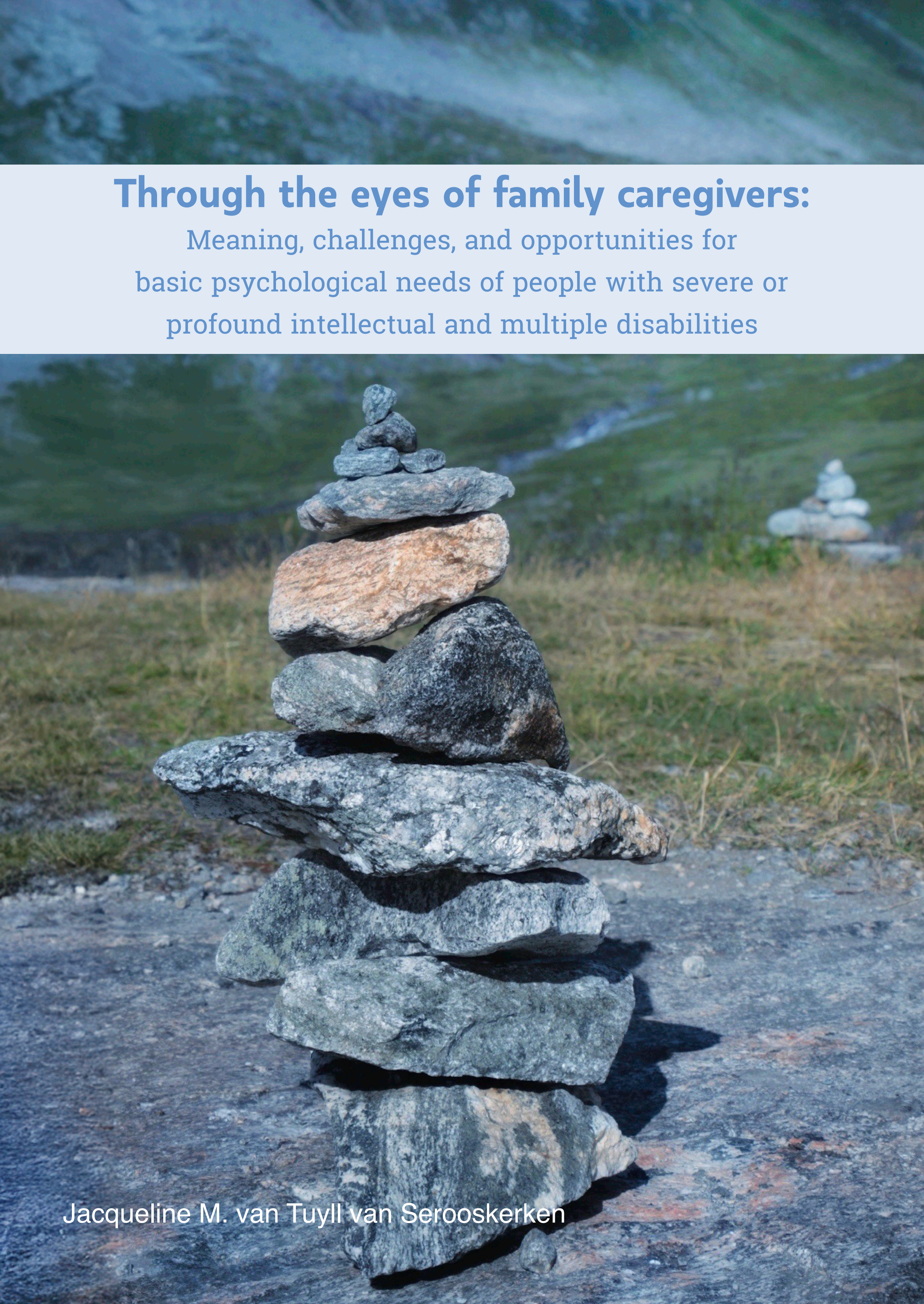

Through the eyes of family caregivers:

Meaning, challenges, and opportunities for basic psychological needs of people with severe or profound intellectual and multiple disabilities

