectual disability, living in residential care facilities in group homes, with a very intensive support need due to severe and persistent challenging behaviour. Typically, in intensive support the client-staff ratio is 4/3:1.

Candidates meeting the inclusion criteria (*N*=543) and their legal representatives were invited to participate in the study. Legal representatives (where applicable, the person with ID themselves) were informed about the study by written and online information and asked for informed consent. Seventy percent of the candidates of the four service organizations responded to the invitation (*N*=381) of which *N*=92 (24.4%) declined participation after receiving information and *N*=289 agreed to participate.

N=56 participants dropped out during the course of the study, due to e.g. moving to another service organization, illness or death, logistic problems within the support team, or withdrawal of consent Furthermore, participants were only included for analyses if they had complete data on all variables of interest for analysis, i.e. DBC-A, cognitive functioning (recent intelligence score, <5 years at inclusion), and Vineland-II, resulting in a final total of *N*=169 participants (115 men, 54 women) whose data were subjected to analysis.

Measures

Level of Cognitive Functioning

IQ scores were derived from scores on standardized cognitive assessments, performed within the last 5 years to inclusion, such as the BSID-II-NL/Bayley-III (Baar et al., 2014), WISC-III-NL, WPPSI-III-NL, WAIS III-NL (Wechsler, 1991; Wechsler, 2012; Wechsler et al., 2011), SON-R, SON 2-8 nonverbal-test (Tellegen & Laros, 2011; Tellegen & Laros, 2017). These tests had sufficient reliability and validity. Variation in developmental/IQ tests was due to variation of use in clinical practice. Participants' own psychologist decided which assessment instrument was most suitable according to each individuals' profile, based on their cognitive level of functioning (including as well language use, motor skills etc.) and aim of assessment, in line with clinical guidelines (Embregts et al., 2019). To facilitate comparability and interpretation of scores, all outcomes were converted to cognitive age equivalents. To further explore the impact of the intellectual disability on challenging behaviour, participants were divided in two groups based on level of cognitive functioning (CF), i.e. CF age equivalent < 4 years vs. CF ≥ 4 years. This division aligns with Došen's (2014) proposed cognitive developmental age differentiation between severe and moderate ID, which is roughly in line with Piagets' (sub)stages of cognitive development (Piaget, 1952). It also corresponds with literature associating lower levels of cognitive functioning (in age equivalents) with more severe levels of intellectual disability (Toffalini et al., 2019).

Communication Skills: Vineland Adaptive Behavior Scale (Vineland II)

The Vineland II (Sparrow et al., 2005), is a commonly accepted measure of adaptive skills and has been used extensively in research in subjects with ID. Data were collected by certified master students and research assistants, who completed training and supervision in Vineland II interviewing. The Vineland II is administered as a semi-structured interview, conducted with the professional primary caretaker, and consists of 577 questions resulting in a total score for adaptive behaviour, as well as scores on four domains of which the domain Communication skills will be used, i.e. age equivalents in months of Expressive and Receptive communication. Written communication was left out as virtually none of the participants were able to write. The Vineland II has good to excellent reliability and validity (Sparrow et al., 2005).

Challenging behaviour, Developmental Behaviour Checklist – Adult (DBC-A)

The DBC-A is a carer-completed 107-item questionnaire that assesses a comprehensive range of emotional, behavioural and mental health problems in adults with mild, moderate and more severe levels of ID (Mohr et al., 2011). Professional primary caretakers were asked to fill out the questionnaire. Questions can be answered by assigning number 0, 1, or 2, a higher number reflecting higher frequency of the particular challenging behaviour. Next to a Total composite score, six problem domains are distinguished, i.e. Disruptive behaviour, Communication Disturbances and Anxiety, Antisocial behaviour, Self-absorbed behaviour, Depressive and Problems Relating Social. Mean item scores (MIS) will be computed for the Total composite and domain scores for a valid comparison between domains. A higher score denotes more challenging behaviour. The DBC-A is a reliable and internally consistent instrument with Cronbach's alpha for the total score of $\alpha = .95$ and for the subscales $\alpha = .71 - .91$ (Mohr et al., 2011).

Statistical analyses

The Vineland age equivalent scores on Receptive and Expressive communication were used. Differences between the groups (lower CF vs. higher CF) in age at assessment, cognitive age equivalent and total Challenging Behaviour (CB) were assessed through independent samples *t*-tests. Two MANOVAs were performed to evaluate eventual differences between groups in receptive and expressive communication and subdomain scores on the DBC-A, respectively.

To test the hypothesis that severity of communication difficulties is associated with severity of CB, a series of regression analyses were planned. First, to identify possible predictors of CB, correlational analyses for lower CF and higher CF, separately, were performed for CB total score, receptive and expressive communication, gender, and age. As the CB total score is the resultant of substantively different domains, i.e. internalizing vs externalizing behaviours, correlations of these predictor variables with the subdomains of CB were also performed for both groups.

For the group with lower CF, total CB did not correlate with any of these variables which allowed us to omit a regression analysis on total CB in this group. For the higher CF group total CB correlated with both Receptive (r=-.464, p<.001), and Expressive communication (r=-.328, p=.002). Receptive communication and Expressive communication appeared to be highly correlated in the higher CF group (r=.68, p<.001), therefore the interaction term of these predictors was added as a predictor and both variables were centered to facilitate interpretation of the coefficients of predictors and the interaction term.

To estimate the contribution of each of the predictors to the amount of explained variance in CB, a hierarchical regression analysis was performed (method ENTER). Gender was added in the first step, level of receptive communication and expressive communication were added in the second step, and the interaction term of the latter two predictors (REC*EXPR) was added in the third step. Exploratory regression analyses were conducted with the same predictors as used in the main analysis for the different domains of CB (DBC), using method BACKWARD, for lower CF and higher CF group.

Preliminary *t*-tests for independent samples were performed to verify whether those who were subjected to data analysis did not differ from those who were lost to analysis, due to missing data on at least one variable of interest. These groups did not significantly differ on calendar age, cognitive functioning, DBC-A total score, and receptive communication (.149<p<.641). The group that was lost to analysis had a significantly lower score on expressive communication (t(220)=-2.306, p=.022). We have demonstrated that the sample with subjects that have all data of all variables of interest, do not differ on main outcome variables from those that have missing values on at least one variable, except for expressive communication. Data were analysed using SPSS statistics version 29 (SPSS, 2023).

RESULTS

With regard to the use of parametric tests, all key assumptions pertaining to the variables of interest were met. The lower CF group (N=80) and the high CF group (N=89) did not differ at distribution of gender ($p=.239$) nor at mean age of assessment in years ($p=.699$) (lower CF $M=41.18$, $SD=14.83$; higher CF $M=40.33$, $SD=14.03$). The groups did differ on total CB ($t(167)=2.528$, $p=.012$, $d=.389$), and, indeed, on mean cognitive age equivalent in months ($t(17)=-15.885$, $p<.001$, $d=-2.447$), to the disadvantage of the lower CF group, see Table 1. A significant effect of group on communication scores was found as well ($F(2,166)=90.796$, $p<.001$, $\eta_p^2=.522$), with the lower CF group having lower levels for both Receptive Communication ($F(1,167)=129.867$, $p<0.001$, $\eta_p^2=.437$) and Expressive Communication ($F(1,167)=174.477$, $p<.001$, $\eta_p^2=.511$.

Furthermore, the multivariate test on the subdomain scores of the DBC-A was significant, ($F(6,162)=13.113$, $p<.001$, $\eta_p^2=.327$). Differences between the two CF groups pertain only to the subscale Self-Absorbed, the group with lower CF having a significantly higher score ($F(1,167)=53.034$, $p<.001$, $\eta_p^2=.241$), see Table 2. On all other subdomains, differences were non-significant ($.104<p<.400$). This result suggests that self-absorbed behaviour is the main contributor to differences in CB between groups.

Table 1

Participants descriptives of level of cognitive functioning (cognitive age equivalent in months from recent IQ/developmental test), challenging behaviour (Developmental Behaviour Checklist-Adults MIS total PBS, range 0-2) and adaptive behaviour (Vineland II age equivalent in months for level of Receptive and Expressive communication) for two groups with lower and higher cognitive functioning (i.e. cognitive age equivalent below or above 48 months).

Group	**lower CF *N*=80**	**higher CF *N*=89**
	Mean *(SD)*	**Mean *(SD)***
Gender (male, %)	72.5%	64%
Age equivalent of cognitive functioning	27.79 (13.62)	85.86 (29.93)
Challenging Behaviour	.60 (.24)	.51 (.23)
Receptive communication	23.63 (13.54)	59.06 (24.66)
Expressive communication	24.95 (17.08)	68.35 (24.52)

Table 2

Domain scores of challenging behaviour (DBC-A, Mean Item Score (MIS, range 0-2) for each domain for lower and higher cognitive functioning (i.e. cognitive age equivalent below or above 48 months).

Group	**lower CF *N*=80**	**higher CF *N*=89**
	Mean *(SD)*	**Mean *(SD)***
Disruptive	.79 (.37)	.72 (.36)
Communication Disturbances/Anxiety	.63 (.33)	.56 (.30)
Self-absorbed	.68 (.35)	.34 (.24)
Antisocial	.46 (.34)	.55 (.35)
Depressive	.46 (.31)	.52 (.32)
Social relating	.77 (.39)	.71 (.39)

For both the lower CF and the higher CF group, MIS scores on domains of CB significantly correlated with receptive and expressive communication or their interaction [Table 3 and Table 4] .

Table 3

Lower Cognitive Functioning (N=85): Correlations of challenging behaviour (Developmental Behaviour Checklist-Adults, Mean Item score for each domain) with receptive and expressive communication scores (Vineland adaptive age equivalent in months) + interaction term.

	Disruptive	**Communication Disturbance/ Anxiety**	**Self Absorbed**	**Antisocial**	**Depressive**	**Social relating**
Gender	.187, *p*=.087	n.s.	n.s.	n.s.	n.s.	n.s.
Receptive Communication	n.s.	.237*	-.579**	.186, *p*=.088	n.s.	-.260*
Expressive Communication	n.s.	.343*	-.494**	.355**	n.s.	-.249*
Interaction REC*EXPR	n.s.	-.238*	n.s.	n.s.	n.s.	n.s.

$^{*}p < .05$. $^{**}p < .001$

Regression analysis in the higher CF group resulted in a significant final model (*F* (4, 84)=6.846, *p*<.001), predicting 24.6% of the variance in CB (see Table 5). Rerunning the same analysis with only the significant predictors yielded the same results. Receptive communication and gender contribute significantly to the prediction of total CB for the group with higher CF, with less receptive communication skills and being male as risk factors for more CB.

Table 4

Higher Cognitive Functioning group (N=89): Correlations of challenging behaviour (DBC-A, Mean Item Score for each domain) with receptive and expressive communication scores (Vineland adaptive functioning age equivalent in months) + interaction term.

	Disruptive	**Communication Disturbances/ Anxiety**	**Self Absorbed**	**Antisocial**	**Depressive**	**Social relating**
Gender	n.s.	n.s.	.211*	-.246*	n.s.	n.s.
Receptive Communication	-.412**	-.455**	-.426**	-.220*	n.s.	-.296*
Expressive Communication	-.266*	-.388**	-.417**	n.s.	n.s.	-.354**
Interaction REC*EXPR	-.200, *p*=.061	0.196*	n.s.	-.239*	n.s.	n.s.

$^{*}p < .05$. $^{**}p < .001$

Table 5

Coefficients in final model for higher CF group.

	B	**Std error**	***β***	***t***	***p***	**95% CI**	
Predictors						**lower**	**upper**
Constant	.607	.067		0.107	*<.001*	.475	.740
Gender	-.078	.045	-.168	-1.750	.084	-.167	.011
Receptive communication	-.004	.001	-.477	-2.993	.004	-.007	-.001
Expressive communication	.000	.001	-.032	-.234	.816	-.003	.002
Interaction REC*EXPR	.000	.001	.060	.517	.606	.000	.000

The exploratory regression analyses for the group with higher CF, predicting specific subdomains of CB, resulted in significant models for Depressive (*p*=.019) and all other subdomains (*p*<.001). The explained variance was 27.3% for Self-Absorbed Behaviour (Gender β=-.253, Receptive Communication β=-.231), 20.7% for Communication Disturbance and Anxiety (Receptive Communication, β=-.455), 17.0% for Disruptive Behaviour (Receptive Communication, β=-.412), 12.6% for Social Relating (Expressive Communication, β=-.354), 11.1% for Antisocial Behaviour (Gender β=-.251, Receptive Communication, β=-.225), 8.9% for Depressive Behaviour (Expressive Communication β=.303, Receptive Communication, β=-.404). Negative β coefficients indicate that lower communication skills were associated with higher CB.

Post hoc analyses were performed in the higher CF group on the regression results for the subdomain Communication Disturbance/Anxiety, in which we separately analysed the items regarding Communication Disturbances and items relating to Anxiety. Regression models remained significant with Expressive Communication as remaining predictor for Communication disturbances (β=-.341) and Receptive Communication for Anxiety (β=-.435), suggesting that Expressive communication difficulties are more linked to Communication disturbances and Receptive communication to Anxiety, the former predictor being weaker, causing its deletion in the analysis of the total subdomain score.

The exploratory regression analyses for the lower CF group, predicting specific subdomains of CB, resulted in significant models for all subdomains except for Disruptive Behaviour. Positive β denotes higher communication skills associated with higher CB. The explained variance was 33.6 % for Self-absorbed (Receptive Communication, β=-.579), 23.1 % for Communication Disturbances-Anxiety (Expressive Communication, β=.432, interaction REC*EXPR, β=-.348), 12.6% for Antisocial Behaviour (Expressive Communication, β=.355), 11.1% for Depressive behaviour (Expressive Communication, β=.556, Receptive Communication, β=-.483), and 6.7% for Social Relating (Receptive Communication, β=-.260).

Figure 1

Adults with ID with lower cognitive functioning: Relation between Expressive communication and Communication disturbances/Anxiety as a function of level of Receptive communication (Vineland-II age equivalents < 24 months vs. ≥ 24 months).

○ Receptive communication <24 months ● Receptive communication ≥ 24 months

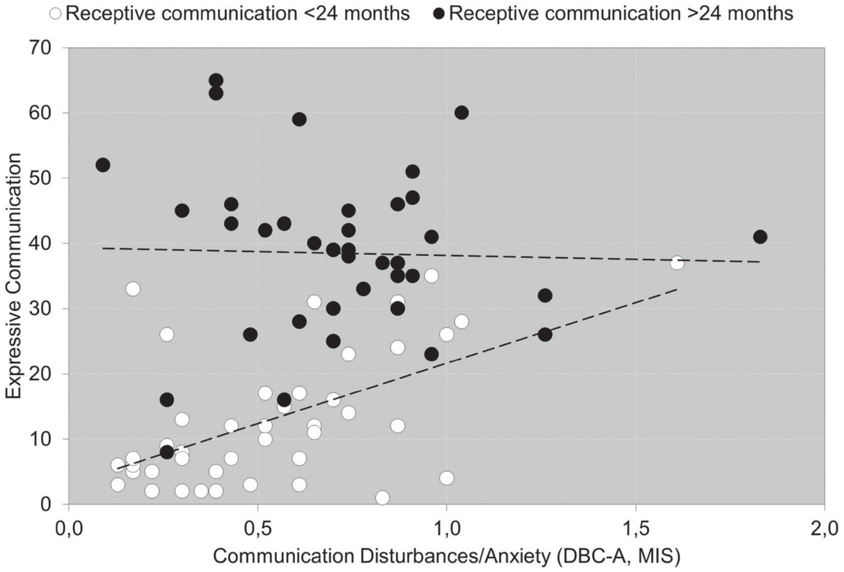


Figure 1 visualizes the significant interaction between receptive and expressive communication as one of the predictors of level of DBC-A Communication/Anxiety in adults with lower CF. For adults with higher receptive skills there is no relation between Expressive communication and Communication/Anxiety. On the other hand, for adults with lower receptive skills, communication disturbances increase with higher expressive skills.

