

Tilburg University

Meaningful moments of interaction with people with profound intellectual disabilities

Penninga, Wieneke; Nijs, Sara L. P.; Van Bakel, Hedwig J. A.; Embregts, Petri J. C. M.

Published in:

Journal of Applied Research in Intellectual Disabilities

DOI:

[10.1111/jar.13019](https://doi.org/10.1111/jar.13019)

Publication date:

2022

Document Version

Publisher's PDF, also known as Version of record

[Link to publication in Tilburg University Research Portal](#)

Citation for published version (APA):

Penninga, W., Nijs, S. L. P., Van Bakel, H. J. A., & Embregts, P. J. C. M. (2022). Meaningful moments of interaction with people with profound intellectual disabilities: Reflections from direct support staff. *Journal of Applied Research in Intellectual Disabilities*. <https://doi.org/10.1111/jar.13019>

General rights





Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Meaningful moments of interaction with people with profound intellectual disabilities: Reflections from direct support staff

Wieneke Penninga^{1,2}  | Sara L. P. Nijs¹  | Hedwig J. A. van Bakel¹  |
Petri J. C. M. Embregts¹ 

¹Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands

²Amerpoort, Baarn, The Netherlands

Correspondence

Wieneke Penninga, Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, P.O. Box 90153, 5000 LE Tilburg, The Netherlands.
Email: w.penninga@tilburguniversity.edu

Funding information

Amerpoort

Abstract

Background: High-quality, affective relationships are built on meaningful moments of interaction, which are challenging for support staff to establish with people with profound intellectual disabilities. Therefore, we explored what makes a moment of interaction meaningful to support staff and what circumstances facilitate meaningful moments of interaction taking place.

Method: Five direct support staff took part in unstructured, in-depth interviews. The interviews were analysed using interpretative phenomenological analysis (IPA). Member checks were also conducted.

Results: Support staff experienced moments of interaction as meaningful because they felt a connection with a person with profound intellectual disabilities and/or they had the feeling of being meaningful for this person. Staff-related and contextual circumstances facilitating meaningful moments of interaction to take place were described.

Conclusions: Meaningful moments of interaction are highly valued by support staff, who believe these moments are valued by persons with profound intellectual disabilities as well. Implications for daily practice are described.

KEYWORDS

interpretative phenomenological analysis, meaningful interaction, meaningful relationship, profound intellectual and multiple disabilities, profound intellectual disability

1 | INTRODUCTION

Intimate and affective interpersonal relationships are important for the quality of life of every human being (Felce, 1997; Schalock, 2004). People with intellectual disabilities, however, often experience difficulties in establishing such relationships. Consequently, support staff are important interaction partners (Kamstra et al., 2015; Meys et al., 2021). In the relationship between support staff and a person with intellectual disabilities, it has been found that people with

borderline intellectual disabilities also value aspects of affection and intimacy (Griffith et al., 2013; Roeleveld et al., 2011), as do parents and support staff of people with profound intellectual disabilities (Forster & Iacono, 2008; Petry et al., 2005). Such high-quality relationships between support staff and people with borderline intellectual disabilities that include these aspects have been described as meaningful (Embregts, 2011).

Establishing a high-quality relationship with a person with profound intellectual disabilities or profound intellectual and multiple

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2022 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd.

disabilities¹ can be challenging for support staff, as the subtle, idiosyncratic way of communicating of persons with profound intellectual disabilities makes it difficult for staff to relate (e.g., Bos & Abma, 2021; De Schauwer et al., 2021). People with profound intellectual disabilities have severe cognitive disabilities (IQ below 20; cognitive level of functioning below 24 months), often combined with sensory, motor and medical problems (Nakken & Vlaskamp, 2007). They communicate primarily on a pre- or protosymbolic (Ogletree et al., 2012; Olsson, 2005), pre-intentional level (Dhondt et al., 2020), expressing their needs and wishes by use of idiosyncratic and context-bound signals (Grove et al., 1999). Due to this pre-intentionality, and the subtlety and idiosyncrasy of their signals, it is a challenge for direct support staff to be aware of and understand the responses of people with profound intellectual disabilities (Griffiths, 2010; Grove et al., 1999; Neerinckx & Maes, 2016). Thus, it is of value to explore what might assist support staff to establish high-quality relationships.

Previous studies that have addressed this matter operationalised the quality of the relationship between people with profound intellectual disabilities and their support staff as the quality of observable dyadic interactions (e.g., Griffiths & Smith, 2016; Hostyn et al., 2011). More specifically, the prevalence and/or sequence of high-quality interactive behaviour was determined (e.g., Healy & Noonan Walsh, 2007; Hostyn et al., 2011; Olsson, 2004) as the prevalence of joint attention (Neerinckx et al., 2014) or attunement-related behaviours (Griffiths & Smith, 2016). These studies provided insight into the quality of the interactive behaviours of people with profound intellectual disabilities and their support staff and into the related issues of reciprocity and attunement. Lessons were learned about what elements in the interactions support reciprocity and assist in eliciting and stimulating high-quality interactive behaviour in people with profound intellectual disabilities (e.g., Hostyn & Maes, 2013; Ten Brug et al., 2015). However, due to the idiosyncrasy of the interactive signals of people with profound intellectual disabilities, this information is only partly applicable, offering only general guidelines for support staff in establishing a relationship with a person with profound intellectual disabilities. Support staff still need to get to know the person well to apply this knowledge based on an understanding of the individual (Bradshaw & Goldbart, 2013; Forster & Iacono, 2008; Hostyn & Maes, 2013).