Jacqueline M. van Tuyll van Serooskerken

Through the eyes of family caregivers: Meaning, challenges, and opportunities for basic psychological needs of people with severe or profound intellectual and multiple disabilities

Jacqueline Marije van Tuyll van Serooskerken

Colofon

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ACADEMISCH PROEFSCHRIFT

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I.M. Karstens

This dissertation is dedicated to my father, Edouard Henri van Tuyll van Serooskerken, the wisest, most generous, modest, and kindest man I have ever known. He would have been proud that I pursued a PhD, and I know he would have challenged me, encouraged me, and walked beside me every step of the way. The photo accompanying this dedication shows me holding his hand while he lies in a hospital bed. For me, this image reflects the deep and lasting bond between parent and child, and the universal human need to feel seen, supported, and cared for, especially in moments of vulnerability. This dissertation is a tribute to his enduring influence on my life and to the way he helped me experience the basic psychological needs I explored in this dissertation, simply by being the person he was.

*Societies for all people “respect” a person’s dignity,
autonomy, and freedom to make choices by ensuring that people have
the opportunities and supports to live self-determined lives.*

M. L. Wehmeyer, 2018

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Chapter 1

General introduction

The general principles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) call to promote and protect the dignity, equal rights, inclusivity, and participation of all individuals with disabilities. Furthermore, these principles serve as guidelines to prevent discrimination, ensure equal opportunities and accessibility, and respect the autonomy and choices of people with disabilities. The development of autonomy in people with disabilities can be supported by caregivers in order to lead fulfilling lives. However, some people with disabilities have extensive and sometimes increasing care needs that may challenge caregivers to foster autonomy (Bigby et al., 2021; Whicker et al., 2019). Particularly when communication is difficult and children need lifelong support to meet their needs, guiding them into adulthood with greater self-direction becomes more demanding. In recent decades, the Dutch care system for persons with disabilities has increasingly focused on recognizing and supporting people's autonomy, independence, and the freedom and ability to make own choices. This shift is evident from various Dutch laws, measures, and organizations that support persons with disabilities in leading an autonomous life. Examples include the Social Support Act[1], Long-Term Care Act[2], personal budget[3], daytime service facilities[4], and housing adjustments. Supporting these initiatives is based on the assumption that acting volitionally according to intrinsic motives (i.e., self-determination) contributes to subjective well-being and quality of life (Deci & Ryan, 2008).

Also in scientific research, increasing attention is focused on self-determination by persons with intellectual disabilities (Wehmeyer, 2020a). The role of perceived autonomy support provided by people in the close environment has been studied extensively in relation to self-determination (e.g., Cudré-Maurous et al., 2020; Estreder et al., 2024; Frielink et al., 2018; Frielink et al., 2024; Vaucher et al., 2020; Vicente et al, 2023). A care environment that matches one's own preferences and is full of relevant and motivating choices would be conducive to feeling autonomous and self-determined (Kuld et al., 2023; Kuld et al., 2024). However, levels of

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[1] A translation of the Dutch "wet maatschappelijke ondersteuning" (WMO).

[2] A translation of the Dutch "wet langdurige zorg" (WLZ).

[3] A translation of the Dutch "persoonsgebonden budget" (PGB).

[4] A translation of the Dutch "dagbesteding" which are special day service centres that resemble school or work tasks to accommodate and stimulate the possibilities of persons with disabilities.

and opportunities for self-determination were negatively related to the severity of the intellectual disability (Stancliffe, 2001; Stancliffe et al., 2000a; Stancliffe et al., 2000b; Stancliffe & Wehmeyer, 1995; Vicente et al., 2023; Wehmeyer, 2020a; Wehmeyer & Abery, 2013). Additionally, people with severe or profound intellectual and multiple disabilities often face unique situations compared to those with less severe or no intellectual disabilities. This highlights the importance of gaining a deeper understanding of self-determination and its related constructs within this specific population, to identify their needs, expectations, and desires regarding support, and to have effective tools available for assessment.