Post hoc analysis showed that level of expressive vs. receptive communication did not differ in the lower CF group (*post hoc analysis p=.265*) and for the higher CF group expressive level was even higher when compared to receptive level (*post hoc analysis <.001).*

DISCUSSION

The regression analysis in the present study demonstrates that lower comprehension of communication and being male is a risk factor for overall challenging behaviour in adults with ID and challenging behaviour, functioning at a relatively higher level of CF, who reside in high-support care. Although the significance of gender as predictor is only *p*=.08, its contribution is of relevance. We agree with Amrhein et al. (2019) that a p-value alone is not enough to decide if a research idea should be pursued further. Our model is informative, and can serve as a solid foundation for additional research. Individuals with severe to profound ID mostly function on a presymbolic level of communication (Boardman et al., 2014) explaining limited development of behavioural skills. We did not find a relationship between skills in communication and challenging behaviour in general for the group that functions at a lower cognitive level, possibly due to a limited variance in the level of communication in this group.

In typical development, some authors argue that aspects of receptive communication precede the development of expressive communication (Luinge et al., 2006) and this holds for children with intellectual disability as well (Vandereet et al., 2010). However, both level of comprehension and expressive communication in our group with lower cognitive functioning (below 48 months) was equally low. Belva et al. (2012) found a communication profile in a sample of people with profound ID with on average higher receptive than expressive communication, which is in contrast with our results, e.g. level of expressive vs. receptive communication did not differ in the lower CF group and for the higher CF group expressive level was even higher when compared to receptive level. It could therefore be argued that the relatively poor comprehension in our sample, i.e. no proof of better receptive than expressive communication skills as found in Belva's study, explains that lower receptive communication skills account for a large part of the variance of not all, but of specific forms of challenging behaviour in this group.

Difficulties in receptive communication and comprehension seems to result in a higher vulnerability for challenging behaviour, predicting different forms of challenging behaviour with the strongest relation with internalizing behaviour at all levels of ID. More difficulties in being able to understand communication of others relates to more self-absorbed behaviour and higher levels of anxiety. At lower levels of cognitive functioning, this could be due to the inability to initiate communication and interaction. A study in children with language difficulties with an age of 24-28 months, showed that difficulties in intentional communication contributed to internalizing problem behaviour (Jansen et al., 2020). They hypothesized that this might reflect feelings of insufficiency, resulting in withdrawal from social interaction, diminished opportunities to practice, all intertwined with further impediment on language development.

Challenging behaviour may have different functions which are believed to be interrelated (Hastings et al., 2013) like stimulation, access to preferred objects, avoidance of demands, pain reduction (relief from discomfort) or attention from and contact with others. The present findings suggest the importance of considering the communicative aspects of challenging behaviour, in line with Hollo and Chow (2015), i.e. a person communicating through challenging behaviour that they are not understanding social communication or can express themselves otherwise. Challenging behaviour can be maintained by environmental responses, for example by carers' reactions. Staff is most likely to attribute challenging behaviour to an internal cause within a person, more than as an expression of needs or desires in the person due to the incapability of other communication, staff might consider it as something that cannot be changed (Poppes et al., 2016). A conscious effort of staff to better understand the communicative function of challenging behaviour might therefore lessen challenging behaviour. The results of our study suggest that there may be an opportunity to improve someone's feelings of competence and successful-interaction in enhancing communication and therefore wellbeing that might result in reduction of persistent challenging behaviour.

Numerous studies have been conducted in how staff can intervene when communication problems arise in interactions. Augmentative and alternative communication refers to interventions that support communication through non-verbal communication modes (gestures, objects, symbols) or for example with assisted technology (Beukelman & Light, 2020). In children with developmental delay different augmented communication interventions are carefully matched to level of comprehension, i.e. of initial receptive language, to maximize the facilitation of communication by caregivers (Dada et al., 2021). A recent study in children and adolescents with ID, found that higher individual communication skills were related to a decrease in challenging behaviour over time (Hofmann & Müller, 2022). Studies into communication interventions with *adults* with ID and challenging behaviour however, are more scarce (Heath et al., 2015). Even more so, a large percentage of adults with ID do not have access to appropriate augmentative communication (Light & Mcnaughton, 2015) and staffs' knowledge about augmentative communication systems for adults with ID appeared to be lacking and a need for training was observed (Sutherland et al., 2014). An important mechanism in which direct staff could intervene, could be by facilitating communication through augmentative communication, based on a thorough communicative assessment. Future evaluation of the role of augmentative communication as targeted contextual support in the development of persistent challenging behaviour over time is urgently needed in adults with ID.

The study also has some limitations. Firstly, due to level of ID, proxy assessment by primary staff was used to complete questionnaires regarding challenging behaviour and adaptive functioning. Acknowledging proxy assessment as the only possible way of gathering data, it is recommended to increase reliability in follow-up research by multiple-proxy assessments.

Furthermore, it is noted that the present study was carried out in a group of people with complex presentation of challenging behaviour, residing in long-term, high support care organizations. Results are therefore most likely only applicable to specialized care settings, where persistent and intense challenging behaviour is a criterion of receiving such care. Another limitation is that the present study only focused on communication and did not control for other factors that may be contribute in with the development of challenging behaviour, for example pain may interact with communication skills but also other factors such as mobility problems, epilepsy, genetic factors/syndromes, traumatic life events and autism should be considered. E.g., pain may have a stronger association with challenging behaviour in people with limited abilities to express their pain to others to get appropriate treatment and support. In future research, the combined effect of these other risk factors should be considered.

Conclusion

The present study shows a need for awareness for the risk of internalizing problems such as withdrawal and anxiety in relation to communication problems. It therefore underlines the importance of assessing level and type of communication abilities when challenging behaviour is present. This study further suggests that interventions targeted at the specific communication difficulties of an individual, could support quality of life by diminishing the intensity of challenging behaviour. Further research is necessary to explore this hypothesis.

REFERENCES

Amrhein, V., Greenland, S., & McShane, B. (2019). Retire statistical significance. *Nature*, *567*(7748), 305-307. https://doi.org/DOI 10.1038/d41586-019-00857-9

Baar, A. L. V., Steenis, L. J. P., Verhoeven, M., & Hessen, D. J. (2014). *Bayley-III-NL Bayley Scales of Infant and Toddler Development – Third Edition – NL*. Universiteit Utrecht.

Belva, B. C., Matson, J. L., Sipes, M., & Bamburg, J. W. (2012). An examination of specific communication deficits in adults with profound intellectual disabilities. *Research in Developmental Disabilities*, *33*(2), 525-529.

Beukelman, D. R., & Light, J. C. (2020). Augmentative and alternative communication: Supporting children and adults with complex communication needs (5th ed.). Paul H. Brookes.

Boardman, L., Bernal, J., & Hollins, S. (2014). Communicating with people with intellectual disabilities: a guide for general psychiatrists. *Advances in psychiatric treatment*, *20*(1), 27-36.

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

Bowring, D. L., Totsika, V., Hastings, R. P., Toogood, S., & Griffith, G. M. (2017). Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices. *British Journal of Clinical Psychology*, *56*(1), 16-32.

CBS. (2023, 27 January 2023). *Personen met indicatie naar gebruik Wlz-zorg; indicatie, leveringsvorm, zzp*. Centraal Bureau voor de Statistiek. Retrieved 13 March 2023 from https://opendata.cbs.nl/#/CBS/nl/dataset/84529NED/table?searchKeywords=verstandelijke%20beperkingen

Chow, J. C., & Wehby, J. H. (2018). Associations between language and problem behavior: A systematic review and correlational meta-analysis. *Educational Psychology Review*, *30*, 61-82.

Dada, S., Flores, C., Bastable, K., & Schlosser, R. W. (2021). The effects of augmentative and alternative communication interventions on the receptive language skills of children with developmental disabilities: A scoping review. *International journal of speech-language pathology*, *23*(3), 247-257.

Došen, A. (2014). *Psychische stoornissen, probleemgedrag en verstandelijke beperking*. Koninklijke Van Gorcum.

Embregts, P., Kroezen, M., Mulder, E., Van Bussel, C., Van der Nagel, J., Budding, M., Busser, G., De Kuijper, G., Duinkerken-Van Gelderen, P., Haasnoot, M., A, H., B, L., DAM, M.-F., V, O.-P., M, O., I, O. L., CJ, S., T, S., J, V. d. H.,...J, W. (2019). *Multidisciplinaire richtlijn probleemgedrag bij volwassenen met een verstandelijke beperking*. Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten.

Emerson, E. (2001). *Challenging behaviour: Analysis and intervention in people with severe intellectual disabilities*. Cambridge University Press.

Felce, D., & Kerr, M. (2013). Investigating low adaptive behaviour and presence of the triad of impairments characteristic of autistic spectrum disorder as indicators of risk for challenging behaviour among adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *57*(2), 128-138.

Hastings, R. P., Allen, D., Baker, P., Gore, N. J., Hughes, J. C., McGill, P., Noone, S. J., & Toogood, S. (2013). A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities. *International Journal of Positive Behavioural Support*, *3*(2), 5-13.

Heath, A. K., Ganz, J. B., Parker, R., Burke, M., & Ninci, J. (2015). A meta-analytic review of functional communication training across mode of communication, age, and disability. *Review Journal of Autism and Developmental Disorders*, *2*, 155-166.

Hofmann, V., & Müller, C. (2022). Challenging behaviour in students with intellectual disabilities: the role of individual and classmates' communication skills. *Journal of Intellectual Disability Research*, *66*(4), 353-367.

Hollo, A., & Chow, J. (2015). Communicative functions of problem behavior for students with high-incidence disabilities. *Beyond Behavior*, *24*(3), 23-30.

Jansen, R., Maljaars, J., Verhappen, A., Zink, I., Steyaert, J., & Noens, I. (2020). Problem behavior in young children referred with language difficulties: Relations to language and intentional communication. *Autism & Developmental Language Impairments*, *5*, 2396941519900076.

Light, J., & Mcnaughton, D. (2015). Designing AAC research and intervention to improve outcomes for individuals with complex communication needs. *31*(2), 85-96.

Luinge, M. R., Post, W. J., Wit, H. P., & Goorhuis-Brouwer, S. M. (2006). The ordering of milestones in language development for children from 1 to 6 years of age. *Journal of Speech, Language, and Hearing Research*, *49*(5), 923-940

Mohr, C., Tonge, B. J., Einfeld, S. L., & Taffe, J. (2011). *Manual for the developmental behaviour checklist for adults (DBC-A). Supplement to the Manual for the Developmental Checklist - DBC-P and DBC-T*. University of New South Wales and Monash University.

Piaget, J. (1952). *The origins of intelligence in children* (M. Cook, Trans.). W. W. Norton & Company.

Poppes, P., Van der Putten, A., Ten Brug, A., & Vlaskamp, C. (2016). Staff attributions of the causes of challenging behaviour in children and adults with profound intellectual and multiple disabilities. *Research in Developmental Disabilities*, *48*, 95-102.

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.

Simons, M., Koordeman, R., Willems, A., Hermsen, M., Rooijackers, L., & Otten, R. (2021). Factors facilitating or hindering meaningful staff–client interactions in people with intellectual disabilities and challenging behaviour: A systematic mixed studies review using thematic synthesis. *Journal of Applied Research in Intellectual Disabilities*, *34*(2), 446-458.

Smith, M., Manduchi, B., Burke, É., Carroll, R., McCallion, P., & McCarron, M. (2020). Communication difficulties in adults with Intellectual Disability: Results from a national cross-sectional study. *Research in Developmental Disabilities*, *97*, 103557.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland adaptive behavior scales: Interview edition, expanded form manual*. American Guidance Service.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland adaptive behavior scales Vineland-II: Survey forms manual*. Pearson Minneapolis, MN.

SPSS, I. (2023). *IBM SPSS statistics for windows*. In *Armonk, New York, USA: IBM SPSS* (Version 29)

Sutherland, D., van der Meer, L., Sigafoos, J., Mirfin-Veitch, B., Milner, P., O'Reilly, M. F., Lancioni, G. E., & Marschik, P. B. (2014). Survey of AAC needs for adults with intellectual disability in New Zealand. *Journal of Developmental and Physical Disabilities*, *26*, 115-122.

Tellegen, P., & Laros, J. (2011). *SON-R 6-40 Snijders-Oomen Niet-verbale intelligentie test*. Amsterdam: Hogrefe.

Tellegen, P., & Laros, J. A. (2017). *SON-R niet-verbale intelligentietest*. Amsterdam: Hogrefe.

Toffalini, E., Buono, S., Zagaria, T., Calcagni, A., & Cornoldi, C. (2019). Using Z and age-equivalent scores to address WISC-IV floor effects for children with intellectual disability. *Journal of Intellectual Disability Research*, *63*(6), 528-538. https://doi.org/10.1111/jir.12589

van den Akker, N., Kroezen, M., Wieland, J., Pasma, A., & Wolkorte, R. (2021). Behavioural, psychiatric and psychosocial factors associated with aggressive behaviour in adults with intellectual disabilities: A systematic review and narrative analysis. *Journal of Applied Research in Intellectual Disabilities*, *34*(2), 327-389. https://doi.org/10.1111/jar.12809

Vandereet, J., Maes, B., Lembrechts, D., & Zink, I. (2010). Predicting expressive vocabulary acquisition in children with intellectual disabilities: A 2-year longitudinal study.

Wechsler, D. (1991). *Wechsler intelligence scale for children–Third Edition. San Antonio, TX: The Psychological Corporation*.

Wechsler, D. (2012). *WAIS-IV-NL: Wechsler Adult Intelligence Scale: Nederlandse bewerking*. Pearson Assessment and Information BV.

Wechsler, D., Hendriksen, J., & Hurks, P. (2011). *WPPSI-III-nl: Nederlandstalige bewerking: afname-en scoringshandleiding*. Pearson Assessment and Information BV.

CHAPTER 5

Augmentative and alternative communication, intellectual disability and challenging behaviour: Effects on adult quality of life

Status: Under review

ABSTRACT

Difficulties in communication for individuals with intellectual disability (ID) often hamper the expression of their needs, which may lead to challenging behaviour (CB). The use of Augmentative and Alternative Communication (AAC) may result in an increase in adaptive communication facilitating the expression of needs, which ultimately is expected to improve Quality of Life. In case AAC goals were present in the Individual Support Plans of persons with ID who receive 24/7 intensive support due to severe CB, we determined whether those goals were actually implemented, and whether quality of life improved after one year, compared to the development of individuals with ID and CB without AAC implementation. The effect of AAC was associated with the quality of its implementation: when implemented as intended, CB remained stable over time and quality of life tended to improve, whereas CB deteriorated and quality of life remained stable over time when implementation was poor.