To gain greater insight into the quality of the interactions between people with profound intellectual disabilities and their support staff, in addition to observations, researchers have also conducted interviews with support staff to collect information about their perceptions of high-quality interactions (Forster & Iacono, 2008). These studies identified important emotional aspects such as affection, warmth and attachment (Forster & Iacono, 2008; Hostyn & Maes, 2009), which may be described as aspects of intimacy and personal involvement characterising a meaningful relationship (Embregts, 2011). To gain further insight into what might help support

staff in establishing this meaningful relationship, we need to identify the building blocks of such relationships—meaningful moments of interaction. Therefore, the focus of this study is to clarify what characterises these meaningful moments of interaction from the perspective of direct support staff, addressing the research questions: ‘What leads support staff to experience a moment of interaction with a person with profound intellectual disabilities as meaningful?’ and ‘What circumstances facilitate meaningful moments of interaction to take place, according to support staff?’

2 | METHOD

2.1 | Procedure

Participants were recruited from two Dutch care organisations for people with intellectual disabilities using purposive sampling. In order to recruit support staff willing to participate in this study, psychologists or managers were asked to assist in identifying staff members matching the inclusion criteria, which were: (1) working for a minimum of 12 h a week in the group, for at least the last 6 months, so that the staff member and a person with profound intellectual disabilities got to know each other (Forster & Iacono, 2014; Neerinckx et al., 2014) and (2) providing care for children with profound intellectual disabilities aged between 5 and 18 years. To meet this second criterion, at least 80% of the children in their group had to: communicate on a pre- or protosymbolic level, have an IQ below 20 or developmental age below 24 months, and be aged between 5 and 18 years. Potential participants received an information letter. All of the participants recruited agreed to participate and gave their written informed consent. Parents of the children with profound intellectual disabilities were informed about the research project. One staff participant withdrew from the study between the interview and the member check for personal reasons. Therefore, this interview was not included in the analysis. The study was ethically approved by the Ethical Review Board of Tilburg University (EC-RP 29).

2.2 | Participants

Five experienced support staff (female, 27–61 years), all working with children and youngsters with profound intellectual disabilities and often additional motor, sensory and/or medical problems, participated in this study (see Table 1).

2.3 | Instruments

In-depth exploration of perceptions of support staff regarding moments of interaction with people with profound intellectual disabilities and the identification of what makes a moment of interaction meaningful to them was undertaken using interpretative phenomenological analysis (IPA) (Smith & Osborn, 2008).

¹To improve readability we use ‘people/person with profound intellectual disabilities,’ which also includes people/person with profound intellectual and multiple disabilities.

TABLE 1 Participants

Staff member	Support staff					Children			
	Educational level	Work in ID care (years)	Work in the group (years)	Part-time factor	Staff-children ratio	Number of children	Ages (years)	Cognitive developmental age (months) ^a	Motor disabilities ^b
Anna	Univ. applied sciences	14	4–5	88%	3:7	7	6–18	0–12	100% motor disability (100% wheelchair user)
Britta	Vocational training	12	4	44%	3:8	8	13–17	12–24	50% motor disability (25% move with aid; 25% move without aid), 50% no motor disability
Caro	Univ. applied sciences	14	6–7	44%	3:7	7	10–15	0–24	100% motor disability (28.6% wheelchair user; 71.4% move with aid)
Deirdre	Univ. applied sciences	6	5–6	88%	3:7	7	8–17	0–24	100% motor disability (57.1% wheelchair user; 42.9% move with aid)
Evy	Univ. applied sciences	13	5	66%	2:8	8	7–12	0–18	100% motor disability (75% wheelchair user; 12.5% move with aid; 12.5% move without aid)

^aAs it is challenging to validly measure the level of cognitive functioning of people with profound intellectual disabilities (Maes et al., 2021), we relied on the clinical judgements of the psychologists involved.

^bAll of the children suffered from additional sensory and/or medical problems, such as epilepsy, eating problems (tube feeding) or problems in sensory information processing. The severity of these additional problems was not assessed.

Data were collected through unstructured interviews. To practice undertaking such unstructured interviews and to find out whether the opening question invited interviewees to share their experiences, four trial interviews were executed. Based on these trials, the interviews with the participants were conducted. Each of these interviews started with a short introduction setting the context of the interview, and the participant was then asked to introduce herself. The researcher then posed the question: ‘When I mention “a meaningful moment of interaction,” what comes to mind?’ The researcher encouraged the participant to elaborate as much as possible in her answers, aiming to elucidate the information by asking open, explorative questions, such as ‘Why does this particular moment affect you?’

Two one-on-one interviews were administered in person and three interviews were held using a secure, online Skype or Teams meeting due to the COVID-19 pandemic. The results of interviews undertaken online were found to be comparable to those held in person (Braun & Clarke, 2013).

The duration of the interviews varied from 36 to 61 min. Within 2 to 5 weeks after the interview, a member check was conducted with the participant. The member checks had a duration varying from 27 to 61 min.