This chapter first introduces persons with severe or profound intellectual and multiple disabilities. It addresses how individuals within this population are characterized in the literature, their similarities and differences, and what we know about their modes of communication. Following this, the chapter discusses the role and impact of their social and physical environments and delineates the promotion of quality of life and the role of self-determination for people with and without intellectual disabilities, employing the theoretical framework of Self-Determination Theory (SDT; Deci & Ryan, 2000; Ryan & Deci, 2000b). The next section introduces the premise of this thesis: a mini-theory within SDT known as the Basic Psychological Needs Theory (BPNT; Deci & Ryan, 2012). This part explains the three fundamental innate psychological needs: autonomy, competence, and relatedness, and the concept of environmental autonomy support. Additionally, it describes their potential relevance to the target populations. Next, transitions are explored as potential opportunities for supporting and fulfilling the basic psychological needs (BPNs) of people in the target population. This introductory chapter concludes by outlining the research objectives and presenting an overview of the various studies included in the following chapters.

Persons with severe or profound intellectual and multiple disabilities

Persons with severe or profound intellectual and multiple disabilities are unique and distinctive, both in their personality and behavior. Despite their individuality, they share a presence of lifelong, complex, and extensive support needs in areas such as development, medical care, education, and general upbringing (Nakken & Vlaskamp, 2007; Petry et al., 2007). These support needs arise from challenges in cognitive, communication, motor skills, sensory, and physical health domains (Van der Putten et al., 2017). Combined with low cognitive abilities (IQ; between 20–34 for severe and below 20 for profound), reliable assessment with current tools is challenging (Thurm et al., 2020; Vlaskamp, 2005). As a result, a developmental age is often estimated and based on variables such as adaptive functioning and level of dependence (Tyrer et al., 2008). Additionally, health conditions can fluctuate within persons, which may cause temporary or permanent regression in functioning across various developmental areas (Mol-Bakker et al., 2024).

Due to the wide variation in the type, number, and severity of problems across individuals, the target population is inherently diverse and heterogeneous (Maes et al., 2021). For example, some individuals can move themselves using a walker, while others require full physical support their whole lives due to deformities or spasticity. Some individuals can use alternative augmentative methods to aid their communication such as speech devices (e.g., eye-controlled), sign language, or pictograms. Others lack the cognitive or motor abilities necessary for such methods and may only be able to communicate through specific sounds, movements, or other unconventional ways. Sensory and health problems such as visual and auditory issues, epilepsy, chronic pain, challenging behavior (e.g., self-harm), and sleep problems vary greatly (Van der Putten et al., 2017). Also, required medical care and the effects of frequent or long-term medication use can significantly impact a person's alertness and behavior, further contributing to the complexity and heterogeneity of this population (Matson et al., 2005; Matson & Mahan, 2010; Valdovinos et al., 2005; Zijlstra & Vlaskamp, 2005).

Communication by people with severe or profound intellectual and multiple disabilities is severely impaired and often occurs non-verbally, idiosyncratically, and at a pre-symbolic level (Forster & Iacono, 2008; Grove et al., 1999; Healy & Walsh, 2007; Iacono et al., 2009). This can involve vocalizations, typical body or facial movements, gestures, facial expressions, focus, or orientation. Communicative signals may often be difficult to notice, fluctuate over time, and vary according to communication partner and context (Grove et al., 1999; Hostyn et al., 2010; Porter et al., 2001). Consequently, caregivers face a daunting task in identifying wants and needs. Those less familiar with the person may resort to inferring or guessing the meaning of signals, while caregivers with experience often rely on *tacit knowledge* an intuitive understanding that is difficult to articulate or formalize (Hoogsteyns et al., 2023; Kruithof et al., 2020; Kruithof et al., 2024). Taken together, communication between persons with severe or profound intellectual and multiple disabilities and their communication partners is a dynamic and reciprocal process which requires a high level of sensitive responsiveness and adaptability in communication skills (Doodeman et al., 2023; Griffiths & Smith, 2016; Hostyn & Maes, 2009; Martin et al., 2022).

The importance of the social environment; who are involved in the lives of persons with severe or profound intellectual and multiple disabilities?