Augmentative and Alternative Communication, Intellectual Disability and Challenging Behaviour: Effects on Adult Quality of Life

Challenging behaviour (CB) in individuals with intellectual disability (ID) is defined as culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, and as behaviour which is 'likely to seriously limit use of ordinary community facilities or results in the person being denied access to those facilities (Emerson & Einfeld, 2011, p. 4). A mismatch between a person's competencies and (contextual) support can result in challenging behaviour (Schalock et al., 2021). This behaviour can add up to multiple negative outcomes, such as lower quality of life, risk of self-harm, seclusion/separation, or may result in risk of harm and distress for the support team. People with ID and CB more often live in specialized care settings, in which a higher prevalence of challenging behaviour, i.e. of 50-80% vs. the estimated 10-18% in people with ID in general (Bowring et al., 2019; Totsika & Hastings, 2009).

Individuals with intellectual disability have more difficulty communicating (Oliver et al., 2022; Schalock et al., 2021), and severity of communication difficulties is associated with higher levels of challenging behaviour (Bowring et al., 2019; Oliver et al., 2022). We therefore argue that individuals with severe challenging behaviour in an intensive support needs setting also have complex communicational needs. Deckers et al. (2024) describe individuals with communication support needs as "people who cannot rely on speech alone to be heard and understood, and to understand their communication partners".

Challenging behaviour or 'behavioural problems' may serve different functions which are believed to be interrelated. The 'unmet needs' framework (Cohen-Mansfield, 2013) states that this behaviour may be a behavioural expression of an attempt to communicate 'a need' or a distressed emotion as a last resort when the individual cannot communicate it in any other way (National Collaborating Centre for Mental Health, 2015). Difficulties in communication therefore can be seen as an important focus of intervention (Oliver et al., 2022).

Communication is an essential part of adaptive functioning and being able to express oneself and having the ability to engage in interactions is considered to be of pivotal importance (Sparrow et al., 1984). Communicative competence is defined by Light (1989, p. 137) as "a relative and dynamic, interpersonal construct based on functionality of communication, adequacy of communication, and sufficiency of knowledge, judgement, and skill in four interrelated areas: linguistic competence, operational competence, social competence, and strategic competence", which can be influenced by psychosocial factors but also environmental barriers and environmental support (Light & McNaughton, 2014). Therefore, not only the individual but also the professional caretakers are an important target for intervention to facilitate effective, adaptive communication for individuals with intellectual disability and challenging behaviour and to reduce barriers (Light & McNaughton, 2014). Communication in individuals with ID and challenging behaviour and therefore communication support needs can be facilitated by the use of augmentative and alternative communication (AAC) strategies.

AAC refers to interventions for people with communication support needs that support communication through non-verbal communication modes (gestures, objects, symbols) or, for example, through assistive technology such as speech output technologies (Beukelman & Light, 2020; Schlosser, 2003). AAC needs to be implemented in the individual's daily life. The implementation of AAC in daily life has indeed been reported to result in better communicative functioning. For example, Benson-Goldberg et al. (2023) showed that children with intensive support needs improve in communication over time when teachers were systematically provided with the skills, knowledge and resources required to provide individualized AAC.

Since communicative competence is believed to be positively related to quality of life (Garcia et al., 2020; Wolters-Leermakers et al., 2022), communication support using AAC should be prioritized within the systems of support for adults with intellectual disability and communicational problems. Support staff indeed report an improvement in quality of life when communication support is prioritized, when it is carefully adjusted to one's needs and competencies (Dalton & Sweeney, 2013). In general, various meta-analyses report positive effects of AAC on communication skills and/or challenging behaviour in children and adolescents with ID (Ganz et al., 2017; Ganz et al., 2023)

Aforementioned studies into effects of AAC were focused on (young) children with ID. Studies on communication interventions with *adults* with intellectual disability and challenging behaviour, however, are scarce and more research is needed, (Ganz et al., 2017; Heath et al., 2015; Walker & Snell, 2013). Reichle et al. (2019), and Light and Mcnaughton (2015) emphasize the importance of tailored AAC strategies, highlighting the necessity to align communication modes with individual skills and contextual demands, stressing the need for further research, including follow-up of the effects of AAC over time.

The present study focusses on AAC and its effectiveness on quality of life and behavioural problems for adults with ID and challenging behaviour residing in an intensive support need setting with 24/7 care. It is the first study to explore the effectiveness of AAC over a one-year period in adults with such intensive support needs.

Essentially, the elements in an Individual Support Plan (ISP) are based on the individual's unique profile of competencies and assessment of contextual factors that can enhance a person's functioning (Buntinx & Schalock, 2010; Shogren et al., 2018; Verdugo et al., 2024). There is a limited amount of research into the value of ISP's, although setting specific goals is thought to sharpen focus of support and facilitate monitoring of implementation (Kamstra et al., 2017).

We argue that the inclusion of goals implying the use of AAC in the ISP helps to improve adaptive communication skills, in particular when these goals are regularly followed up by the multidisciplinary support team that developed those goals, so they can be adjusted constantly to the persons' needs and growth in a given period in time. Therefore, we expect the group with AAC goals included in the ISP will improve in adaptive communication which is further hypothesized to at least stabilize or improve functioning over time as expressed in Quality of Life and challenging behaviour. It is further explored whether the planned AAC goaled interventions, as described in the ISP goals, were implemented as intended (appropriate use of AAC) or were not (no or inappropriate use of AAC), and whether this adds positively to the effect of the interventions over time in individuals with appropriate use of AAC.

METHOD

Procedure

Data used in this study were collected during a large longitudinal study [*SCORE*]. The SCORE study evaluating the effects of regular care of persons living in group homes, with intellectual disability and intensive support needs due to persistent challenging behaviour. Four service organizations for people with intellectual disability participated in this study. Participants all reside in group homes in residential care facilities, where they receive 24 hour care for support in all areas of life, provided by a specialized support team. Typically, in intensive support the client-direct caretaker ratio is 4/3:1.

The design of the present study is longitudinal, collecting survey data in two time waves, starting in 2017, with one-year follow-up starting in 2018. Ethical approval for the study was granted by the ethics committee of the Faculty of Social and Behavioural Sciences, Department of Clinical Neurodevelopmental Sciences, University of Leiden, The Netherlands (ECPW-2015/094), and the ethical committee of the largest participating service organization (Ipse de Bruggen).

Participants

Persons and their support teams were eligible for inclusion when individuals met the following criteria: Adults with intellectual disability, living in residential care facilities in group homes, with a very intensive support need due to severe challenging behaviour, i.e. persistency of challenging behaviour over at least two years.

Candidates eligible for inclusion (*N*=543) and their legal representatives were invited to participate in the study. Legal representatives (and where applicable, the persons with ID themselves) were informed about the study by written and online information and asked for informed consent. Seventy percent of the candidates of the four service organizations responded to the invitation (*N*=381) of which *N*=92 (24.4%) declined participation and *N*=289 agreed to participate.

N=56 participants dropped out during the course of the study, due to e.g. moving to another service organization, illness or death, logistic problems within the support team, or withdrawal of consent. Further, participants were only included in this study when, ISP data and at least one of the questionnaires were available. This resulted in a further loss of *N*=37 participants, due to not returned questionnaires or interview planning difficulties resulting in a total of *N*=196 participants (66% male), mean age 41.21 years (*SD*=14.59).

In the longitudinal outcome analyses, we lost participants at the follow-up (after one year) because of missing values (on measures DBC-A *N*=11, Vineland Screener *N*=28, SMS *N*=32). Missing value analyses demonstrated that these participants did not differ from the participants remaining in the study on measures of challenging behaviour, adaptive communication, gender distribution or age (336.>*p*.799). Participants were only included in the analyses if they had measures on both T1 and T2, per variable of interest.

All participants had a multidisciplinary support team that developed their ISP. This support team is typically composed of direct caretakers, relatives and/or representatives, location management, and other care professionals (such as at least a physician, a psychologist or a pedagogue or specialists regarding specific interventions, such as a speech/language therapist, occupational therapist, psychomotor therapist, physiotherapist). If possible, the support team involves the individual with ID during the design of the ISP.

Measures

Challenging Behaviour, Developmental Behaviour Checklist – for Adult (DBC-A)

The DBC-A is a carer-completed 107-item questionnaire that assesses a comprehensive range of emotional, behavioural and mental health problems in adults with ID (Mohr et al., 2005; Mohr et al., 2011; Mohr et al., 2012). Professional primary caretakers were asked to fill out the questionnaire. Questions can be answered by assigning 0, 1, or 2, a higher number reflecting higher frequency of the particular challenging behaviour. Next to a Total composite score, six problem domains scores are computed, i.e. for Disruptive behaviour, Communication Disturbances and Anxiety, Antisocial behaviour, Self-absorbed behaviour, Depressive symptoms, and Problems Relating to Social interaction. Mean item scores (MIS) were computed for the total composite score. A higher score denotes more challenging behaviour.

Equivalent mean scores can either be derived by a large number checked '1' or a low range of items checked '2'. To gain a better understanding of the experienced range and intensity of behaviour, the Proportion of Items positively Checked (PIC) and the Intensity Index (DBC I.I.), i.e. the proportion of positively checked items which are scored '2', were calculated, as suggested by Taffe et al. (2008). First, Proportion of Items Checked for the total problem behaviour score was calculated (PIC, proportion of number of checked items/total items of subdomain), representing a measure of the range in severity of displayed challenging behaviour. The sum of items checked 2 per domain was then divided by the PIC, resulting in a DBC-I.I. score per subdomain, representing a measure of intensity of CB. The DBC-A is a reliable and internally consistent instrument with Cronbach's alpha for the total score of α = .95 and for the subscales α = .71 - .91 (Mohr et al., 2011).

Quality Of Life: San Martin Scale

The San Martin Scale (SMS) (Verdugo et al., 2014) was used to measure quality of life (QoL). The SMS contains 95 items, resulting in eight domains (11-12 items per domain), based on the Quality of Life framework by Schalock et al. (2002). The San Martin Scale has a good reliability and validity (construct, convergent and divergent) for persons with intensive support needs and different levels of intellectual abilities (Verdugo et al., 2014), including relatively higher ID-levels which allows comparisons to be made across different levels of ID (Navas et al., 2024; Traina et al., 2022; Verdugo et al., 2014). Cronbach's alpha ranges from .82 to.93 (domains) and .97 (total score) (Verdugo et al., 2014). Domains included are Self-Determination, Emotional Well-being, Physical Well-being, Material Well-being, Rights, Personal Development, Social Inclusion, and Interpersonal Relations. The SMS is completed by a caretaker who knows the participant best. Items are statements about the participant's life scored on a 4-point Likert scale, ranging from 'never (1)' to 'always (4)'. Item scores result in a Total QoL Score, converted to Mean Item Scores (SMS MIS) for total QoL.

Example items are "He/she has the opportunity to deny doing certain activities that are irrelevant to his health (e.g., partake in leisure activities, go to sleep at a certain time, wear the clothes that other choose)" (Self-Determination), "The person is previously informed about changes in the person that provides support (e.g., due to shifts, leaves, vacations, familial situations, etc.)" (Emotional Well-being), "Has adequate hygiene (e.g., teeth, hair, nails, body) and self-presentation (e.g., clothes that are adequate for his age, for the occasion etc.)" (Physical Well-being), "He/she has his own material possessions to entertain himself (e.g., games, magazines, music, television, etc.)" (Material Well-being), "His/her rights are defended and respected (e.g. confidentiality, information about his/her rights as users, etc.)" (Rights), "He/she is provided with new instructions and models to learn new things" (Self Development), "Participates in inclusive activities that interest him/her" (Social Inclusion), "He/she has the opportunity to meet people outside from the support group" (Interpersonal Relationships).

Adaptive Communication: Vineland Adaptive Behavior Scales (Vineland II) And Vineland Screener

The Vineland II (Sparrow et al., 2005), administered at the first time wave, is a commonly accepted measure of adaptive skills and has been used extensively in research in subjects with intellectual disability. Data were collected through semi-structured interviews with the professional primary caretaker by certified master students and research assistants who completed training and supervision in Vineland II interviewing.

The Communication domain of the Dutch translation of the Vineland screener 0-12 (Sparrow et al., 1993; van Duijn et al., 2009), a shortened version of the Vineland-II (Sparrow et al., 2005), was used to assess adaptive communication. The Vineland Screener (VS) is a commonly accepted measure of adaptive behaviour and consists of a questionnaire of 90 items, each rated from 0-2. It was administered at the second time wave and is a short form of the expanded interview, which covers the same four domains on Communication, Daily living skills, Socialization and Motor skills. A composite score of the four domains, as well as the four domain scores individually showed good internal consistency and reliability: Cronbach's α >.95, (van Duijn et al., 2009). Since the expanded interview was only administered in the first wave, items corresponding with the screener items were selected from the expanded interview to create comparable total and domain scores of adaptive behaviour over time, expressed as mean item scores. For the present study, the domain Communication was used as a measure of adaptive communication (VS Com MIS at T1 and T2). A higher score means higher adaptive communication skills.

For the descriptive variable regarding speech, we used Norrelgen et al. (2015) classification of verbal, minimally verbal and speech, for which we used with two items from the Vineland-II Expressive Subdomain: "Names at least three common objects (bottle, dog, favorite toy, etc.)" and "Uses phrases containing a noun and a verb". This resulted in three subgroup as follows: (1) *nonverbal*: does not speak three words, (2) *minimally verbal*: does speak three words, but does not use sentences with a noun and a verb, and (3) *verbal*: uses >3 words and speaks in sentences using a noun and verb.

AAC Intervention Goals In The Individual Support Plan (ISP)

Intervention goals in the ISP referring in any sense, i.e. ignoring quality of formulated goals, to the use of AAC were counted. Intervention goals (IG) were coded as 'AAC-intervention goal' when AAC was mentioned in the intervention goals, i.e. referring to the use of objects, gestures, pictograms, and photos in the IG. Participants were divided into two groups, with or without planned intervention goals relating to AAC (AAC vs. No-AAC).

Actual Implementation Of AAC

In practice there may be a discrepancy between planned and actually implemented interventions. To address this issue, an expert delegation of each involved multidisciplinary support team, i.e. a member of the direct staff, the primary involved psychologist/orthopedagogue and a family member/representative, were interviewed about the quality and quantity of contextual care for each specific individual. They were asked to find consensus about their opinion about the following statement "The daily support team makes appropriate use of AAC for this individual". Appropriate meant as intended and consistently. Examples of AAC were furthermore given verbally, like working with gestures, pictures, sensations, objects, pictograms, and were discussed when needed. The question whether daily AAC support was present and appropriately used was assigned a score of 1 (totally disagree or 'not applicable', i.e. AAC was not present at all) to 5 (totally agree). In the end, for the final answer, the three respondents had to reach consensus. Higher scores signify higher appraisal of the use of AAC, lower scores refer to less or no use of AAC. These scores were dichotomized into a Group variable AACuse. No-AACuse representing scores 1-3 (no or insufficient daily use of AAC) an AACuse representing scores 4 – 5 (appropriate daily use of AAC).

Statistical Analyses

As the groups differed sharply in sample size, Levene's test for equality of variances of the variables of interest were used. All analyses met the necessary assumptions, except for DBC PIC and VS Com MIS. After applying square root transformation, assumptions were met for VS Com MIS (Levene's n.s.). For DBC PIC, the removal of five outliers (one in AAC group, four in No AAC group) was sufficient to meet the assumptions.