2.4 | Analysis

Following IPA guidelines, the first author transcribed the audiotaped interview verbatim and read each interview several times to gain

familiarity with the text. Second, descriptive, linguistic and conceptual analyses were conducted. The descriptive analysis focused on the literal content of the interview: the subjects and issues the participant mentioned. The linguistic analysis focused on how the participant shared her information, for example the words she used or the tone of her voice. Finally, the conceptual analysis focused on interpretation on a more abstract level (Smith et al., 2009). Third, the first author formulated themes based on the analyses and wrote a summary based on these themes. To ascertain that the interpretations adequately reflected what the participant said, the outcome of every step was discussed with the second author until consensus was reached.

The summary was also presented to the participant in the member check to ensure it reflected the participant's perceptions (Voermans et al., 2021). The researcher asked questions to check the interpretation of the interview in order to deepen the understanding of the perception of the participant. The member check was also analysed using IPA, as described above. The information gathered during the member check was integrated into the summary of the initial interview. The analyses and summary were then discussed with the third and fourth authors. Any additions were integrated into the summary. After analysis of both interview and member check of each participant, an interview with the next participant was planned.

Fourth, after all of the interviews and member checks were conducted, analysis of each interview aimed to formulate the underlying meaning of each part of the text into emerging themes. Subsequently, these emerging themes were clustered into overarching themes. The

first and second authors discussed these overarching themes until consensus was reached. Based on the themes identified for each participant, we formulated overarching themes across all of the interviews. These themes were discussed with the third and fourth authors until consensus was reached.

The interviews were in Dutch, as were the verbatim transcripts and the analyses. For this report, the results and quotes were translated into English and checked by an English native speaker.

3 | RESULTS

The IPA analysis resulted in four overarching themes. The first two themes describe what makes a moment of interaction meaningful to support staff. Theme 1 concerns experiencing a connection with the person with profound intellectual disabilities. Theme 2 focuses on the impact of the experience of support staff in making a difference to a person with profound intellectual disabilities. The third and fourth themes address circumstances that are related to meaningful moments of interaction taking place. Theme 3 focuses on the role and needs of support staff in relation to facilitating meaningful moments of interaction. Theme 4 focuses on organisational and practical circumstances.

3.1 | Theme 1: Feeling connected

3.1.1 | I feel connected during a moment of interaction

Moments of interaction were meaningful to support staff when they felt connected to a person with profound intellectual disabilities. They described enjoying meaningful moments of interaction themselves and experienced that the person with profound intellectual disabilities also appreciated these moments. However, they reported that, with persons with profound intellectual disabilities, experiencing even a behavioural connection could be challenging, because people with profound intellectual disabilities frequently showed a minimal response or no response at all. Therefore, support staff considered moments of interaction meaningful when a person with profound intellectual disabilities responded, anticipated or changed his or her behaviour or mood positively in response to an initiative by them. When a person with profound intellectual disabilities initiated contact, support staff valued the moment of interaction even more.

Because [at these moments] the child approaches you: it is not you who initiates the interaction, it is him. That is the difference. [In taking care of the children] we take over many things and the children follow our lead. Therefore, the moments of interaction in which the child takes the initiative are so meaningful. (Anna).

Anna, Britta and Caro also shared moments of teasing and having fun together as examples of meaningful moments. In these moments, the connection they experienced seemed to have an emotional connotation.

Then he started grinning... His hand went to the ball and pushed the ball out of the tree... We [staff members] responded immediately, teasing 'oh oh... you cannot do that'..... Hihi... He just really enjoys it... [He experiences:] I act and they respond (Anna).

There were moments that Deirdre and Evy mentioned, that seemed to reflect the experience of an existential connection. Deirdre shared the experience of being in the same bubble, sensing a shared 'being', with a person with profound intellectual disabilities. In line, during these moments, Deirdre and Evy experienced they saw the person as who he or she was, and felt seen and accepted by the person with profound intellectual disabilities in the same way.

Because I feel we totally sense each other, are aware of each other, perceive each other (...). I am who I am in these moments. (Deirdre).

3.1.2 | I feel connected over time

The support staff felt that the connection they experienced during meaningful moments of interaction contributed to their experience of a connection over time. The support staff felt that they were able to get to know the person with profound intellectual disabilities and vice versa. The support staff agreed that to get to know a person with profound intellectual disabilities they needed to undertake activities together and spend time together, while observing the subtle signals of the person with profound intellectual disabilities and exploring his or her responses.

By spending time together, staff felt the person with profound intellectual disabilities also became familiar with his or her support worker. By getting to know each other, support staff experienced a bond could develop.

In this way I can establish a bond [with a child]. Because [the child] often sees me. That is mutual. Um ... I think the more often I spend time with a child the easier it is for me to connect, as I start noticing more signals that are communicative. That works both ways I think. (Evy).

As Britta and Evy explained, becoming familiar with staff helped a person with profound intellectual disabilities to anticipate engagement. Consequently, meaningful moments of interaction more readily developed. In developing a bond, Caro described, feelings of mutual affection could develop. Deirdre shared an example in which she felt a person with profound intellectual disabilities was trying to comfort her.