Individuals with severe or profound intellectual and multiple disabilities are entirely dependent on others for all daily tasks, 24 hours a day, 7 days a week (Nakken & Vlaskamp, 2007). Their caregivers often include parents, other family members, relatives, and healthcare professionals (Hostyn & Maes, 2009; Petry et al., 2005). The early years of any child's life can be challenging for parents (Schuengel & Oosterman, 2019). However, parents of individuals with severe or profound intellectual and multiple disabilities face unique care demands and complex situations and emotions. Due to the significant impairments, intensive daily attention is required (Geuze et al., 2023; Lahaije et al., 2023b; Luijkx et al., 2019; Luitwieler et al., 2021; Tadema & Vlaskamp, 2009). Parents report spending significantly more time on tasks like medical care, nutrition, mobility, and personal care compared to parents of children without disabilities (Doyle, 2022a; Luijkx et al., 2017). As a result, the physical and psychological challenges these parents face take a great toll (Luitwieler et al., 2021; Patty et al., 2024; Rousseau et al., 2019). For example, parents may experience their emotional state as one of chronic sorrow or living loss as they adjust to the reality that their child's development and future will differ significantly from their initial expectations (Buthelezi & Mawila, 2024; Coughlin & Sethares, 2017; Gordon, 2009; Keirse, 2017). Parents may also face increased levels of uncertainty, anxiety, and stress, stemming from concerns about their child's health, future care needs, and the stability of support systems (Coiffait, 2012; Kruithof et al., 2021; Lloyd & Hastings, 2009; White & Hastings, 2004).

The need for parents to continuously adapt daily routines, work schedules, and social activities, places an additional strain on the family dynamics and relationships (Dos Santos & Pereira-Martins, 2016; Jenaro et al., 2020; Luijkx et al., 2017; Patty et al., 2024). Frequent limitations in social interactions and participation in community activities can lead to feelings of isolation (Geuze & Goossensen, 2021; Geuze et al., 2022). Additionally, parents often have to adjust plans for their own future, including career goals and personal aspirations, to accommodate the extensive needs of their child (Geuze & Goossensen, 2019; Luijkx et al., 2017; Sato & Araki, 2022). Nevertheless, parents also may experience positive aspects of having a child with severe to profound intellectual and multiple disabilities (Arai et al., 2024; Beighton & Wills, 2018). Such positive experiences may include a deeper appreciation for what is truly valuable in life, greater tolerance and awareness of the needs and struggles of others with disabilities, and an appreciation for the distinct qualities and personalities of children as individuals (Luijkx et al., 2019).

Due to the comprehensive role and lifelong and intensive connection, parents of individuals with severe or profound intellectual and multiple disabilities are the crucial experts regarding their child's care and support, and often serve as advocates in communicating their child's wants and needs to third parties (De Geeter et al., 2002; Kruithof et al., 2020; Vandesande et al., 2019). The vital role of parents in this population as supporters and facilitators extends beyond early childhood and continues throughout all stages of life. Siblings also often take on significant and supportive roles, such as providing emotional and practical assistance and coordinating or supervising care (Lee & Burke, 2018; Nguyen et al., 2024). Both parents and siblings, however, need informational, practical, and emotional support throughout the person's lifespan, encompassing medical and assistive care, family and social resources, and system-wide support (Jansen et al., 2013; Lahaije et al., 2023a; Nguyen et al., 2024). Healthcare professionals are therefore an important piece of the puzzle in the support network for families of individuals with severe or profound intellectual and multiple disabilities as well, collectively sharing the responsibility of care.

