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

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