[I was sad] ... I was sitting next to him... He was getting active... And I thought 'are you going to cheer me up?' (...) He did not let his motor disabilities hold him back and tried to hug me... And I thought... This is such a moment we connect... and he wants to support me as well (Deirdre)

Although the support staff reported familiarity and predictability encouraged meaningful moments of interaction, they also mentioned the power of trying something new. Anna, Britta, Caro and Evy all gave examples in which a familiar support worker acting spontaneously or a new approach by an unfamiliar support worker encouraged a meaningful moment of interaction to take place.

3.2 | Theme 2: Being meaningful for the other

All of the support staff considered it meaningful when they felt they could make a difference to a person with profound intellectual disabilities. This feeling occurred when they had a sense of contributing to the emotional wellbeing and development of a person with profound intellectual disabilities. They considered the two to be linked. For example, the person with profound intellectual disabilities feeling safe and comfortable were linked to his or her opportunities for development by Evy:

When a child feels safe and comfortable, you can try something new (Evy).

At the same time, the participants acknowledged the development of communicative and social skills might also contribute to the emotional wellbeing of a person with profound intellectual disabilities. Staff described that these moments in which they felt they could make a difference to a person with profound intellectual disabilities, were not self-evident. Therefore, these moments were special to them.

3.2.1 | I can contribute to the emotional wellbeing of a child

Caro and Evy described their wish to contribute to the emotional wellbeing of the person with profound intellectual disabilities, and shared how it affected them positively when they succeeded. As Evy stated:

Then I realize ... this is the most valuable aspect of my work ... to get such a content smile on their faces. And um ... Yes ... It makes me very happy. (Evy).

Finding ways to contribute to the emotional wellbeing of a person with profound intellectual disabilities was often perceived as challenging. Staff mentioned it could be a persistent search to find out what

made a person with profound intellectual disabilities unhappy or happy and find the best way to support. Therefore, a moment they succeeded, was perceived as meaningful.

Well, at that moment, I am really happy I am able to help him. (...). You do not always understand his signals ... Then it is like ... You are trying to find out what is going on and um ... you just cannot find a way to help him. That is also possible ... (Caro).

3.2.2 | I can contribute to the development of the person with profound intellectual disabilities

Anna and Britta gave examples in which development contributed to the emotional wellbeing of the person with profound intellectual disabilities. For example, Anna was able to stimulate the person to explore new communicative abilities, which seemed to make the person happy, and confirmed to Anna that she could contribute to her development. This encouraged Anna to explore opportunities for further development.

... at a certain moment it just hit me... [The girl] moved her eyes to say yes... I checked... And I saw her think (holds her breath): she noticed! (...) That was so cool. We are still working on that... (...) She was really proud... Happy... Feeling she was able to influence [the world around her] (Anna).

During a meaningful moment of interaction, support staff felt connected to a person with profound intellectual disabilities and/or they felt they could be of meaning to a person with profound intellectual disabilities. Therefore, they described these meaningful moments as the core aspect of their job. During these moments, they experienced joy and emotional nourishment, which contributed to their job satisfaction and gave them the energy they needed to continue the intensive work.

You really have to be patient, and then it is also possible to connect with him. Sometimes it is just for two seconds. Then you catch his attention. These are the moments you must grab. And I can live on that for a week. (Britta).

3.3 | Theme 3: Being able to have an influence

3.3.1 | I affect the chance of a meaningful moment taking place

The support staff related their own behaviour to the chance of a meaningful moment of interaction taking place. They felt that they could influence this by optimising circumstances for a meaningful moment of interaction to take place.

Then I was able to create a nice atmosphere ... safe ... familiar. And then I was allowed to enter [his world]. (Britta).

An important condition for all of the support staff was to bring their full attention to their engagement with a person with profound intellectual disabilities, which, they reported, was necessary to be able to notice their subtle signals.

It is so tiny. It is easy to miss. When you do not take the time to pause and watch hey what is happening ... well ... Then you will miss it. (Anna).

Thus, the support staff linked their ability to notice the subtle signals of a person with profound intellectual disabilities to their own attitudes, mindset and characteristics, such as patience, taking time, being attentive and present in-the-here-and-now.

3.3.2 | I have to be conscious of my needs

Being attentive, taking time and having patience were conditions staff reported, that optimised circumstances for a meaningful moment of interaction to take place. The support staff agreed that they have to actively do something to realise these conditions. Anna, Britta and Deirdre mentioned that having to be continuously present and alert was demanding and, therefore, they emphasised that support staff also needed to take care of themselves. For example, they mentioned that it was important to pay attention to their own mood and wellbeing to create the mental space required to meaningfully interact.

When I feel stressed (...) I allow myself to take a little time (...) and try to resolve that feeling... Because to me it is really important to give the group my full attention. (Deirdre).

In addition to the conditions mentioned above, Deirdre added the importance of 'being you', which she explained as 'daring to be vulnerable' and undertaking the tasks of a support worker in your own way.

That is another condition to reach such a special moment. You have to be ... [The contact] has to be pure ... You have to be yourself, and so does the other (...) To be who you are without any judgments whatsoever. (Deirdre).

3.4 | Theme 4: Coping with contextual circumstances

3.4.1 | I am experiencing a tension between personal values and limited possibilities

Meaningful moments of interaction were important to support staff. They described they sometimes felt that the care giver—care receiver

ratio or the demands of daily work, such as unexpected medical care, could hamper their ideal of offering each person their full attention. This could be frustrating. Caro, for example, felt that she fell short when she did not succeed in realising these moments.