Professional caregivers can include a diverse range of specialists, such as doctors, nurses, physiotherapists, occupational therapists, dieticians, psychologists, remedial educators, and educational or direct support staff from daytime service facilities or residential institutions. Meaningful interactions and relationships between professional caregivers and individuals with severe or profound intellectual and multiple disabilities are essential for effective care and support (Beadle-Brown et al., 2016; Hostyn & Maes, 2009; Nind & Grace, 2024; Penninga et al., 2024a). Personalized care may be established when caregivers are attuned to the subtle cues and non-verbal communication methods of individuals, allowing them to interpret needs and preferences more accurately (Griffith & Smith, 2016; Griffith & Smith, 2017; Penninga et al., 2024b). Comprehensive training is essential to equip professionals with the skills and up-to-date knowledge needed to understand and respond effectively to these unique needs while also safeguarding their own well-being (Droogmans et al., 2024; Hostyn & Maes, 2009; Overwijk et al., 2021; Rousseau et al., 2017). Furthermore, fostering a strong, collaborative partnership between individuals with severe or profound intellectual and multiple disabilities, their parents and other family caregivers, and professionals is essential to ensure responsive, person-centered care (Doyle, 2022b; Jansen et al., 2013; Jansen et al., 2017; Kruithof et al., 2022; Overwijk et al., 2021). This involves valuing each other's expertise, integrating insights from all perspectives, and working collaboratively towards shared goals.

Evolving perspectives on self-determination and its role in quality of life for individuals with intellectual disabilities

Quality of life (QoL) is a multidimensional concept that includes both objective (e.g., physical health and economic status) and subjective factors (e.g., emotional well-being, personal relationships, and social engagement) and encompasses an individual's overall well-being and life satisfaction (Felce & Perry, 1995; Schalock & Felce, 2004). Promoting QoL means that individuals can live their lives as fully, satisfying, and meaningfully as possible. Individuals with severe or profound intellectual and multiple disabilities are at risk for experiencing low levels of QoL (Beadle-Brown et al., 2016; Maes et al., 2007). Additionally, assessing and promoting the QoL of individuals within this population presents several challenges for their environment (Nieuwenhuijse et al., 2022; Nieuwenhuijse et al., 2023). According to parents and support workers, universal sub-domains of QoL such as physical, social, emotional, and material well-being, remain relevant, yet their specific content and importance may differ from those for people without or with less severe disabilities (Petry et al., 2005). For instance, the complex medical and therapeutic care needs require an integrated and continuous approach by specialized caregivers. Communicative impairments make it difficult for individuals with severe or profound intellectual and multiple disabilities to express their needs and wishes in a way that is understandable to others, complicating the provision of adequate care. QoL is further restricted by factors such as limited financial resources or support aids and environments that lack opportunities and accommodations tailored to the person's abilities and preferences. Additionally, lack of access to effective and evidence-based support programs (Goldbart & Caton, 2010; Maes et al., 2007; Vlaskamp & Nakken, 2008; Windsor et al., 2023), negative and stigmatizing perceptions about the target population (Adams & Jahoda, 2019; Pelleboer-Gunnink et al., 2021b; Werner, 2015), and complexity of collaboration among stakeholders and shortcomings in policies and legislation, all contribute to the challenges in improving the QoL of individuals within this population (Hogg & Lambe, 2007; Jacobs et al., 2018; Kuijken et al., 2019; Matérne & Holmefur, 2022).

Enhancing self-determination in people with severe or profound intellectual and multiple disabilities may offer opportunities for improving their QoL and well-being (Nieuwenhuijse et al., 2024; Schalock & Verdugo, 2002; Wehmeyer, 2020b). According to the Self-Determination Theory (SDT; Deci & Ryan, 2000; Ryan & Deci, 2000b), self-determination refers to the ability of individuals to have influence and freedom of choice over their own lives and decisions. Self-determination is considered essential for intrinsic motivation and psychological well-being (Lachapelle et al., 2005; Deci, 2004; Ryan & Deci, 2000b). Intrinsic motivation drives individuals to engage in inherently satisfying activities and is seen as the most conducive form of motivation (Ryan & Deci, 2000b). An environment that encourages autonomy helps people to become self-determined (Ryan & Deci, 2000b). Such an environment may provide appropriate choice options and support decisions once these are taken, offer empathy and flexibility, and support the pursuit of a person's own goals and preferences (Reeve, 2002; Ryan et al., 2015). The Causal Agency Theory (CAT; Shogren et al., 2017c) complements SDT by offering a deeper understanding of self-determination. This model emphasizes the individual's causal role in shaping their own life. Within CAT, self-determination is defined as an inherent characteristic that enables individuals to make autonomous decisions, act purposefully, and make choices that affect the direction of their lives (Shogren et al., 2017c). While the specific implications of SDT and CAT for individuals with severe or profound intellectual and multiple disabilities remain unclear, studying these concepts might provide valuable insights to support self-determination and, consequently, improve QoL.

