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Contextual support and quality of life of individuals with intellectual disability and severe and persistent challenging behaviour
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CHAPTER 2

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

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.

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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

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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,

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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

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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

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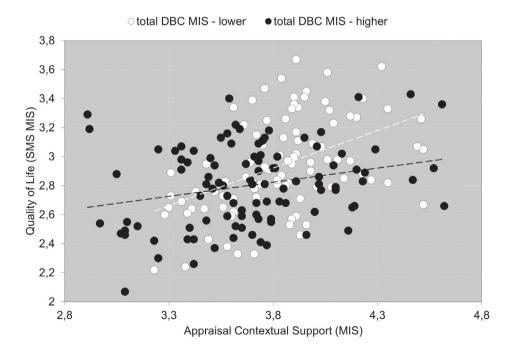
Furthermore, the prediction success of the separate domains of QoL (SMS subdomains) was examined. Approximately similar models were obtained for Self Determination and Rights (with 20% explained variance), Social Inclusion and Interpersonal Relationships (with 15% explained variance) and Physical Wellbeing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

Table 3

Coefficients in final model

Predictors	B	Std error	β	t	p	95% CI 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

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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

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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.

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