Five RM ANOVAs were planned to explore whether quality of life, challenging behaviour, and adaptive communication differed between individuals with and without AAC goals in their ISP, whether outcome on these variables of interest changed over time, and whether eventual changes were different between groups. The analyses were performed with Group (AAC goals vs. No-AAC goals) as between subjects (BS) factor, Time (T1 vs. T2) as within-subject (WS) factor, and DBC measures (DBC MIS, DBC PIC, DBC I.I.), Vineland (VS Com MIS) and SMS (SMS MIS) as dependent variables, respectively. When interpreting Group and Time effects, possible interaction effects are taken into account.

Only for the group *with* AAC goals in their ISP, it is further explored whether (quality of the) actual use of AAC had an impact on the effect of the AAC intervention over time. The inquiry into actual daily use of AAC resulted in the formation of two groups: AACuse and No-AACuse. Another series of five similar RM ANOVAs were conducted, but this time with (AACuse vs. No-AACuse) as BS factor.

Data were analysed using SPSS statistics version 29 (IBM, 2023). Significance level was set at $p<0.05$.

RESULTS

Description

For a total of *N*=196 participants on T1, in the support plans of only 24.5% (*N*=48) participants, intervention goals were found in which AAC was mentioned in their goals as tool. In 75.5% (*N*=148) of the cases participants did not have AAC mentioned in their goals

Among participants with data available for measures on T1 and T2, gender was equally distributed (65% vs. 64% male respectively, p=.621) among groups with and without AAC related goals. Individuals without AAC related goals had a higher calendar age in years (*M*=43.01, *SD*=15.09) than those with AAC goals (*M*=37.81, *SD*=12.42), [$t(170)=2.048$, $p=0.42$]. Verbality was not equally distributed across both groups [$\chi^2(2, N = 166) = 6.792$, $p < 0.034$]. Of those with AAC-goals 36.4% were non-verbal, 4.5% minimally verbal and 59.1% verbal. Of individuals without AAC-goals 19% were non-verbal,, 10.7% minimally verbal and 71.3% verbal.

AAC Goals Vs. No AAC Goals In The ISP

For Quality of Life (SMS MIS), the RM ANOVA resulted in a significant main effect of time [$F(1,152)=13.480$, $p<.001$, $\eta_p^2=.081$], indicating an overall improvement over time in Quality of Life. The main effect of Group (AAC goals vs. No-AAC goals) and the Time*Group interaction were non-significant (p=.280 and p=.517, respectively), indicating no differences between groups on T1 and T2.

For challenging behaviour the analyses with total DBC-A MIS, PIC, and I.I. as dependent variables, respectively, yielded only non-significant results for the main effect of Time and the interaction Time*Group ($.147<p<.758$), suggesting that, independent of group, changes over time were not significant. Main effects of Group were significant for total DBC-A MIS [F(1,170)=8.988, *p*=.003, η_p^2=.05], and DBC PIC [F(1,170)=8.190, *p*=.005, η_p^2=.046, indicating more severe behaviour for the AAC group (Table 1).

Table 1

*Characteristics (M, SD) for individuals with severe CB in intensive 24/7 support settings, divided in groups with (N1)/without (N2) AAC related goals mentioned in their Individual Support Plan (ISP), i.e. only for those included with scores on T1 and T2 on challenging behaviour [DBC total Mean Item Score (DBC-MIS), Proportion of Items Positively Checked (DBC-PIC), and Intensity Index (DBC-II)], adaptive communication (VS Com MIS), and quality of life (SMS MIS). ** significant differences between Groups at p<.05.*

		AAC goals		**No AAC goals**	
	***N*1/*N*2**	**T1**	**T2**	**T1**	**T2**
Adaptive Communication VS Com MIS**	39/120	.54 (.38)	.53 (.45)	.93 (.58)	.93 (.60)
Challenging Behaviour					
DBC MIS**	44/128	.60 (.19)	.63 (.20)	.51 (.21)	.51(.23)
DBC PIC**		.43 (.11)	.45 (.11)	.38 (.13)	.37 (.14)
DBC-I.I.		.40 (.17)	.39 (.20)	.34 (.18)	.33 (.20)
Quality of Life SMS MIS	38/116	2.84 (.33)	2.93 (.29)	2.88 (.29)	3.00 (.33)

For adaptive communication (VS Com MIS), a significant Group effect [F(1,156)=13.13, *p*<.001, η_p^2=.0278, and a non-significant main effect of Time (*p*=.241) were found. Combined with a nonsignificant Time*Group interaction (*p*=.721), this indicates that groups differ on adaptive communication, with the group with AAC goals scoring lower, and that group differences remained stable over time.

Actual (Daily) Use Of AAC Goals When Included In ISP

For those with goals in their ISP relating to AAC, for *N*=22 (45.8%) direct support staff actually used AAC in daily life of this individual (AACuse), and for N=26 (54.2%) AAC goals were not fully, insufficiently or not at all implemented (No-AACuse). We examined how the appropriateness of the use of AAC (carried out as intended vs. not fully, insufficiently or not at all) affected the outcome on the variables of interest.

For QoL (SMS MIS), the RM ANOVA showed a non-significant effect of Time (*p*=.126) and Group (*p*=.605), but a trend significant effect of Time*Group, accompanied by a moderate effect size [F(1,36)=5,973, *p*=.074, η_p^2=.086], suggesting that those with AAC use showed an improvement in QoL over time whereas those without AAC use did not. Post hoc analysis confirmed a significant change (improvement) only for this group [*t*(20)=-2,603, *p*=.017]

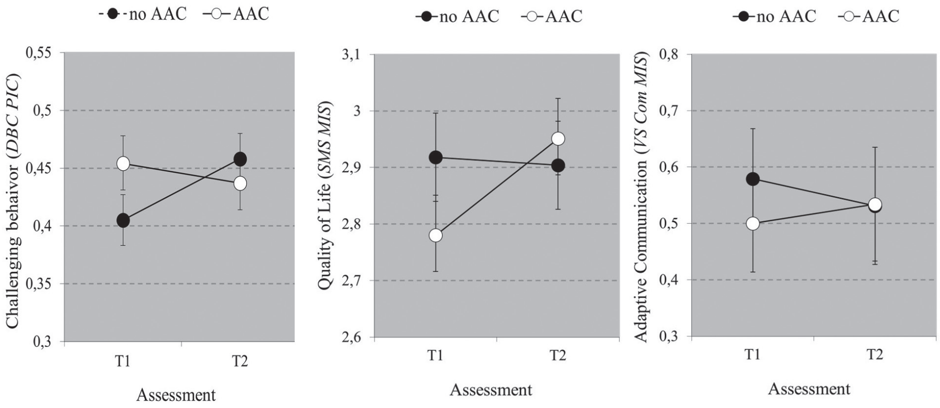
RM ANOVAs for Adaptive Communication (VS Com MIS) yielded a non-significant main effect of Time (*p*=.862) and Group (*p*=.770), accompanied by a nonsignificant Time*Group interaction, indicating no differences in outcomes on adaptive communication for those with and without AAC-use.

As regards Challenging Behaviour, only for DBC PIC, a significant Time*Group interaction was found, accompanied by a large effect size [F(1,43)=6.898, *p*=.012, η_p^2=.138, Figure 1, left panel]. reflecting a deterioration in challenging behaviour, for those individuals for whom AAC was not implemented in clinical practice although it was mentioned in their support plan. Post hoc analysis confirmed a significant change (deterioration) only for this group [*t*(23)=-2,781, *p*=.011]. Time-effect (*p*=.178) and Group-effect (*p*=.625) were non-significant for DBC PIC.

We have rerun the analyses with Vineland domain Communication as covariate, with no differences in results.

Figure 1

*Left panel: Challenging Behaviour (DBC PIC) over time for individuals with ISP goals, as a function of Group: AAC use in daily practice (yes vs. no), with a higher value meaning higher CB (± SEM) showing a significant Time*Group interaction. Centre panel: Quality of Life (SMS MIS) over time for individuals with ISP goals, as a function of Group: AAC use in daily practice (yes vs. no), with a higher value meaning higher QoL (± SEM). Adaptive Communication (VS Com MIS) over time for individuals with ISP goals, as a function of Group: AAC use in daily practice (yes vs. no), with a higher value meaning higher level of adaptive communication (± SEM)*



DISCUSSION

The present study focused on individuals with intellectual disability (ID), who, due to severe challenging behaviour (CB), need intensive 24/7 support on all domains of daily functioning. Challenging behaviour in these individuals is known to be partly associated with difficulties in expressing their needs, resulting in frustration which may manifest itself in increased challenging behaviour. This follow-up study examined to what extent the use of Augmentative and Alternative Communication (AAC), as expressed in AACrelated goals in individual support plans (ISP), has a favorable effect on adaptive communication, on challenging behaviour, and consequently on quality of life. Furthermore, if AAC-related goals were present in individual support plans, we were interested whether the quality of AAC use (i.e. whether AAC was implemented as intended versus insufficiently or not at all) in daily life, influenced outcomes over time.

First of all, it was found that for only twenty-four percent of the 196 participants AAC was part of their ISP goals, which was unexpectedly low, given the nature of the intensive support they require, especially with respect to communication. This percentage may suggest that the need for individual AAC goals in care for persons with communication problems, severe behavioural problems and intellectual disability, is not fully recognized, or may reflect challenges in implementing AAC or a lack of expertise among the staff with regard to AAC implementation in care for adults with ID and CB, in line with earlier findings regarding staff's knowledge about AAC systems (Dalton & Sweeney, 2013; Sutherland et al., 2014). Andzik and Chung (2022) argue that it is crucial that service providers acknowledge that communication needs of adults may shift as they grow older and that attention for and re-assessment of AAC needs may be necessary, especially in an intensive support setting, where staff not only serve as daily caregivers but also as primary communication partners.

We found that individuals without AAC goals exhibited less challenging behaviour and showed better adaptive communication than individuals with AAC goals in their ISP. Individuals without AAC goals were more often able to verbally communicate, suggesting that support teams assign AAC supported treatment more often to individuals with more challenging behaviour and low levels of adaptive communication. While this may seem to be adequate, this may actually reflect what Deckers et al. (2024) describe as the tendency in clinical practice of AAC often being indicated on the basis of observable communication features (output level), which in our population may have been the inability to produce spoken words. Persons with communication problems despite higher verbal skills therefore could have been overlooked as candidates for support by AAC. One might even argue that challenging behaviour in itself should be indicative for need of AAC.

It was found that, if AAC-goals were implemented in individual support plans, and when AAC goals were implemented as intended, i.e. quality and quantity of AAC was appropriate (vs. improper or not al at all), challenging behaviour remained stable over time and quality of life tended to improve. When AAC related intervention goals were present in the support plan but AAC was not actually used in daily practice or judged as insufficient, indicating failed implementation, challenging behaviour increased over time and quality of life remained the same. Our results seem to be partly in line with the outcome of reviews into single case AAC interventions in children and adults by Walker and Snell (2013) and Heath et al. (2015). They found that these interventions were effective in reducing challenging behaviour in children, but less effective in adults with challenging behaviour, possibly due to their long established patterns of communication through challenging behaviour. The present study demonstrated that challenging behaviour deteriorated over time when implementation of AAC-related goals failed and underscores that AAC has a potentially beneficial effect on Quality of life and challenging behaviour, when utilized expertly.

For individuals with severe challenging behaviour, guidelines for disentangling different aspects of challenging behaviour highlight that a multidisciplinary support team should utilize the outcome of repeated evaluation of implementation of interventions focusing on communication problems (Embregts et al., 2019) (National Collaborating Centre for Mental Health, 2015). The potential benefits of AAC when properly implemented, underline that support teams should use expertise to properly implement AAC interventions and avoid or correct shortcomings by evaluation of implementation. It is therefore suggested that implementation of AAC should be set up, guided and monitored by a multidisciplinary team, as laid out in a clear and comprehensive plan that focuses on environmental changes and improvement in quality of life, as recommended by Denne (2020).

A limitation of our study is the lack of information regarding the specific type of AAC interventions, which precludes to draw more specific conclusions about the efficacy of specific types of AAC, although this would require a larger number of participants than were available. Moreover, future studies should examine not only whether AAC is available and used in daily practice in long-term care for adults with ID and CB, but also whether and how individuals themselves take the initiative to use AAC in their daily environment. This would add to the further understanding of the mechanisms by which AAC can contribute to communicative competence, to challenging behaviour and quality of life. Furthermore, based on the finding that AAC goals were given to persons with severe verbal communication difficulties, future research could focus on the added value of AAC interventions for individuals with a broader profile of communication difficulties instead of verbal communication problems alone. An assessment framework for AAC could aid in the decision-making process for initiating AAC, by evaluating a broader range of (dys) functions (Deckers et al., 2024; Jansen et al., 2020; Van Balkom et al., 2017).

In conclusion, this study highlights that a focus on AAC potentially can have a positive impact on quality of life and managing challenging behaviour. Therefore, we advocate for a focus on AAC, especially when challenging behaviour is present. Clinically, the findings implicate the need for multidisciplinary efforts to ensure that AAC goals are effectively implemented.

REFERENCES

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.

Benson-Goldberg, S., Geist, L., & Erickson, K. (2023). Expressive communication over time: A longitudinal analysis of the project core implementation model. *Communication Disorders Quarterly*, *45*(1), 64-72. https://doi.org/10.1177/15257401221120790

Beukelman, D. R., & Light, J. C. (2020). Augmentative and alternative communication: Supporting children and adults with complex communication needs (5th ed.). Paul H. Brookes.

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

Buntinx, W. H. E., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(4), 283-294.

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

Dalton, C., & Sweeney, J. (2013). Communication supports in residential services for people with an intellectual disability. *British Journal of Learning Disabilities*, *41*(1), 22-30. https://doi.org/10.1111/j.1468-3156.2011.00717.x

Deckers, S., van Onna, M., Gros, E., & van Balkom, H. (2024). Developing a screening instrument for underlying core domains of communicative competence in children with communication support needs. *Augmentative and Alternative Communication*, 1-14. https://doi.org/10.1080/07434618.2024.2367991

Denne, L. D., Gore, N. J., Hughes, J. C., Toogood, S., Jones, E., & Brown, F. J. (2020). Implementing evidence-based practice: the challenge of delivering what works for people with learning disabilities at risk of behaviours that challenge. *Tizard Learning Disability Review*, *25*(3), 11.

Embregts, P., Kroezen, M., Mulder, E., Van Bussel, C., Van der Nagel, J., Budding, M., Busser, G., De Kuijper, G., Duinkerken-Van Gelderen, P., Haasnoot, M., A, H., B, L., DAM, M.-F., V, O.-P., M, O., I, O. L., CJ, S., T, S., J, V. d. H.,...J, W. (2019). *Multidisciplinaire richtlijn probleemgedrag bij volwassenen met een verstandelijke beperking*. Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten.