The concept of self-determination as an indicator of QoL gained significant attention in the disability field during the late twentieth century and has experienced remarkable growth in recent decades (Mumbardó-Adam et al., 2023; Wehmeyer et al., 2017; Wehmeyer, 2020a; Wehmeyer, 2020b). Consequently, a substantial body of knowledge has emerged regarding self-determination among individuals with mild intellectual disabilities. For instance, experiencing higher levels of self-determination is shown to be related to achieving personal goals, better academic and employment outcomes, and enjoying a greater sense of autonomy and life satisfaction (e.g., Gaumer Erickson et al., 2015; McConnell et al., 2021; Shogren et al., 2015; Wehmeyer, 2020a; Zheng et al., 2014). In this target population, self-determination is further associated with psychological well-being, social relationships, community participation, and overall quality of life (e.g., Frielink et al., 2021; Mumbardó-Adam et al., 2023; Shogren et al., 2017a; Wehmeyer & Bolding, 2001). Moreover, interventions designed to promote self-determination, such as goal-setting programs and decision-making skills training, have been found effective in empowering people in this group (Wehmeyer, 2020a; Willow et al., 2023). This growing body of research on self-determination by individuals with mild intellectual disabilities offers stepping stones for studying this topic in people with more severe intellectual disabilities, even though unique challenges remain.

Research conducted in the past decades concerning self-determination and its support for persons with severe or profound intellectual and multiple disabilities primarily focused on specific components that fall under this umbrella concept, such as choice-making, independence, problem-solving (e.g., in leisure and household activities), and assistance from professionals (Kúld et al., 2023). There are several possible explanations for this focus. Firstly, research within this target group faces various methodological problems. For example, there are issues related to recruitment (e.g., small populations make it hard to achieve sample sizes that are sufficient for statistical testing), data analysis (e.g., difficulties taking heterogeneity into account), and the appropriateness of general theoretical models (Maes et al., 2021). Furthermore, standard tests and questionnaires are rarely validated for this target population. Many questions or items about new constructs of interest are inapplicable, as they are typically designed for children or adults without disabilities and usually do not align with the lived experiences of individuals with severe or profound intellectual and multiple disabilities. Verbal interviews with individuals in this population are also not feasible, necessitating reliance on the experiential knowledge of those closest to them, such as parents and professionals (Kruithof et al., 2020). However, the viewpoints of parents and professionals do not always align (e.g., De Geus-Neelen et al., 2019; Jansen et al., 2017). Parents, thanks to their lifelong and intimate connection, are a primary source of information about the needs and experiences of their child. This highlights the value of involving their perspectives when exploring concepts like self-determination for persons with severe or profound intellectual and multiple disabilities. Moreover, parents in this population not only carry primary responsibility for their child's care and support but also navigate complex systems and act as representatives and advocates for the rights and QoL of their child with disabilities (Alsem et al., 2025). Consequently, understanding how parents perceive and assign meaning to self-determination is an important topic in its own right, not only for advancing research but also for developing better support systems for families.

Basic psychological needs and autonomy support

In her review, Skarsaune (2023) argued that "all people have the potential for self-determination, by being understood through embodied communication in caring relationships” (p. 16), including individuals with severe or profound intellectual and multiple disabilities. Existing theories of self-determination, such as the Basic Psychological Needs Theory (BPNT; Ryan & Deci, 2012; Vansteenkiste et al., 2010; Vansteenkiste et al., 2020) may be critically investigated as a potential tool to study and understand self-determination in persons of this target population. Central to this theory are three fundamental BPNs: autonomy, competence, and relatedness (Deci & Ryan, 2000). BPNs are thought to be universal, indicating they apply to every person, regardless of culture, age, gender, background, or intellectual disability (Deci & Ryan, 2000; Ryan & Deci, 2000b). Furthermore, these needs form the core of what people require to feel mentally and emotionally well and to function optimally in their daily lives.