In the past we took care of seven [children] with two [support staff]. Then ... often you were in a hurry. When there are unexpected issues (...) you could not [give the children] your full attention. That is exhausting. It does ... It does make me feel uncomfortable. (Caro).

The support staff tried to find solutions so they could give the people with profound intellectual disabilities their full attention as much as possible. For example, to prevent other care professionals from disturbing the group process, Deirdre placed a stop sign on the door.

3.4.2 | I have to deal with differences in the importance given to interpersonal contact

Britta, Deirdre and Evy described that they sometimes perceived that not all of the people involved in the care of a person with profound intellectual disabilities, such as other colleagues, managers and parents, seemed to value moments of contact in the same way they did. They were well aware of these differences and acknowledged the importance of other activities for the wellbeing of persons with profound intellectual disabilities. Therefore, they would experience a tension, when they followed their heart and chose to create circumstances in which a meaningful moment of interaction could develop, instead of another, planned activity.

Then you almost feel guilty, because [the child] did not spend time in his walking aid [that day] ... Instead ... I took the opportunity to sit him on my lap for fifteen minutes ... And yes, in those moments, I decide to do that. (Deirdre).

They also related this tension they experienced, to a more general issue. They described they felt that in the care for persons with profound intellectual disabilities 'quantifiable activities', such as physical training programs, seemed to be preferred over 'less quantifiable activities', such as contact, by persons involved in the care for persons with profound intellectual disabilities and in policy.

4 | DISCUSSION

In this study, we explored meaningful moments of interaction with people with profound intellectual disabilities from the perspective of support staff in line with Embregts' (2011) concept of meaningfulness. In the interviews, the support staff explained what makes moments of interaction with people with profound intellectual disabilities

meaningful to them. They also shared their thoughts concerning the development of meaningful moments of interaction.

The results of the IPA analysis showed that the support staff perceived a moment of interaction with a person with profound intellectual disabilities as meaningful for two reasons: first, because of the connection they experienced with the person with profound intellectual disabilities, for example, because the person responded or initiated contact; second, because meaningful moments of interaction confirmed to support staff that they could make a difference to a person with profound intellectual disabilities by contributing to his or her emotional wellbeing and/or development. The support staff indicated that these moments in which they felt a connection or felt they made a difference to a person with profound intellectual disabilities, were not self-evident. Therefore, also the frequency in which these moments took place was related to experiencing a moment as meaningful.

The connection with a person with profound intellectual disabilities that the support staff experienced was behavioural, emotional and existential. The behavioural and emotional connections they described are in line with previous studies focusing on high-quality interactions between people with profound intellectual disabilities and support staff. For example, when the support staff described reciprocity on a behavioural level, they mentioned aspects that were also found in these previous studies, such as joint attention (e.g., Neerinx et al., 2014) and reciprocal attunement (e.g., Forster & Iacono, 2014; Griffiths, 2010). The support staff emphasised that, in order to recognise responses and initiatives of a person with profound intellectual disabilities, it is necessary to notice and give meaning to their subtle and idiosyncratic signals.

In addition, in line with Healy and Noonan Walsh (2007), the support staff emphasised that, in order to recognise these signals, it is necessary to know the person well. To do this, support staff and a person with profound intellectual disabilities need to spend time together, as various authors have found as well (Bradshaw & Goldbart, 2013; Forster & Iacono, 2008). In this way, a bond or meaningful relationship may also be established. The emotional connection was also related to experiencing the moment together, sharing joy, and a sense of emotional reciprocity. This emotional reciprocity was described by Forster and Iacono (2008) as well, as the staff members interviewed in their study mentioned, for example, they experienced friendship and mutual support.

The existential connection that the support staff described was not denoted as such in previous studies. This connection concerned seeing and accepting each other in terms of who they were. It also related to the experience of being in the same bubble, which seems to refer to experiencing the present moment, as described by Stern (2004). Some previous studies seem to implicitly refer to aspects on this existential level. For example, in a study by Hostyn and Maes (2013), the support worker described experiencing a sense of unity during a moment of interaction with a person with profound intellectual disabilities.

During a meaningful moment of interaction, the support staff felt they could be of meaning to the person with profound intellectual

disabilities. In line with a study by Forster and Iacono (2008), success and surprise events in these interactions made support staff feel good and contributed to their job satisfaction. In our study, the support staff reported that these experiences gave them the energy to continue their work, which could be demanding. In addition, they mentioned how such interactions motivated them to explore opportunities for a person with profound intellectual disabilities to develop further.

In our study, meaningful moments of interaction, were all positively valued. Staff spoke of meaningful interactions when describing having a shared positive emotion with a person with profound intellectual disabilities, experiences in which perceived negative emotions of this person were regulated or an unexpected success in the interaction. These moments of successful regulation or unexpected successes in the interaction are in line with what Tronick (2017) described as overcoming mismatches in the process of attunement between parent and infant. Repairing those mismatches is part of attunement and successfully overcoming such a mismatch makes the interaction partners feel good.