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

Ganz, J. B., Morin, K. L., Foster, M. J., Vannest, K. J., Genc Tosun, D., Gregori, E. V., & Gerow, S. L. (2017). High-technology augmentative and alternative communication for individuals with intellectual and developmental disabilities and complex communication needs: a meta-analysis. *Augmentative and Alternative Communication*, *33*(4), 224-238. https://doi.org/10.1080/07434618.2017.1373855

Ganz, J. B., Pustejovsky, J. E., Reichle, J., Vannest, K. J., Foster, M., Pierson, L. M., Wattanawongwan, S., Bernal, A. J., Chen, M., Haas, A. N., Liao, C. Y., Sallese, M. R., Skov, R., & Smith, S. D. (2023). Participant characteristics predicting communication outcomes in AAC implementation for individuals with ASD and IDD: a systematic review and meta-analysis. *Augmentative and Alternative Communication*, *39*(1), 7-22. https://doi.org/10.1080/07434618.2022.2116355

Garcia, J. C., Diez, E., Wojcik, D. Z., & Santamaria, M. (2020). Communication support needs in adults with intellectual disabilities and its relation to quality of life. *International Journal of Environmental Research and Public Health*, *17*(20). https://doi.org/10.3390/ijerph17207370

Heath, A. K., Ganz, J. B., Parker, R., Burke, M., & Ninci, J. (2015). A meta-analytic review of functional communication training across mode of communication, age, and disability. *Review Journal of Autism and Developmental Disorders*, *2*, 155-166.

Jansen, R., Maljaars, J., Verhappen, A., Zink, I., Steyaert, J., & Noens, I. (2020). Problem behavior in young children referred with language difficulties: Relations to language and intentional communication. *Autism & Developmental Language Impairments*, *5*, 2396941519900076.

Kamstra, A., van der Putten, A. A., & Vlaskamp, C. (2017). Efforts to increase social contact in persons with profound intellectual and multiple disabilities: Analysing individual support plans in the Netherlands. *Journal of Intellectual & Developmental Disability*, *21*(2), 158-174. https://doi.org/10.1177/1744629516653037

Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, *5*(2), 8.

Light, J., & McNaughton, D. (2014). Communicative competence for individuals who require Augmentative and Alternative Communication: A new definition for a new era of communication? *Augmentative and Alternative Communication*, *30*(1), 1-18. https://doi.org/10.3109/07434618.2014.885080

Light, J., & Mcnaughton, D. (2015). Designing AAC research and intervention to improve outcomes for individuals with complex communication needs. *31*(2), 85-96.

Mohr, C., Tonge, B. J., & Einfeld, S. L. (2005). The development of a new measure for the assessment of psychopathology in adults with intellectual disability. *Journal of Intellectual Disability Research*, *49*, 469-480. https://doi.org/10.1111/j.1365-2788.2005.00701.x

Mohr, C., Tonge, B. J., Einfeld, S. L., & Taffe, J. (2011). *Manual for the developmental behaviour checklist for adults (DBC-A). Supplement to the Manual for the Developmental Checklist - DBC-P and DBC-T*. University of New South Wales and Monash University.

Mohr, C., Tonge, B. J., Taffe, J., & Einfeld, S. L. (2012). The availability of normative data for the Developmental Behaviour Checklist for Adults. *Journal of Intellectual & Developmental Disability*, *37*(1), 61-64. https://doi.org/10.3109/13668250.2011.649719

Navas, P., Esteban, L., Arias, V., & Verdugo, M. A. (2024). Improving Quality of Life and Reducing Behavioral Problems of People With Intellectual and Developmental Disabilities Through Deinstitutionalization. *Psicothema*, *36*(2), 113-122. https://doi.org/10.7334/psicothema2023.303

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/

Norrelgen, F., Fernell, E., Eriksson, M., Hedvall, A., Persson, C., Sjolin, M., Gillberg, C., & Kjellmer, L. (2015). Children with autism spectrum disorders who do not develop phrase speech in the preschool years. *Autism*, *19*(8), 934-943. https://doi.org/10.1177/1362361314556782

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.

Reichle, J., Simacek, J., Wattanawongwan, S., & Ganz, J. (2019). Implementing aided augmentative communication systems with persons having complex communicative needs. *Behavior Modification*, *43*(6), 841-878. https://doi.org/10.1177/0145445519858272

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

Schlosser, R. (2003). Roles of speech output in augmentative and alternative communication: Narrative review. *Augmentative and Alternative Communication*, *19*(1), 5-27.

Shogren, K. A., Luckasson, R., & Schalock, R. L. (2018). The responsibility to build contexts that enhance human functioning and promote valued outcomes for people with intellectual disability: Strengthening system responsiveness. *Intellectual and Developmental Disabilities*, *56*(4), 287-300. https://doi.org/10.1352/1934-9556-56.5.287

Sparrow, S., Carter, A., & Cicchetti, D. (1993). Vineland Screener: Overview, reliability, validity, administration, and scoring. *New Haven, CT: Yale University Child Study Center*.

Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland adaptive behavior scales: Interview edition, expanded form manual*. American Guidance Service.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). *Vineland adaptive behavior scales Vineland-II: Survey forms manual*. Pearson Minneapolis, MN.

Sutherland, D., van der Meer, L., Sigafoos, J., Mirfin-Veitch, B., Milner, P., O'Reilly, M. F., Lancioni, G. E., & Marschik, P. B. (2014). Survey of AAC needs for adults with intellectual disability in New Zealand. *Journal of Developmental and Physical Disabilities*, *26*, 115-122.

Taffe, J. R., Tonge, B. J., Gray, K. M., & Einfeld, S. L. (2008). Extracting more information from behaviour checklists by using components of mean based scores. *International Journal of Methods in Psychiatric Research*, *17*(4), 232-240. https://doi.org/10.1002/mpr.260

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

Traina, I., Mannion, A., & Leader, G. (2022). Transition program from school to employment in youths with intellectual disability: Evaluation of the Irish pilot study E-IDEAS. *Developmental Neurorehabilitation*, *25*(2), 87-100. https://doi.org/10.1080/17518423.2021.1941373

Van Balkom, H., Deckers, S., & Stoep, J. (2017). Assessment of communicative competence in children with severe developmental disorders. In E. S. P. v. d. Broek (Ed.), *Developmental per spectives in written language and literacy: In honor of Ludo Verhoeven*. John Benjamins Publishing Company.

van Duijn, G., Dijkxhoorn, Y., Noens, I., Scholte, E., & van Berckelaer-Onnes, I. (2009). Vineland Screener 0-12 years research version (NL). Constructing a screening instrument to assess adaptive behaviour. *International Journal of Methods in Psychiatric Research*, *18*(2), 110-117. https://doi.org/10.1002/mpr.282

Verdugo, M. A., Gomez, L., Arias, B., Santamaria, M., Navallas, E., Fernandez, S., & Hierro, I. (2014). *San Martin Scale: Assessment of quality of life in persons with significant intellectual and developmental disabilitie*s. Salamanca: Institute on Community Integration.

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

Walker, V. L., & Snell, M. E. (2013). Effects of augmentative and alternative communication on challenging behavior: A meta-analysis. *Augmentative and Alternative Communication*, *29*(2), 117-131.

Wolters-Leermakers, N., Van den Bogaard, K., & Prins, M. (2022). Understanding quality of life in people with complex and multiple communicative disabilities: A narrative overview of the empirical research literature. *Journal of Intellectual & Developmental Disability*, 17446295221146849. https://doi.org/10.1177/17446295221146849

6

CHAPTER 6

Summary and discussion

It was investigated whether and how several aspects of contextual support contribute to quality of life of adults with intellectual disability and severe and persistent challenging behaviour. The studies we performed were part of the *SCORE* project, a follow-up study evaluating the effects of interventions in 24/7 intensive support facilities that are offered to adults with Intellectual Disability (ID) and severe challenging behaviour (CB) (in Dutch: *Systematische Cliënt Ondersteuning en Resultaat Evaluatie)*. The studies were carried out in four specialized service organizations for people with intellectual disability in The Netherlands.

The study in Chapter 2 had the objective of examining the relationship between personalized contextual support and quality of life in a 24/7 long term care context for people with ID and CB. The appraisal of the personal fit of the contextual support, covering all relevant aspects of contextual support, was found to be related to outcomes on quality of life. Our findings show that perceived satisfaction with the fit between contextual support and its recipient is positively related to quality of life, but this relationship is much less pronounced for individuals presenting with the severest challenging behaviour.

In the study in Chapter 3, the question was answered whether extra funding to optimize contextual support contributed to a better quality of life over time for individuals with intensive support needs due to challenging behaviour. Our study found that adults receiving extra intensive support appeared to show higher levels of challenging behaviour, accompanied by a higher number of mental health diagnoses and a stronger focus in Individual Support Plans on reducing challenging behaviour compared to those who did not receive extra individual support. Over time, intensity of challenging behaviour decreased in adults receiving extra intensive support, although Quality of Life and adaptive functioning did not improve.

The objective of the study in Chapter 4 was to gain more insight into the relative contribution of receptive (comprehension) and expressive communication problems to different forms of CB in individuals with ID and persistent CB. Less receptive comprehension and being male were found to be associated with a higher risk for challenging behaviour in general, in particular for individuals with relatively higher cognitive functioning. However, for all individuals, the strongest relationship with challenging behaviour was found for lower receptive comprehension and more internalizing problems such as self-absorbed behaviour, anxiety and problems in interactive behaviour.

The next study (Chapter 5) examined whether the use of augmentative and alternative communication (AAC) is effective in reducing adaptive communication difficulties, which is ultimately expected to improve quality of life in individuals with ID and severe CB. First, a relatively low number of targets was found in the individual support plans (ISP's) in which AAC as a means was mentioned. Furthermore, there appeared to be a discrepancy between the intended use of AAC as reported in the ISP's and its actual implementation in practice as seen in the actual day to day implementation of AAC. The effect of AAC was associated with the quality of its implementation. If implemented as intended, CB remained stable over time and quality of life tended to improve, whereas CB deteriorated, and quality of life remained stable over time when implementation was poorly or not implemented.

Our findings in the first study (Chapter 2) show that perceived satisfaction with the fit between provided contextual support and the needs of a person with ID and CB is positively related to quality of life. This is in line with findings of Schalock et al. (2020) and Gómez et al. (2021) who reported that personalized support contributes to outcomes in quality of life. Our studies validate this also for individuals with ID and intensive support needs due to severe and persistent challenging behaviour.

The results of our study in Chapter 2 are based on a consensus procedure to evaluate the fit of personalized contextual support between professionals and family members in (mental) healthcare. It is believed that there is added value in consensus procedures for monitoring support, that involve professionals as well as relatives, for the well-being of an individual with ID and his or her family, according to a recent review by van Beurden et al. (2025) who argue that family members of individuals with severe or profound ID should be recognized in their need to be seen as experts regarding their relative, to be informed, to be involved in support and to feel empathy.

The positive relationship between appraisal of contextual support and quality of life was stronger if challenging behaviour was less severe, suggesting that under the most challenging behaviour conditions contextual support is more likely to reach its limits. On the one hand, this outcome might underscore the notion that challenging behaviour affects quality of life negatively (Bowring et al., 2019), on the other hand, the outcome might reflect the effect of quality of care being intertwined with quality of life. Previous research has shown, for example, that the presence of challenging behaviour in people with ID leads to more stress and negative emotions in caregivers, as well as to lower quality of staff-client interactions (Simons et al., 2020; Ryan et al., 2019). If contextual support does not (or no longer) yields meaningful improvements and CB seems to be resistant to change - and persistently high – despite tailored support, caregivers may perceive their interventions as ineffective. This could potentially lead to high stress in caregivers and eventually to decreased motivation and lower engagement in interactions with the client with ID, which could result in lower QoL. Furthermore, if caregivers are primarily motivated to enhance quality of life, the perceived lack of results may itself negatively impact the caregiver's efforts to provide contextual support. Professionals working with individuals with CB should be equipped with knowledge of causes and management of CB (including the effect for caregivers' own stress and emotions), as this can contribute to their wellbeing and thus influences the quality of the care (Ryan et al. 2021).

When designing support for people with intellectual disabilities and challenging behaviour, professionals must continually assess the underlying mechanisms that result in challenging behaviour, taking into account person-environment interactions (Embregts et al., 2019; Van den Bogaard et al., 2020). Guidelines for disentangling challenging behaviour are used to shape support (Embregts et al., 2019; NICE, 2015) and highlight that a multidisciplinary approach is necessary for indication and implementation. In the Dutch context, behavioural experts, i.e. professionals with a background in clinical child and adolescent studies or developmental psychology, form an important part of this multidisciplinary support team. These experts do not only carry out the individual treatment but above all are responsible for overseeing the goals and direction of the contextual support and the multidisciplinary team itself, and they play a key role in setting targets for treatment, constantly working to untangle the mechanisms underlying behaviour. Being part of the support team, rather than only being consulted when problems arise, is a distinctive feature of practice in the Netherlands that could potentially facilitate effective support systems. This aligns with findings from international research on leadership in practice, such as that of (Deveau & Rickard, 2023), which emphasize the importance of strong, unified leadership in healthcare settings, although they did not specifically focus on behavioural experts.

As expected, the study in Chapter 3 shows that adults receiving extra intensive support on indication show higher intensity of challenging behaviour, higher numbers of mental health diagnoses and stronger focus on treatment goals in their individual support plan to reduce challenging behaviour, suggesting that the extra funding was justified. Tevis (2020) argues that intensity and frequency of aggressive behaviour towards others and oneself is the most important factor associated with higher costs, but in our study, this applied not only to aggression, but to *all* forms of CB in the extra intensive support group. Level of adaptive functioning was not a relevant factor regarding extra intensive support, in line with Buntinx (2016), who shows adaptive behaviour is only partly relating to support needs, emphasizing that adaptive functioning and support needs are distinct constructs and thus should be considered separately. Furthermore, Cullinan et al. (2024) also found that the determining factor for high-intensity care is not the characteristics of the individual, but rather the way the service organization is structured. The service organization's organizational features play a far more significant role, in line with the work of Olivier-Pijpers et al. (2020), who argue for the importance of considering the organizational context in relation to challenging behaviour.

Over time, in our sample, intensity of challenging behaviour decreased in the group with extra intensive support needs, but quality of life and adaptive functioning did not change over time. In contrast, individuals receiving 'regular' intensive support showed an improvement in quality of life over time but not in challenging behaviour. Results suggest that in the extra intensive support group, focus could have been more on management of challenging behaviour rather than on development and quality of life, highlighting the importance of focus of support in relation to outcome targets.

This fits very well with what Bisschops et al. (2024) describe as the "quality of care dilemma", which states that staff working with people with ID and challenging behaviour must continually consider whether they should invest their limited time in short-term care and practical matters around individuals they take care of, or whether they should invest that time in long-term goals to improve an individual's quality of life. Often there is not always a conscious choice, but a continuous attempt throughout the day to prevent serious disadvantages for an individual or his environment.

The study described in Chapter 4 shows that less receptive comprehension was associated with a higher risk for challenging behaviour in general. A most intriguing result, however, was that for all levels of cognitive functioning, this relation was stronger for internalizing problems than externalizing problems, with higher risk for social withdrawal (self-absorbed behaviour and less interaction) and anxiety. Furthermore, for lower levels of cognitive functioning, lower receptive communication in combination with better expressive communication was linked to a higher risk for more challenging behaviour, particularly for disturbing ways of communicating and anxiety. Better verbal skills may suggest that a person understands more than he or she actually does Therefore, inadequate communication support may contribute to challenging behaviour as the environment may overestimate comprehension based on expressive skills alone.