Vansteenkiste et al. (2020) gave a comprehensive overview of descriptions of the three BPNs. They defined the need for autonomy as the desire to exercise one’s own will. This need encompasses not only the freedom to make decisions that align with personal values, interests, and goals but also the absence of constraining external factors, such as coercion or punishment. The authors further stressed that autonomy is not a synonym for independence, but rather refers to the experience of self-direction even when receiving help from others. The need for competence refers to the desire to influence one’s environment effectively in daily life. This includes the ability to solve problems, learn new skills, and adapt to changing circumstances. It is about facing challenges and utilizing skills, with the experience of growth being just as valuable as the outcome of success. The need for relatedness is defined by the human desire to feel loved, cared for, valued, and accepted by others, while also experiencing opportunities to offer the same in return.

When BPNs are satisfied, people experience intrinsic motivation, personal growth, and greater well-being, while unmet or frustrated BPNs are associated with adverse outcomes (Milyavskaya & Koestner, 2011; Tang et al., 2020; Vansteenkiste & Ryan, 2013). This has appeared for persons with mild intellectual disabilities as well (e.g., Akkerman et al., 2018; Frielink et al., 2018; Westera et al., 2023). When persons have opportunities to engage in activities that align with personal values and interests (i.e., autonomy), their inner drive to participate increases. Similarly, successfully undertaking challenges (i.e., competence) makes activities more satisfying, which increases the likelihood of taking on new challenges. Establishing and maintaining meaningful relationships with others (i.e., relatedness) enhances a sense of social safety, allowing individuals to be themselves and explore their environment. In contrast, a lack of fulfillment (i.e., dissatisfaction) or being thwarted (i.e., frustration) in BPNs can lead to various negative outcomes. These include physical and mental health issues, behavioral problems, and social issues such as isolation (Vansteenkiste & Ryan, 2013).

An autonomy-supportive environment is crucial for experiencing BPN fulfillment and the development of self-determination, as it provides room for self-reflection, encouragement, and assistance in setting and achieving one's goals (Ryan et al., 2015; Vansteenkiste et al., 2020; Vansteenkiste & Ryan, 2013). In addition, such an environment respects personal preferences, offers diverse choices, and avoids controlling or directive behaviors. The importance of perceived autonomy support is highlighted by its frequent associations with positive outcomes across various contexts. These contexts include education (e.g., learning performances and engagement), work (e.g., job satisfaction), healthcare (e.g., health or therapeutic outcomes), and family and parenting situations (e.g., self-confidence and quality of life in children) (e.g., Bradshaw, 2024; Grolnick et al., 2002; Guay et al., 2008; Hardré & Reeve, 2009; Mammadov & Schroeder, 2023; Núñez & León, 2015; Reeve et al., 2004; Slemp et al., 2018; Vansteenkiste, 2004; Vasquez, 2016; Williams et al., 2006). Studies by Alonso-Sardón et al. (2019), Carey et al., (2024), Estreder et al. (2024), and Emond Pelletier and Joussemet (2017) showed similar positive effects of autonomy support in persons with mild to borderline intellectual disabilities.

Uncovering the nuances of BPNs and perceived autonomy support and gaining a more comprehensive understanding of these concepts through insights from those in daily intimate contact (e.g., parents), can aid in developing suitable instruments (e.g., ones that match the unique experiences of people within this population) with promising psychometric properties. This, in turn, could enable testing whether these concepts are universally related to QoL-related outcomes such as well-being.