We also explored what circumstances are related to meaningful moments to take place. First, staff pointed out they had to be conscious of their own role and take care of their needs, in order to be able to give their full attention to a person with profound intellectual disabilities. Creating the necessary mental space depends on being able to take care of oneself and clearing one's mind, which can also be described as coping with stress. Staff gave examples of coping strategies that van Oorsouw et al. (2014) found to be used by staff working in the care for persons with intellectual disabilities before, such as planning and prioritising and seeking social support. For example, in our study, staff mentioned, to clear their mind, they would make a list of their tasks and prioritise, or talk to a colleague for social support. Second, staff described they had to cope with contextual circumstances that influenced meaningful moments of interaction to take place. They mentioned practical circumstances, such as sufficient time and staff. Having to cope with these practical circumstances was also mentioned by staff members in the study of Nieuwenhuijse et al. (2020) in relation to quality of life of persons with profound intellectual disabilities, as they described that in some cases they knew how to support the person with profound intellectual disabilities best, but could not provide that care because of challenges regarding financial or human resources. Next to having to cope with practical challenges, in our study, staff also reported they sometimes felt they had to cope with differences in the value given to moments of contact. For example, in some situations, they experienced that managers, policy makers and other people involved, seemed to prefer 'quantifiable activities' over 'less-quantifiable activities', such as interpersonal contact.

5 | LIMITATIONS

Although the interviews were partly conducted online, which might have affected the outcome, this study led to rich and in-depth descriptions of the perceptions of support staff. During member

checks, the support staff felt free to add information or explain nuances, giving us confidence that the results reflect the participants' views. However, in accordance with IPA, this study was conducted in a small group of five participants (Smith et al., 2009). They worked in day care centres for children and youngsters with profound intellectual disabilities. Thus, although our findings are in line with previous studies, due to the small group of participants and their heterogeneity, and the heterogeneity of the group of people with profound intellectual disabilities, we should be cautious about generalising the results.

5.1 | Implications and further research

As it comes to practical implications, support staff considered meaningful moments of interaction the core aspect of their job. Meaningful moments of interaction with persons with profound intellectual disabilities enhance work satisfaction and support them in persisting such intense work. However, to facilitate such meaningful moments between support staff and persons with profound intellectual disabilities, organisations and professionals involved in the care for persons with profound intellectual disabilities need to take the challenges staff face seriously. They need to truly acknowledge the value of these moments for support staff and presumably for persons with profound intellectual disabilities themselves, and translate this value in policy and resources. First, organisations and policy makers need to facilitate staff to spend quality time with persons with profound intellectual disabilities and have enough time to clear their minds. For example, in our study, participants mentioned a relation with the care giver—care receiver ratio. It might be relevant to consider the number of persons with profound intellectual disabilities as well in this context (Simons et al., 2021). The group size that optimally facilitates interactions between staff and persons with severe or profound intellectual disabilities, was found to be one to four, with one staff member providing care (Felce et al., 1991). Second, it needs to be self-evident for staff to be conscious of their needs and act upon them. Addressing coping with stress in training might support this consciousness, as Van Oorsouw et al. (2014) found for staff working with persons with intellectual disabilities and challenging behaviour. Third, it would be valuable to reconsider the value given to interpersonal contact in policy and practice. Such reconsideration of interpersonal contact between staff and persons with disabilities in determining quality of care, instead of the current focus on quantifiable criteria, was suggested by Reinders (2010) earlier. Such reconsideration would also be in line with Nieuwenhuijse et al. (2020) who suggested a relation between the quality of life of persons with profound intellectual disabilities and their interpersonal relationship with staff.

In order to support staff to initiate meaningful moments of interaction, it would be valuable to link characterizations based on our in-depth analyses of the perceptions of support staff to observable data. Exploring what observable behaviour is related to meaningful moments of interaction in further research would make these perceptions more concrete and contribute to a better understanding of

meaningful moments of interaction, including information about how people with profound intellectual disabilities experience these moments.

Staff mentioned it is sometimes easier for them to connect to one person with profound intellectual disabilities than to another person with profound intellectual disabilities. This could be due to their own preferences, personality traits or communication skills and/or due to those of the person with profound intellectual disabilities. Regarding the latter, when staff experienced more openness from the person with profound intellectual disabilities, it seemed easier for them to connect. This seems to be in line with the findings of Seys et al. (1998) who found that persons with profound or severe intellectual disabilities who are more attentive, have more communicative abilities and/or less motor disabilities, get more qualitative attention from staff. In order to make sure all persons with profound intellectual disabilities will all get sufficient qualitative attention, in future research, it would be valuable to explore the relation between the characteristics of both persons with profound intellectual disabilities and staff and meaningful moments of interaction taking place.

Next, participating staff assumed that people with profound intellectual disabilities also appreciated the moments they experienced as meaningful. Maybe staff even labels a moment of interaction meaningful because of that. Further exploration is needed, to find out whether this is a condition for staff to experience a moment of interaction as meaningful. However, staff emphasised that they could not know for sure how the person with profound intellectual disabilities valued a moment of interaction. This is a challenge for proxies in general (Maes et al., 2021), as well as for ethnographic and phenomenological researchers (e.g., Bos & Abma, 2021). Although there will always be some uncertainty in how persons with profound intellectual disabilities perceive and experience situations, additional information about how people with profound intellectual disabilities perceive such moments of interaction might be obtained by using physiological parameters in combination with observation (e.g., Vos et al., 2013). This might also contribute to a validation of the perceptions of support staff as found in this study. As these perceptions were mostly based on elements that are defined as tacit knowledge (Reinders, 2010), such a validation might affect the value given to feeling, sensing and following ones intuition in the professional care for persons with profound intellectual disabilities.