In Chapter 5, the results show the importance of adequate AAC for adults with ID and CB. When AAC was implemented as intended, challenging behaviour remained stable and quality of life tended to improve over time. In contrast, for those without (proper) implementation of AAC, challenging behaviour deteriorated. This suggests that a lack of effective communication, both in expressing oneself and being understood, may lead to an increased 'need' for displaying challenging behaviour. Our findings furthermore suggest to consider the use of AAC broader and not only for persons without verbal communication skills. Our study showed furthermore the relatively low implementation rate (25%) of AAC for individuals with communication support needs. Implementation in practice often proves to be a challenge (Wood et al., 2014; Zorginstituut Nederland, 2021). These challenges may arise from a lack of understanding or from discomfort by the staff about effective application of AAC, which may lead to inconsistent use of AAC or no use at all. As a result, the positive benefits of AAC could disappear or even lead to an increase in challenging behaviour, which is in line with what Mace and Nevin (2017) describe to be a risk if AAC is not always used or used without training by communication partners. To summarize, stimulating proper implementation of AAC is often overlooked, despite being a relatively accessible strategy to enhance communication when taking care of individuals with ID and CB, if expertise is present in the support team.

Conclusions

Our results underscore the crucial role of contextual support for a vulnerable individuals with ID and high support needs due to severe and persistent challenging behaviour. Our findings confirm the expectation that contextual support is important in relation to quality of life. Personalized support, intensive support and communication are relevant for outcomes over time. Taken together, the results argue for the importance of systematically mapping, monitoring and evaluating the contextual support to meet the support needs in persons with intellectual disability and CB. Recent research indicates a changing attitude towards individuals with severe challenging behaviour. For example in defining CB, Spivakovsky et al. (2023) propose looking at the importance of the fit of contextual support in addition to the individual's behaviour only. They argue that challenging behaviour – or behaviours of concern – although originally viewed as a characteristic of the individual, no longer should be seen this way and are better considered as 'adaptive behaviours to maladaptive environments' (Spivakovsky et al., 2023, p. 6). The results of our studies underscore this notion and confirm the Quality of Life Supports Model (QOLSM) (Verdugo et al., 2024) for those with the highest level of challenging behaviour, by showing the significant contribution of scaffolding contextual support to optimize quality of life. Furthermore, it was demonstrated that with the availability of extra support through extra funding in a very serious challenged group, even high support needs can be met sufficiently in most cases.

Jorgensen et al. (2023) also argue for a reorientation towards targeting the environment when the purpose is change of behaviour, in particular when this behaviour is characterized by its persistency. From a human-rights framework, they argue that current views towards challenging behaviour still hold a potential to invalidate human rights of people with intellectual disability, since the definition of challenging behaviour is 'defined by society, but not explicitly caused by it' (p.96). In other words, they argue that the focus on environments as a factor in challenging behaviour should be highlighted. Using the concept 'environments of concern' could be helpful, emphasizing environments as a target of intervention (Jorgensen et al., 2023).

Aware of the role of the environment it is argued by Jorgensen et al. (2023) that because the presence of challenging behaviour is more and more considered to result from person-environment interactions instead of personal factor alone, assessment and support planning should start to include more tools that explicitly address social and physical environments. In line with this, the framework of McGill et al. (2020) of capable environments highlights the need for environments to include essential elements for reducing or preventing CB, such as positive social interactions, support for communication, mindful and skilled carers and effective organizational context.

Optimizing contextual support to increase quality of life in adults with persistent and severe CB can be considered a challenge, as our studies clearly show. Even when contextual support is considered well suited to an individual's support needs, an increase in quality of life is seen at best as a trend when the challenges are very large and if specific goals in ISP's are consistently implemented in practice. One explanation is that persistency in these behaviours is difficult to combat. Another explanation may be found in the study by Dinora et al. (2023), they conclude that the highest support needs in persons with ID were associated with the worst personal outcomes on measures such as quality of life; possibly indicating that higher expenditures not necessarily translate to the best match in support, and consequently to better outcomes.

Based on our findings, we suggest that the focus should not only be on 'what is needed', in addition it is important to monitor if the plans are implemented in practice, since this relates to outcome over time in quality of life.

Limitations and implications for future research

A number of limitations of our studies should be mentioned here. Several factors, known to influence challenging behaviour and quality of life, such as pharmacological interventions, pain, were not taken into account during the evaluation over time.

A key limitation is the inherent difficulty of conducting research in this particular population. For example, we faced challenges related to keeping participants and their carers engaged over time throughout the study which has affected the number of participants. On the other hand, the longitudinal study of a rather large sample of a population that is often underrepresented in research can be considered a strength.

Another limitation is the use of proxies (opinion of significant others) for reporting on quality of life, challenging behaviour as well as contextual support. It is important to note that when self-report is not feasible, such as by people with intensive support needs in our sample, proxies are considered a valid alternative (Balboni et al., 2013). These indirect measures can be prone to bias and possibly do not precisely reflect the individual's own experiences, wants and needs. However, in clinical practice one relates on professional opinion as well. Shogren et al. (2021) highlight the importance of including the opinion of the client with high priority if possible. This was acknowledged by us since we prioritized this in the construction of our contextual interview as described in Chapter 2. In future research other proxies of individual experienced QoL may be explored, like physiological measures of stress, such as done by de Vries et al. (2024) and Van Der Nulft et al. (2023).

Clinical Implications

The outcomes of the studies in this dissertation may help to better shape care for individuals with ID and severe challenging behaviour. The results stress the crucial importance of contextual support for people with intensive support needs due to challenging behaviour.

Our results underscore that in highly specialized care for individuals with intellectual disabilities and challenging behaviour the way services are structured to facilitate contextual support may play a more critical role in managing these behaviours than is often assumed. In addition to the common assumption that challenging behaviour is inherently linked to characteristics of a person, our study emphasizes acknowledging the importance of context as well and therefore the need for service organizations to actively adapt their organization of supportive care around the individual support needs of individuals with CB, in line with the recommendations by (Embregts et al., 2019).

The results in this thesis emphasize that professionals should systematically monitor relevant outcome parameters such as challenging behaviour, adaptive functioning, and quality of life over time, making data-driven adjustments to intervention strategies when necessary. More specifically, the assessment of effectiveness of contextual support should be systematically evaluated. In clinical practice, assessment of contextual support should be related to those outcome parameters that are relevant for persons with intellectual disability and challenging behaviour like quality of life, which, in the end, may result in individualized evidence-based decision making frameworks facilitating decisions based on whether relevant outcomes have deteriorated, stabilized, or improved. Professionals responsible for the treatment plan should actively document contextual support. Service organizations should facilitate this possibility in digital support plan systems

Monitoring and evaluation in general, in accordance with clinical guidelines is considered important in clinical practice (Embregts et al., 2019), although this remains largely insufficient (Zorginstituut Nederland, 2021). This includes the follow-up of interventions that are outlined in individual support plans to ensure they are effective.

Our studies further show that challenging behaviour can be persistent, even within a setting of specialized care. Shaping contextual support can be more difficult when more challenging behaviour is present. Professionals, together with representatives, sometimes have to accept that the challenging behaviour no longer changes substantially, or that a relapse occurs. Improving quality of life is not merely dependent on reducing challenging behaviour, it may also be achieved by adapting the contextual support to better meet the individuals' needs and desires.

We showed that extra intensive support can reduce challenging behaviour, although quality of life might not improve. In light of these higher costs, service organizations could look for ways to flexibly adjust resource allocation, that is, by gradually reducing care once stability is achieved to avoid unnecessary expenditure after the initial crisis has passed, and by gradually scaling back up if the situation worsens, while monitoring quality of life. This is relevant to an ongoing national debate in the Netherlands about whether the rates for complex care services for individuals, in particular for those with the highest level of care needs are sufficient (Den Boer & Spijkerman, 2025). Furthermore, based on our findings we might recommend improving allocation policies for extra funding by the use of assessment of success of contextual support by evaluating challenging behaviour, adaptive behaviour, and quality of life over time. Moreover, instruments such as the Supports Intensity Scale may complement this decision-making by focusing the intensity and nature of support required (Thompson et al., 2004; Wehmeyer et al., 2009), though adaptation may be necessary to adequately reflect the diversity and complexity of needs within this population with the highest CB.

Our studies also raise the more general question of how to balance the intensity of support without compromising stability of behaviour and quality of life. Achieving this balance is delicate, we therefore recommend that the procedure of reducing intensity of support should be based on an informed, systematic approach, guided by the individual's needs.

Conclusion

This thesis shows that personalized, contextual intensive support plays an important role in the quality of life of individuals with intellectual disability and severe challenging behaviour. Higher appraisal of contextual support of a multidisciplinary team is positively associated with quality of life in adults with severe ID and CB, particularly when challenging behaviour is less severe. Additionally, extra intensive support is effective in reducing challenging behaviour over time, although its impact on adaptive functioning and overall quality of life remains limited. Furthermore, less communicative abilities are related to more challenging behaviour, emphasizing the need for targeted interventions that enhance both receptive and expressive communication skills. Strategies of Augmentative and Alternative Communication (AAC) can be beneficial, provided that it is implemented effectively. Overall, these findings highlight the necessity of individualized, well-implemented individual contextual support to improve both behavioural outcomes and quality of life for individuals with ID and severe CB.

REFERENCES

Balboni, G., Coscarelli, A., Giunti, G., & Schalock, R. L. (2013). The assessment of the quality of life of adults with intellectual disability: the use of self-report and report of others assessment strategies. *Research in Developmental Disabilities*, *34*(11), 4248-4254. https://doi.org/10.1016/j.ridd.2013.09.009

Bisschops, E. H., Clasien de Schipper, J., Salhi, Z., Embregts, P., & Schuengel, C. (2024). Communities of practice for implementing methods to reduce involuntary care in intellectual disability care: Insights from tacit and experiential knowledge exchange. *Journal of Intellectual & Developmental Disability*, *49*(3), 286-297. https://doi.org/10.3109/13668250.2023.2275225

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

Buntinx, W. (2016). Adaptive behaviour and support needs. In *The handbook of intellectual disability and clinical psychology practice* (pp. 107-135). Routledge.

Cullinan, J., O'Brien, T., & Yacoub, E. (2024). What explains regional variation in privately provided out-of-area residential placement costs for people with intellectual disability in Ireland? *Journal of Intellectual Disability Research*, *68*(5), 537-551. https://doi.org/10.1111/jir.13129

De Vries, S., van Oost, F., Smaling, H., de Knegt, N., Cluitmans, P., Smits, R., & Meinders, E. (2024). Real-time stress detection based on artificial intelligence for people with an intellectual disability. *Assistive Technology*, *36*(3), 232-240. https://doi.org/10.1080/10400435.2023.2261045

Den Boer, H., & Spijkerman, C. (2025). *Voor ernstig verstandelijk beperkten is in de zorg amper nog plek*. Onderzoekscollectief Spit. Retrieved March 20 from https://www.onderzoekscollectiefspit.nl/longreads/voor-ernstig-verstandelijk-beperkten-is-in-de-zorg-amper-nog-plek

Deveau, R., & Rickard, G. (2023). Contextual and individual barriers to providing practice leadership by frontline managers in community services for adults with intellectual disabilities: A qualitative study. *British Journal of Learning Disabilities*, *52*, 11-22.

Dinora, P., Prohn, S. M., Bogenschutz, M., Broda, M. D., Lineberry, S., & West, A. (2023). An examination of support needs, supports, and outcomes for people with intellectual and developmental disabilities. *Journal of Intellectual & Developmental Disability*, *61*(1), 65-78. https://doi.org/10.1352/1934-9556-61.1.65

Embregts, P., Kroezen, M., Mulder, E. J., Van Bussel, C., Van der Nagel, J., Budding, M., Busser, G., De Kuijper, G., Duinkerken-Van Gelderen, P., Haasnoot, M., Helder, A., Lenderink, B., Maes-Festen, D. A. M., Olivier-Pijpers, V., Oud, M., Oude Luttikhuis, I., Schilt, C. J., Smit, T., Van den Heuvel, J., ... Wieland, J. (2019). *Multidisciplinaire richtlijn probleemgedrag bij volwassenen met een verstandelijke beperking*. Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten.

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

Jorgensen, M., Nankervis, K., & Chan, J. (2023). 'Environments of concern': reframing challenging behaviour within a human rights approach. *International Journal of Developmental Disabilities*, *69*(1), 95-100.

Mace, F. C., & Nevin, J. A. (2017). Maintenance, generalization, and treatment relapse: A behavioral momentum analysis. *Education and Treatment of Children*, *40*(1), 27-42.

McGill, P., Bradshaw, J., Smyth, G., Hurman, M., & Roy, A. (2020). Capable environments. *Tizard Learning Disability Review*, *25*(3), 109-116.

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/

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. L., Luckasson, R., & Shogren, K. A. (2020). Going beyond environment to context: Leveraging the power of context to produce change. *International Journal of Environmental Research and Public Health*, *17*(6). https://doi.org/10.3390/ijerph17061885

Shogren, K. A., Bonardi, A., Cobranchi, C., Krahn, G., Murray, A., Robinson, A., Havercamp, S. M., & Function, N. R. H. (2021). State of the field: The need for self-report measures of health and quality of life for people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 286-295. https://doi.org/10.1111/jppi.12386

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.

Tevis, K. (2020). *Long-term behavioral health care unbundled: The impact of comorbidity and aggression on caregiver strain and service costs for individuals with intellectual disabilities.* The University of Nebraska-Lincoln.

Thompson, J. R., Bryant, B., Campbell, E., Craig, E., Hughes, C., & Rotholtz, D. (2004). *Supports Intensity Scale*. American Association on Mental Retardation.

Van Beurden, K., Vereijken, F. R., Frielink, N., & Embregts, P. (2025). The needs of family members of people with severe or profound intellectual disabilities when collaborating with healthcare professionals: a systematic review. *Journal of Intellectual & Developmental Disability*, *69*(1), 1-29. https://doi.org/10.1111/jir.13199

Van den Bogaard, K. J. H. M., Nijman, H. L. I., & Embregts, P. J. C. M. (2020). Attributional styles of support staff working with people with intellectual disabilities exhibiting challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, *33*(3), 465-474. https://doi.org/10.1111/jar.12688

Van Der Nulft, V., De Vries, S., Visschedijk, J., Smits, R., Meiland, F., Adam, E., Smaling, H., & Meinders, E. (2023). Impact of real-time stress monitoring in people with an intellectual disability. *Cognitive Computing and Internet of Things*, *73,* 56-67.

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

Wehmeyer, M., Chapman, T. E., Little, T. D., Thompson, J. R., Schalock, R., & Tasse, M. J. (2009). Efficacy of the Supports Intensity Scale (SIS) to predict extraordinary support needs. *American Journal on Intellectual and Developmental Disabilities*, *114*(1), 3-14. https://doi.org/10.1352/2009.114:3-14

Wood, S., Gangadharan, S., Tyrer, F., Gumber, R., Devapriam, J., Hiremath, A., & Bhaumik, S. (2014). Successes and challenges in the implementation of care pathways in an intellectual disability service: Health professionals' experiences. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(1), 1-7.

Zorginstituut Nederland. (2021). *Verbetersignalement mensen met een verstandelijke beperking en probleemgedrag: Zinnige zorg*. Retrieved March 21 from https://www.zorginstituutnederland.nl/site/binaries/site-content/collections/documents/2021/08/24/zinnige-zorg---verbetersignalement-mensen-met-een-verstandelijke-beperking-en-probleemgedrag/Verbetersignalement+Mensen+met+een+verstandelijke+beperking+en+probleemgedrag.pdf

A

APPENDICES

Nederlandse Samenvatting

Curriculum Vitae Linda Verhaar

Dankwoord

Contextuele ondersteuning en kwaliteit van bestaan
van mensen met een verstandelijke beperking
en ernstig en aanhoudend moeilijk verstaanbaar gedrag

NEDERLANDSE SAMENVATTING

Dit proefschrift richt zich op de contextuele ondersteuning van volwassenen met een verstandelijke beperking en moeilijk verstaanbaar gedrag (MVG). Voor deze mensen geldt dat de intensiteit van dit moeilijk verstaanbaar gedrag vaak maakt dat zij een zeer intensieve ondersteuningsbehoefte hebben. In Nederland komen deze mensen in aanmerking voor financiering vanuit de Wlz (Wet langdurige zorg) met een zorgprofiel VG6 of VG7, wat betekent dat zij recht hebben op (zeer) intensieve begeleiding, verzorging en gedragsregulering (Regeling langdurige zorg, 2025). In deze samenvatting wordt deze groep aangeduid als mensen met moeilijk verstaanbaar gedrag (MVG). De studies in dit proefschrift zijn onderdeel van het SCORE (Systematische Cliënt Ondersteuning Resultaat Evaluatie) onderzoek naar de evaluatie van de zorg voor mensen met een VG6 en VG7, mogelijk gemaakt door vier zorginstellingen voor mensen met een verstandelijke beperking: Ipse de Bruggen, Ons Tweede Thuis, Cordaan en de Hartekamp Groep.

In *Hoofdstuk 1* wordt beschreven hoe er in de zorg voor mensen met MVG elke dag uitdagingen zijn om deze zorg zo goed mogelijk vorm te geven. Deze zorg richt zich altijd op het verbeteren of behouden van kwaliteit van bestaan. Kwaliteit van bestaan wordt, volgens het model van Schalock en Verdugo, gedefinieerd als een multidimensioneel, universeel concept van welbevinden bestaande uit acht domeinen die relevant zijn voor iemands kwaliteit van bestaan: lichamelijk welbevinden, psychisch welbevinden, betekenisvolle contacten en relaties, materieel welbevinden, persoonlijke ontwikkeling, zelfbepaling, belangen en betekenisvolle relaties. Meerdere factoren zijn van invloed op de kwaliteit van bestaan van mensen met een verstandelijke beperking, zoals normen en waarden van betrokkenen, hoe ondersteuningssystemen binnen een organisatie de contextuele ondersteuning voor cliënten vormgeven en op welke wijze dat gefaciliteerd wordt. Er bestaan kwaliteitsstandaardaarden zoals het Kwaliteitskompas Gehandicaptenzorg, waaraan zorginstellingen moeten voldoen. Echter, er is meer wetenschappelijke onderbouwing nodig naar wat werkt, juist voor de groep mensen met MVG. In Hoofdstuk 1 wordt beschreven waarom het van belang is meer te weten over de factoren die kwaliteit van bestaan bepalen.

In *Hoofdstuk 2* wordt een cross-sectionele studie beschreven naar de relatie tussen contextuele ondersteuning en kwaliteit van bestaan bij mensen met MVG. Contextuele ondersteuning wordt gedefinieerd als ondersteuning die voortkomt uit alle inspanningen van professionals en andere belangrijke personen in de leefomgeving van een persoon, die samen de context en interventies kunnen vormgeven met als doel kwaliteit van bestaan te verbeteren. Door middel van de DELPHI-methode is er een interview ontwikkeld om de belangrijkste factoren van contextuele ondersteuning, specifiek voor deze populatie, in kaart te brengen. In meerdere feedbackrondes werd bij verschillende stakeholders (mensen met een verstandelijke beperking, hun naasten/wettelijk vertegenwoordigers, behandelaren van verschillende disciplines, (zorg)managers) van alle betrokken organisaties uitgevraagd welke factoren in de contextuele ondersteuning kunnen bijdragen aan kwaliteit van bestaan voor volwassenen met MVG. Vervolgens is voor *N*=196 personen van de vier verschillende zorgorganisaties aan een team bestaande uit een betrokken gedragskundige, een wettelijk vertegenwoordiger en een persoonlijk begeleider gevraagd in hoeverre de contextuele ondersteuning als passend ervaren werd. Er blijkt een positieve relatie te zijn tussen de mate van tevredenheid over de contextuele ondersteuning van dit team en de ervaren kwaliteit van bestaan voor een individu. Daarnaast werd aangetoond dat deze relatie minder sterk of niet aanwezig was bij de personen die zeer ernstig moeilijk verstaanbaar gedrag lieten zien. Het vormgeven van contextuele ondersteuning om de kwaliteit van bestaan te verbeteren lijkt dan minder effectief, danwel is mogelijk moeilijker uitvoerbaar.

Hoofdstuk 3 betreft het onderzoek naar de effectiviteit van extra intensieve ondersteuning (Meerzorg) ter verbetering van de kwaliteit van bestaan. Door extra financiële middelen kan (tijdelijk) meer zorg geboden worden dan vanuit de reguliere zorgfinanciering mogelijk is. Echter, wetenschappelijk onderzoek naar de effectiviteit van de inzet van deze extra intensieve ondersteuning is nauwelijks ondernomen. Kwaliteit van bestaan, adaptieve vaardigheden en moeilijk verstaanbaar gedrag worden gemeten over een periode van drie jaar, bij personen met extra intensieve ondersteuning (Meerzorg) en personen met enkel VG7. De groep met Meerzorg heeft op het eerste meetmoment een hoger niveau van moeilijk verstaanbaar gedrag (in voorkomen en intensiteit) maar er is geen verschil tussen de groepen op kwaliteit van bestaan en adaptieve vaardigheden. Over een periode van drie jaar nam de intensiteit van het moeilijk verstaanbaar gedrag af voor de groep met Meerzorg, waarbij dat voor de groep met VG7 stabiel bleef. Kwaliteit van bestaan daarentegen bleef in de groep met Meerzorg stabiel waar dat in de groep met VG7 over tijd toenam. Het resultaat in de groep met Meerzorg was onverwacht omdat bij een afname van moeilijk verstaanbaar gedrag een toename van kwaliteit van bestaan verwacht kan worden. Mogelijk duurt het voor de groep met Meerzorg langer voordat een toename in kwaliteit van bestaan te zien is omdat verandering wellicht meer tijd kost. Anderzijds kan een grotere nadruk op de afname van het moeilijk verstaanbare gedrag in de Meerzorggroep mogelijk geleid hebben tot minder ruimte en aandacht voor het bevorderen van kwaliteit van bestaan. Toekomstig onderzoek zou zich moeten richten op het beter begrijpen van waarom een afname van moeilijk verstaanbaar gedrag niet zonder meer leidt tot een betere kwaliteit van bestaan in dit type zorg.

Hoofdstuk 4 richt zich op de relatie tussen adaptieve communicatievaardigheden en moeilijk verstaanbaar gedrag bij mensen met MVG. Communicatievaardigheden zijn essentieel in het kunnen aangeven wat je wil en bedoelt en begrijpen van de omgeving. Als iemand dat minder goed kan, kan dat negatieve gevolgen hebben, want de omgeving weet dan minder goed wat er nodig is of de omgeving wordt minder goed begrepen, en dat kan dan bijvoorbeeld leiden tot frustratie waardoor het moeilijk verstaanbaar gedrag toeneemt. In deze studie hebben we niet enkel onderscheid gemaakt tussen al dan niet kunnen spreken, waartoe eerdere studies zich beperkten, maar zijn we uitgegaan van (ordinale) scores op adaptieve communicatievaardigheden, daarbij onderscheid makend tussen receptieve en expressieve vaardigheden. Receptieve communicatievaardigheden gaan over het begrijpen van de communicatie in de wereld om je heen en expressieve communicatievaardigheden gaan over het vermogen om jezelf uit te drukken naar anderen. In de groep mensen met een hoger cognitief functioneren gaan hogere receptieve vaardigheden samen met minder moeilijk verstaanbaar gedrag. Met andere woorden: minder begrijpen van de communicatie om je heen, hangt samen met meer moeilijk verstaanbaar gedrag in de vorm van angst en in zichzelf gekeerd gedrag zoals zelfverwondend gedrag.

Op domeinniveau zijn er duidelijke verbanden tussen receptieve en expressieve communicatie en probleemgedrag zowel voor de groep met lager en hoger niveau van cognitief functioneren. Dit maakt dat men zich bewust moet zijn dat de invloed van receptieve en expressieve communicatie anders kan zijn voor verschillende gedragscomponent. De regressieanalyses tonen namelijk aan dat de verbanden tussen communicatievaardigheden en MVG sterker zijn voor internaliserend dan voor externaliserend gedrag. Deze relaties zijn het sterkst zijn bij de groep met een lager cognitief functioneren

Bij de mensen met een lager cognitief functioneren ging hogere expressieve vaardigheid, in combinatie met lagere receptieve vaardigheid, samen met meer moeilijk verstaanbaar gedrag terwijl bij hogere receptieve vaardigheid er geen relatie was tussen expressieve vaardigheid en moeilijk verstaanbaar gedrag. Mogelijk is hier sprake van overschatting van mogelijkheden door de omgeving van diegenen die wel kunnen spreken maar minder begrijpen. Overvraging kan tot meer frustratie, terugtrekking of angst leiden. De omgeving heeft dus een belangrijke taak om dit mechanisme te onderkennen en daar maatregelen op te treffen. Deze mensen kunnen mogelijk baat hebben bij het gebruik van strategieën om de communicatie te ondersteunen.

In *Hoofdstuk 5* wordt het onderzoek beschreven naar de invloed van ondersteunde communicatie in relatie tot moeilijk verstaanbaar gedrag over een periode van een jaar. In de zorgplannen van deelnemers is gezocht of het ondersteunen van de communicatie in de behandeldoelen werd genoemd. Daarnaast is het ondersteuningsteam vervolgens bevraagd of en in hoeverre ondersteunde communicatie in de praktijk geïmplementeerd was. Het onderzoek liet zien dat bij personen waarbij ondersteunde communicatie in het zorgplan stond én bij wie het goed was geïmplementeerd er een toename in kwaliteit van bestaan was. Bij de personen bij wie ondersteunde communicatie in het zorgplan stond maar níet (goed) geïmplementeerd bleek te zijn, zagen we een jaar later een toename in moeilijk verstaanbaar gedrag. Dit laat het belang zien van een zorgvuldige implementatie van ondersteunde communicatie. Het liet ook zien dat er in de praktijk feitelijk maar weinig van ondersteunde communicatie gebruik gemaakt werd, waar het wel voor de hand zou liggen.

In *Hoofdstuk 6* worden de belangrijkste bevindingen van dit proefschrift samengevat en besproken in een bredere wetenschappelijke en maatschappelijke context. De bevindingen geven aan dat het belangrijk is om per individu in kaart te brengen of, en in welke mate, de contextuele ondersteuning door de bij de zorg betrokkenen aansluit bij wat een persoon nodig heeft aan support.

Actuele maatschappelijke ontwikkelingen rondom extra intensieve zorg verhogen de druk op de financiering van deze zorg en dat vraagt om het maken van scherpe en goed onderbouwde keuzes bij de inzet van de middelen op basis van het te verwachten effect daarvan op de kwaliteit van bestaan. Ons onderzoek laat zien dat moeilijk verstaanbaar gedrag kan verminderen door extra intensieve zorg. Daarmee bieden de resultaten van deze studies een basis voor verder onderzoek naar de effectieve inzet van zeer intensieve zorg. De relatie tussen contextuele ondersteuning en kwaliteit van bestaan is minder sterk in de groep met het meeste MVG in vergelijking met individuen met minder problemen in de gedragsregulatie. Dit laat zien dat inzet van ondersteuning minder effectief kan zijn voor deze groep, wat suggereert dat monitoring op individuele effectiviteit van groot belang is.

Bij het interpreteren van de bevindingen op basis van het onderzoek dat in dit proefschrift wordt beschreven is het belangrijk om rekening te houden met de beperkingen die aanwezig waren bij het uitvoeren ervan. Ten eerste, de verklarende variantie van de getoetste modellen is bescheiden, wat suggereert dat andere, niet meegenomen factoren ook van invloed zijn op de gevonden verbanden. Denk bijvoorbeeld aan factoren die van invloed zijn op gedrag en welbevinden zoals gebruik van psychofarmaca en het ervaren van pijn. De gevonden effectgroottes zijn klein tot matig, wat de praktische impact van de relaties nuanceert. Hoewel de resultaten statistisch significant zijn, wijzen op relevante verbanden en waardevolle inzichten bieden, is verdere verdieping nodig om deze steviger te onderbouwen.

Een andere beperking is dat er gebruik gemaakt werd van proxy-maten in plaats van metingen bij de persoon zelf, wat mogelijk niet altijd een volledig beeld geeft van hun ervaringen en behoeften. Mogelijk kunnen in vervolg onderzoek fysiologische maten van bijvoorbeeld stress gebruikt worden om het welbevinden van een persoon in beeld te brengen, zodat ook het perspectief meegenomen kan worden van personen die dat wellicht niet altijd goed zelf in woorden kunnen vatten.

Tot slot is het belangrijk op te merken dat de bevindingen van ons onderzoek laten zien dat moeilijk verstaanbaar gedrag niet los gezien kan worden van interacties tussen de persoon en de omgeving: MVG is niet alleen een persoonskenmerk, maar komt mede door interactie met de omgeving tot stand, daarom zijn keuzes die gemaakt worden voor intensiteit en aard van contextuele support van groot belang. Het is daarom relevant om verder onderzoek te doen naar het effect van maatwerk op basis van individuele kenmerken in interactie met de omgevingskenmerken bij de inzet van contextuele support, door zorgvuldige monitoring van het effect op de intensiteit van MVG en de kwaliteit van bestaan.

CURRICULUM VITAE

Linda Verhaar werd geboren in 1986 te Leiderdorp. Na het behalen van haar VWO diploma aan het Veenlanden College te Mijdrecht begon zij in 2004 aan haar bachelor Pedagogische Wetenschappen aan de Universiteit Leiden. In 2006 kwam zij in aanmerking voor een uitwisseling naar Engeland middels het Europese Erasmus-programma en heeft zij de keuzeruimte van haar bachelor ingevuld met vakken van de master *Special and Inclusive Education* aan de University of Manchester. Tijdens haar bachelor werd zij geselecteerd voor het Honours Programme van de Universiteit Leiden, *Developmental Disorders: the link between behaviour, cognition and neurobiology*, gecoördineerd door prof. dr. Ina van Berckelaer-Onnes. Aansluitend aan de bachelor startte Linda in 2007 met de tweejarige Research Master "*Developmental Psychopathology in Education and Child Studies*", track Clinical Practice and Research. Haar afstudeeronderzoek omvatte een follow-up studie naar kinderen met een ADHD diagnose en de invloed van medicatiegebruik op later middelenmisbruik. Zij liep haar klinische stage bij het Ambulatorium der Universiteit Leiden (nu: Leids Universitair Behandel- en Expertise Centrum, LUBEC), spreekuur ontwikkelingsstoornissen, waar zij na het afronden van haar studie werkzaam bleef als orthopedagoog. In 2011 startte Linda daar met de opleiding tot gezondheidszorgpsycholoog (GZ) en Orthopedagoog-Generalist NVO (OG), waar zij zich verder specialiseerde in diagnostiek en behandeling van kinderen, jongeren en (jong)volwassenen met ontwikkelingsstoornissen en hun ouders. Gelijktijdig werkte zij tijdens haar opleiding en daarna als docent en coördinator bij de afdeling Orthopedagogiek van de Universiteit Leiden. Naast scriptiebegeleiding heeft zij vooral een bijdrage geleverd aan klinische vakken in zowel bachelor- als masteronderwijs. Linda is in de jaren daarna tevens werkzaam geweest als behandelaar bij Centrum Autisme (GGZ Rivierduinen) en als coördinator bij het Centrum voor Consultatie en Expertise (CCE), waar zij betrokken was bij consultatietrajecten in vastgelopen situaties binnen zowel de gehandicaptenzorg, GGZ, jeugdzorg en ouderenzorg.