ACKNOWLEDGEMENT

We would like to thank support staff who were willing to participate in this study.

FUNDING INFORMATION

This study was funded by Amerpoort.

CONFLICT OF INTEREST

The authors declare not to have any conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ORCID

Wieneke Penninga  <https://orcid.org/0000-0002-9937-0348>
 Sara L. P. Nijs  <https://orcid.org/0000-0002-6672-1009>
 Hedwig J. A. van Bakel  <https://orcid.org/0000-0002-9224-5261>
 Petri J. C. M. Embregts  <https://orcid.org/0000-0003-3567-1528>

REFERENCES

- Bos, G., & Abma, T. (2021). Putting down verbal and cognitive weaponry: The need for 'experimental-relational spaces of encounter' between people with and without severe intellectual disabilities. *Disability & Society*, 1-25, 1–25. <https://doi.org/10.1080/09687599.2021.1899896>
- Bradshaw, J., & Goldbart, J. (2013). Staff views of the importance of relationships for knowledge development: Is training by specialists a waste of money? *Journal of Applied Research in Intellectual Disabilities*, 26(4), 284–298. <https://doi.org/10.1111/jar.12020>
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.
- De Schauwer, E., Daelman, S., Vandebussche, H., Sergeant, S., Van de Putte, I., & Davies, B. (2021). Desiring and critiquing humanity/ability/personhood: Disrupting the ability/disability binary. *Disability & Society*, 36(2), 286–305. <https://doi.org/10.1080/09687599.2020.1735306>
- Dhondt, A., Van keer, I., Van der Putten, A., & Maes, B. (2020). Communicative abilities in young children with a significant cognitive and motor developmental delay. *Journal of Applied Research in Intellectual Disabilities*, 33(3), 529–541. <https://doi.org/10.1111/jar.12695>
- Embregts, P. J. C. M. (2011). *Zien, bewogen worden, in beweging komen [See, be moved, start moving]*. Tilburg University.
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41(2), 126–135. <https://doi.org/10.1111/j.1365-2788.1997.tb00689.x>
- Felce, D., Repp, A. C., Thomas, M., Ager, A., & Blunden, R. (1991). The relationship of staff: Client ratios, interactions, and residential placement. *Research in Developmental Disabilities*, 12(3), 315–331. [https://doi.org/10.1016/0891-4222\(91\)90015-K](https://doi.org/10.1016/0891-4222(91)90015-K)
- Forster, S., & Iacono, T. (2008). Disability support workers' experience of interaction with a person with profound intellectual disability. *Journal of Intellectual and Developmental Disability*, 33(2), 137–147. <https://doi.org/10.1080/13668250802094216>
- Forster, S., & Iacono, T. (2014). The nature of affect attunement used by disability support workers interacting with adults with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 58(12), 1105–1120. <https://doi.org/10.1111/jir.12103>
- 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>
- Griffiths, C. (2010). *Attuning: A theory of interaction of people with severe and profound intellectual and multiple disability and their carers* [doctoral dissertation]. Dublin: Trinity College Dublin.
- Griffiths, C., & Smith, M. (2016). Attuning: A communication process between people with severe and profound intellectual disability and their interaction partners. *Journal of Applied Research in Intellectual Disabilities*, 29(2), 124–138. <https://doi.org/10.1111/jar.12162>
- Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 12(3), 190–203. <https://doi.org/10.1111/j.1468-3148.1999.tb00076.x>
- Healy, D., & Noonan Walsh, P. (2007). Communication among nurses and adults with severe and profound intellectual disabilities: Predicted and observed strategies. *Journal of Intellectual Disabilities*, 11(2), 127–141. <https://doi.org/10.1177/1744629507076927>
- Hostyn, I., & Maes, B. (2009). Interaction between persons with profound intellectual and multiple disabilities and their partners: A literature review. *Journal of Intellectual and Developmental Disability*, 34(4), 296–312. <https://doi.org/10.3109/13668250903285648>
- Hostyn, I., & Maes, B. (2013). Interaction with a person with profound intellectual and multiple disabilities: A case study in dialogue with an experienced staff member. *Journal of Intellectual & Developmental Disability*, 38(3), 189–204. <https://doi.org/10.3109/13668250.2013.798400>
- Hostyn, I., Petry, K., Lambrechts, G., & Maes, B. (2011). Evaluating the quality of the interaction between persons with profound intellectual and multiple disabilities and direct support staff: A preliminary application of three observation scales from parent-infant research. *Journal of Applied Research in Intellectual Disabilities*, 24(5), 407–420. <https://doi.org/10.1111/j.1468-3148.2010.00618.x>
- Kamstra, A., Van der Putten, A. A. J., & Vlaskamp, C. (2015). The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 28(3), 249–256. <https://doi.org/10.1111/jar.12134>
- Maes, B., Nijs, S., Vandesande, S., Van keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J., Petitpierre, G., & Van der Putten, A. (2021). Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 34(1), 250–262. <https://doi.org/10.1111/jar.12803>
- Meys, E., Hermans, K., & Maes, B. (2021). The role of professionals in strengthening social relations of adults with a disability in independent supported living: Practices and influencing factors. *Journal of Intellectual & Developmental Disability*, 46(2), 150–163. <https://doi.org/10.3109/13668250.2020.1786963>
- Nakken, H., & Vlaskamp, C. (2007). A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4(2), 83–87. <https://doi.org/10.1111/j.1741-1130.2007.00104.x>
- Neerinx, H., & Maes, B. (2016). Joint attention behaviours in people with profound intellectual and multiple disabilities: The influence of the context. *Journal of Applied Research in Intellectual Disabilities*, 29(6), 574–584. <https://doi.org/10.1111/jar.12217>
- Neerinx, H., Vos, P., Van den Noortgate, W., & Maes, B. (2014). Temporal analysis of attentional processes in spontaneous interactions between people with profound intellectual and multiple disabilities and their support workers. *Journal of Intellectual Disability Research*, 58(8), 721–733. <https://doi.org/10.1111/jir.12067>
- Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., & Olsman, E. (2020). The perspectives of professional caregivers on quality of life of persons with profound intellectual and multiple disabilities: A qualitative study. *International Journal of Developmental Disabilities*, 68(2), 190–197. <https://doi.org/10.1080/20473869.2020.1737469>
- Ogletree, B. T., Bartholomew, P., Wagaman, J. C., Genz, S., & Reisinger, K. (2012). Emergent potential communicative behaviors in adults with the most severe intellectual disabilities. *Communication Disorders Quarterly*, 34(1), 56–58.
- Olsson, C. (2004). Dyadic interaction with a child with multiple disabilities: A system theory perspective on communication. *Augmentative and Alternative Communication*, 20(4), 228–242. <https://doi.org/10.1080/07434610400005622>
- Olsson, C. (2005). The use of communicative functions among pre-school children with multiple disabilities in two different setting conditions: Group versus individual patterns. *Augmentative and Alternative Communication*, 21(1), 3–18. <https://doi.org/10.1080/07434610412331270516>
- Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual*

- Disabilities*, 18(1), 35–46. <https://doi.org/10.1111/j.1468-3148.2004.00209.x>
- Reinders, H. (2010). The importance of tacit knowledge in practices of care. *Journal of Intellectual Disability Research*, 54, 28–37. <https://doi.org/10.1111/j.1365-2788.2009.01235.x>
- Roeleveld, E., Embregts, P., Hendriks, L., & Van den Bogaard, K. (2011). *Zie mij als mens! Belangrijke competenties voor begeleiders volgens mensen met een verstandelijke beperking [See me as a person! Important qualities of support staff according to people with an intellectual disability]*. HAN University Press.
- Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203–216. <https://doi.org/10.1111/j.1365-2788.2003.00558.x>
- Seys, D., Duker, P., Salemink, W., & Franken-Wijnhoven, J. (1998). Resident behaviors and characteristics as determinants of quality of residential care: An observational study. *Research in Developmental Disabilities*, 19(3), 261–273. [https://doi.org/10.1016/S0891-4222\(98\)00007-9](https://doi.org/10.1016/S0891-4222(98)00007-9)
- Simons, M. A. G., Koordeman, R., Willems, A. P. A. M., Hermsen, M., Rooijackers, L. M., & 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. <https://doi.org/10.1111/jar.12830>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method, and research*. Sage Publications.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Sage Publications.
- Stern, D. N. (2004). *The present moment in psychotherapy and everyday life*. Norton & Company.
- Ten Brug, A., Van der Putten, A. A. J., Penne, A., Maes, B., & Vlaskamp, C. (2015). Making a difference? A comparison between multi-sensory and regular storytelling for persons with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 60(11), 1043–1053. <https://doi.org/10.1111/jir.12260>
- Tronick, E. (2017). The caregiver - infant dyad as a buffer or transducer of resource enhancing or depleting factors that shape psychobiological development. *Australian and New Zealand Journal of Family Therapy*, 38(4), 561–572. <https://doi.org/10.1002/anzf.1274>
- Van Oorsouw, W. M. J., Embregts, P. J. C. M., Bosman, A. M. T., & Jahoda, A. (2014). Writing about stress: The impact of a stress-management Programme on staff accounts of dealing with stress. *Journal of Applied Research in Intellectual Disabilities*, 27(3), 236–246. <https://doi.org/10.1111/jar.12066>
- Voermans, M. A. C., Taminiau, E. F., Giesbers, S. A. H., & Embregts, P. J. C. M. (2021). The value of competitive employment: In-depth accounts of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 34(1), 239–249. <https://doi.org/10.1111/jar.12802>
- Vos, P., De Cock, P., Petry, K., Van den Noortgate, W., & Maes, B. (2013). See me, feel me. Using physiology to validate behavioural observations of emotions of people with severe or profound intellectual disability. *Journal of Intellectual Disability Research*, 57(5), 452–461. <https://doi.org/10.1111/jir.12030>

How to cite this article: Penninga, W., Nijs, S. L. P., van Bakel, H. J. A., & Embregts, P. J. C. M. (2022). Meaningful moments of interaction with people with profound intellectual disabilities: Reflections from direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 1–10. <https://doi.org/10.1111/jar.13019>