In 2018 maakte zij de overstap naar Ipse de Bruggen, waar zij als gedragskundige was betrokken bij mensen met een zeer ernstige tot licht verstandelijke beperkingen met uiteenlopende ondersteuningsbehoeften. Haar interesse in vraagstukken rondom complexe zorg resulteerden onder andere in actieve betrokkenheid bij de coördinatie van Meerzorg. In 2020 startte zij als buitenpromovendus met haar promotie onderzoek bij de

Universiteit Leiden (Pedagogische Wetenschappen: Neuropedagogiek en Ontwikkelingsstoornissen), onder begeleiding van prof. dr. Hanna Swaab, dr. Yvette Dijkxhoorn en dr.ir. Leo de Sonneville. Dit SCORE onderzoek, naar mensen met een verstandelijke beperking en een intensieve ondersteuningsbehoefte (VG6 en VG7), is mogelijk gemaakt door vier zorginstellingen voor mensen met een verstandelijke beperking (Ipse de Bruggen, Ons Tweede Thuis, Cordaan en de Hartekamp Groep). In dit onderzoek vervulde Linda een actieve rol in verschillende fasen van dit project als ook in de vertaling van de resultaten naar de praktijk van de dagelijkse zorg. Zij heeft onder andere verschillende lezingen en kennissessies verzorgd, en denkt daarnaast regelmatig mee over thema's rondom complexe zorg in klankbordgroepen, werkgroepen of (beleids) vraagstukken vanuit bijvoorbeeld de NVO en bij het Ontwikkelprogramma Complexe Zorg. In 2024 heeft zij samen met enkele collega's op het IASSIDD congres – de internationale vereniging voor onderzoek naar mensen met een verstandelijke beperking – in Chicago, USA, een symposium georganiseerd.

Momenteel is Linda werkzaam bij Ipse de Bruggen, als GZ-psycholoog/ Orthopedagoog-Generalist, Wet zorg en dwang (Wzd)-functionaris en onderzoeker.

Scholing/congressen tijdens PhD-traject (2020-2025):

Scholing bij *Graduate School - Faculty of Social and Behaviour Sciences*:

- Scientific Conduct
- Data management training
- 5 minute talks in English
- Online Presenting Skills for PhDs
- Pitfalls for Advanced Writers of Academic English
- Empower your PhD
- Statistical Learning and Prediction Modelling (Quantitative Methods - Winter School Programme)
- Multilevel and Longitudinal Data Analysis (Quantitative Methods - Winter School Programme)
- Qualitative Methods for Social Scientists (Winter School Programme)

Overige scholing extern:

- Verstaan van ondersteuningsbehoeften bij mensen met een verstandelijke beperking:
- de Supports Intensity Scale (*Fortior*)
- AAIDD-handboek 'Intellectual Disability' (12th ed.) (*Fortior*)
- ADOS-2 basistraining (*Accare*)
- EMDR basistraining (*EMDR Kind & Jeugd*)
- Wzd-functionaris in de gehandicaptenzorg (8daagse opleiding - *Medilex*)

Lezingen/congressen bijgewoond: Studiedag "Stil in mij" (NVO), Autisme – een concept in beweging (Rino), EVB+ platform congres 2023, EAMHID NEED conference 2022 [online], Herdenkingssymposium Anton Dosen 2023, Focus op Onderzoek 2023, IASSIDD 2021 [European conference, online], IASSIDD 2024 [world conference, Chicago, USA].

Incompany (Ipse de Bruggen): Suïcide, preventie, handelen en nazorg; AAIDD model voor gedragskundigen (dr. Wil Buntinx); Masterclass Positief Leef- werkklimaat (prof. dr. Peer van der Helm); Embodied begeleiden – vanuit affectief neuropsychologisch perspectief (Hugo Bijsterbosch, KNP)

Publicaties proefschrift:

Verhaar, L., Dijkxhoorn, Y. M., de Sonneville, L., & Swaab, H. (2024). A three-years follow- up of extra intensive support for individuals with intellectual disability and severe challenging behaviour in the Netherlands. *Journal of Intellectual Disabilities*, https://journals.sagepub.com/doi/full/10.1177/17446295241252918

Verhaar, L., Dijkxhoorn, Y. M., de Sonneville, L., & Swaab, H. (2024). The impact of personalized contextual support on quality of life of Dutch persons with intellectual disability and severe challenging behaviour. *International Journal of Developmental Disabilities.* https://doi.org/10.1080/20473869.2024.2428892

Verhaar, L., Dijkxhoorn, Y. M., de Sonneville, L., & Swaab, H. (under review). Augmentative and alternative communication, intellectual disability and challenging behaviour: Effects on adult quality of life.

Overige publicaties:

Lindley, E., Brinkhuis, R., **Verhaar, L.** (2010) Too young to have a voice? Exploring how to include very young children in a school council. In: S. Miles, M. Ainscow and M. Moore (Eds.). *Responding to diversity in schools: An inquiry-based approach*. London: Taylor & Francis. (boekdeel)

Van der Ban, E., Van der Heijden, K., **Verhaar, L**., Souverein, P., Van Engeland, H., Egberts, T.C.G., Heerdink, E.R., Swaab, H. (2014). Association between stimulant treatment for ADHD and daily or life time drug use: a follow-up from childhood into adulthood. In: E. van der Ban (2014), *ADHD medication use and long-term consequences* (proefschrift dr. E v.d. Ban).

Van der Heijden, K.B., Suurland, J., **Verhaar, L**., Arends, J.B.A.M., & Gunning, W.B. (2009). The validity of actigraphy in children with ADHD and insomnia: A comparative study with polysomnography. In S. Overeem, T. De Boer, V. Van Kasteel, G. Van Luijtelaar, G.S.F. Ruigt, J. Verbraecken (Eds.), Sleep-Wake: Research in The Netherlands (NSWO), volume 20. Enschede: Ipskamp BV. (boekdeel)

Lezingen tijdens promotietraject:

- International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), European conference 2021, Amsterdam. Symposium*: Evaluating specialized care for people with ID and severe mental health problems*.
  Presentatie: *Evaluation of contextual support as a means to address challenging behaviour*: dr. Y.M. Dijkxhoorn, Linda Verhaar
- International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), World conference 2024, Chicago. Symposium: *Exploring the effect of contextual support*.
  Presentatie: *Intellectual Disability and (extra) intensive support needs*: Linda Verhaar
- EVB+ platform (2023) Presentatie: *Meerzorg inzetten bij mensen met EVB+, bevindingen uit het SCORE onderzoek.* Linda Verhaar
- *Kennissessie SCORE*, Universiteit Leiden. Presentaties: dr. Y.M. Dijkxhoorn, D.M. van Winden, L. Verhaar, I. Migchelsen
- Congres 'Focus op onderzoek' (Kenniscoalitie voor de sector van zorg voor mensen met verstandelijke beperkingen). Presentatie: *SCORE Onderzoek*, door dr. Y.M. Dijkxhoorn, D.M. van Winden, L. Verhaar, I. Migchelsen
- European Association for Mental Health in Intellectual Disability (EAMHID)
  (accepted for presenting, September 2025).
    - *A three-years follow-up of extra intensive support for individuals with intellectual disabilities and severe challenging behaviour in the Netherlands*. Linda Verhaar.
    - *Impact of very intensive one-on-one care for people with ID and challenging behaviour: resident representatives and professional caregivers perspectives*. L. Verhaar en dr. Y.M. Dijkxhoorn

DANKWOORD

Dat ik na mijn Research Master ooit nog een promotietraject wilde doen, stond vast. Ik ben enorm blij dat ik eerst ruime klinische ervaring heb op kunnen doen in diverse sectoren, bij het Ambulatorium (nu LUBEC) van de Universiteit Leiden, Centrum Autisme en het Centrum voor Consultatie en Expertise (CCE). De overstap naar Ipse de Bruggen bleek een schot in de roos: daar kreeg ik al snel de ruimte om mijn onderzoekambities te verwezenlijken door aan te sluiten bij het SCORE onderzoek. Dit proefschrift was er niet gekomen zonder de begeleiding van mijn promotor prof.dr. Hanna Swaab en co-promotoren dr. Yvette Dijkxhoorn en dr.ir. Leo de Sonneville.

Hanna, ik heb grote bewondering voor je uitzonderlijke wetenschappelijke én klinische expertise. Ik heb regelmatig sneller naar je moeten luisteren dan dat mijn brein met momenten aankon, maar juist dát daagde me steeds uit om scherper te denken en te werken, en te groeien als onderzoeker. Dank voor al je betrokkenheid en voor alles wat ik van je heb mogen leren.

Yvette, vanaf de eerste colleges in de propedeuse heb ik zoveel geleerd van je klinische blik, en van je vermogen om bij werkelijk elke ingewikkelde situatie, of het nu praktijk of onderzoek is, een treffende analyse en plan te maken. Daarnaast heb ik mooie herinneringen aan onze (internationale) congresbezoeken. Dank voor al je steun gedurende de afgelopen jaren.

Leo, vanaf mijn bachelorscriptie heb je me al geïnspireerd voor onderzoek. Je hebt me vooral vertrouwen gegeven in mijn eigen onderzoeksvaardigheden. Ik heb zoveel van je geleerd over statistiek, methodisch werken, grote vraagstukken behapbaar maken en in het tot de kern komen in wetenschappelijk schrijven. Zelfs wanneer dat betekende zinnen schrappen waar ik net nog trots op was. Dank voor al je zorgvuldige begeleiding.

Het SCORE-onderzoek had niet kunnen bestaan zonder de grote inzet van cliënten, familieleden, vertegenwoordigers en collega's in alle lagen van de betrokken organisaties: Ipse de Bruggen, Ons Tweede Thuis, Cordaan en de Hartekamp Groep. Ondanks alle praktische uitdagingen zoals covid of personeelstekorten is er wel steeds ruimte gemaakt voor interviews, vragenlijsten en reflectie-sessies. Mijn dank is groot aan iedereen die hieraan heeft bijgedragen: alle betrokken cliënten, cliëntvertegenwoordigers en familie, begeleiders, gedragskundigen, vaktherapeuten, managers, andere behandelaren, directies en RvB's, en ook de masterstudenten Orthopedagogiek van de Universiteit Leiden.

Ook de collega's die deel zijn (geweest) van het SCORE onderzoeksteam verdienen een bijzondere vermelding. Guus Wulms, dank voor je visie op dit onderzoek, je initiatief en enthousiasme. Desiree van Winden, Iris van Puffelen, Ilse Migchelsen, ook dank voor jullie zorgvuldige werk bij dataverzameling en verwerking.

Dank Marian, voor de prachtige schilderijen die de basis van deze omslag mochten vormen.

Ik ben sinds mijn eerste stappen in de gehandicaptenzorg onder de indruk en trots op waar deze sector als geheel in het niet al te verre verleden vandaan komt en hoe zij gegroeid is. Trots op hoe hard er elke dag gewerkt wordt voor kwaliteit van bestaan. Het is ook bijzonder mooi hoe binnen Ipse de Bruggen het belang van wetenschappelijk onderzoek steeds wordt erkend. Ik ben dankbaar voor het vertrouwen en de ruimte die ik daarin heb gekregen, op manieren die steeds aansloten bij wat passend was voor mijn persoonlijke situatie. Dank aan iedereen, zoals Jan van Hoek, Ilse van Esch, Marieke Speet, Wendy te Slaa, Karin Stolwijk, die hieraan bijgedragen hebben.

Dank aan de overige collega's van Ipse de Bruggen, teveel om op te noemen. Maar een aantal wel: Jenny, voor de wandelrondjes en je luisterend oor. Nieuwveen-collega's, die er altijd voor me waren op de flex, voor steun, inhoudelijk overleg, en de bijzonder fijne teamspirit. Jacqueline Roos, voor het sparren (ook in Chicago). Vanessa Olivier-Pijpers, voor het nodige relativeren af en toe. Ook dank aan mijn collega's van Bureau Wzd en het Meerzorgcoördinatiepunt: dank voor me steeds de ruimte voor mijn onderzoek geven, maar ook voor de gesprekken over ethiek en (beleids)vraagstukken die rondom Meerzorg, Wzd en complexe zorg dagelijks voorbijkomen. Wetenschappelijk onderzoek en praktijk vullen elkaar wederzijds steeds aan!

Mijn oud-collega's en kamergenootjes bij Pedagogische Wetenschappen (Universiteit Leiden); Petra en Gemma. Jullie promotietrajecten van zo dichtbij zien, heeft me nu geholpen om door te zetten en om te begrijpen waar ik steeds was in mijn traject.

Paranimfen Ilse en Kim, dank dat jullie bij de verdediging aan mijn zijde staan. Ilse Migchelsen, jij was echt mijn maatje in het schrijven en brainstormen! Kim van Leeuwen, dank voor alle belletjes waarin we even konden stilstaan, en een veelheid aan onderwerpen hak-op-de-tak in een heerlijk snel tempo moeiteloos aan elkaar konden verbinden.

Dank aan alle lieve vrienden bij wie ik de afgelopen jaren dit proces kon delen, maar vooral met wie ik het leven kon vieren: o.a. Eli, Sarah, Simone, Marlies, dispuutsvriendinnen, schoolpleinmoeders-vriendinnen, Hof van Kairos-retraite-vriendinnen. Maar ook vooral Mar & Saar, vanaf basisschool en brugklas, onvoorwaardelijk diepe vriendschap.

Lieve schoonfamilie, dank voor jullie steun en aanmoediging.

Mijn eigen familie, een warm (Verharen)-nest. Ik ben ontzettend gezegend met zoveel lieve mensen om me heen, met 'De werft' als kern. Dick en Mike, Maikel, Julia, Emma, Mir en natuurlijk pap en mam: dank voor jullie onvoorwaardelijke aanwezigheid, altijd, hopelijk mogen we nog heel lang met elkaar zo zijn.

Anne Fleur en Florian, ik ben zo blij met jullie! Mijn boek is eindelijk af, mijn 'spreekbeurt' komt eraan. Ik geniet van jullie groot zien worden, jullie vragen, hoe jullie de wereld zien. Ik kijk uit naar onze volgende reizen.

Joost, mijn rots in alles. In deze intense tropenjaren - met onze allerliefste kinderen grootbrengen, mantelzorgen, marathontrainingen, verhuizen - heb je zoveel opgevangen. En dan ook nog eens een vrouw die een proefschrift schrijft. Ik had dit niet gekund zonder jou.