Transitions

Possible contexts for gaining a deeper understanding of how BPNs and environmental autonomy support are experienced by persons with severe or profound intellectual and multiple disabilities include transitions. Transitions refer to a psychological process of adapting to changes in key life stages or circumstances, such as developmental stages, housing, care and support resources, education, leisure, daytime service facilities, finances, and reaching adulthood (Bridges, 2004; Kralik et al., 2006). Transitions may offer opportunities for self-determination, as they involve new choices that can, to a greater or lesser extent, influence the direction of one's life course (Mill et al., 2010; Schalock et al., 2020). For parents and caregivers of typically developing children, ample general knowledge is often available for so-called "normative transitions" (e.g., Cowan & Cowan, 2003). However, individuals with more severe intellectual disabilities face unique transitions or experience normative transitions in other ways. Reaching puberty or adulthood, for example, may look different and have different consequences for this target group than for children with less severe or without disabilities (Gauthier-Boudreault et al., 2017; Schoenmakers & De Vos-Dijkslag, 2016). Consequently, less comparative knowledge about these transitions is available for individuals and their families (Foley et al., 2012). This difference complicates the process of transitioning, making it difficult for parents and caregivers of individuals with severe or profound intellectual and multiple disabilities to prepare for them gradually (Gauthier-Boudreault et al., 2017; Neece et al., 2009; Raghavan et al., 2013). As a result, transitions may appear unexpectedly and opportunities to promote volitional choices and increase self-determination may be missed (Kúld et al., 2024).

Transitions can have a significant impact on individuals with severe or profound intellectual and multiple disabilities, as well as on their social environment (Gauthier-Boudreault et al., 2021; Jacobs et al., 2018; Roos & Søndenaa, 2020). On the one hand, transitions can bring feelings of stress, tension, and anxiety. For instance, moving to a new, unfamiliar residential location can be daunting. Additionally, transitions can trigger other changes, such as switching educational institutions, transportation services, and caregivers, which can all bring new challenges on their own. On the other hand, transitions can be experienced positively, especially when they promote physical and emotional health or facilitate more social interactions. The likelihood of positive experiences during transitions increases when the process, such as changing from special education to adult day care, is organized gradually, supervisors are knowledgeable and flexible, effective methods and technologies are used, and programs are customized to individual needs (Gauthier-Boudreault et al., 2018). In addition, effective long-term care in working towards transitions ideally involves operating methodically, promptly, and together with individuals with severe or profound intellectual and multiple disabilities and their parents. This collaborative approach ensures that everyone is ready for upcoming changes, can make informed decisions, and is autonomously motivated to realize the choices made. Expanding our understanding of theoretical principles and practical applications related to BPNs, perceived environmental autonomy support, and QoL during transitions may positively influence transition experiences and outcomes. Moreover, this knowledge enables the development of tools and interventions to foster environments that can create opportunities for self-determination and guide individuals with severe or profound intellectual and multiple disabilities through significant transitions (Schalock et al., 2020; Vicente et al., 2020).

Dissertation outline

The aims of this thesis were developed in cooperation with parents and other stakeholders. This included a close interaction before and during the project with a think-tank of parents, professionals, and client organizations, ensuring their active role in shaping the agenda. The continuous cooperation and input from various stakeholders, including care organizations and academic institutions, was instrumental in bringing the research project about and doing so while taking their perspectives and needs into account. The overall goal of this dissertation was to better understand and measure self-determination, viewed in terms of BPNs, and its support for people with severe or profound intellectual and multiple disabilities. This resulted in four main research aims. The first aim was to explore the meaning and expressions of satisfaction and motivation for autonomy, competence, and relatedness in people with severe or profound intellectual and multiple disabilities as perceived by parents. The second aim was to understand the needs, challenges, and expectations of parents regarding the support of BPNs and to identify which events and opportunities are important for experiencing BPN satisfaction (i.e., self-determination). The third aim was to develop and adapt psychometrically sound questionnaires to measure perceptions of parents on BPNs and perceived environmental autonomy support for people with severe or profound intellectual and multiple disabilities. The fourth aim was to explore how important transitions may go along with changes in self-determination-related constructs and what role caregivers' expectations and engagement during such transitions play. The research findings answering these four aims are found in the following chapters. Chapter 2 describes a qualitative study in which family caregivers were interviewed about their perceptions of autonomy, competence, and relatedness regarding their family member with severe or profound intellectual and multiple disabilities. They also discussed how they supported their family member in meeting specific BPNs and the challenges they encountered in doing so. Chapter 3 reports on the development and preliminary psychometric evaluation of two instruments into parent-perceived autonomy-supportive experiences and BPNs of people with severe or profound intellectual and multiple disabilities (N = 63). Chapter 4 uses a longitudinal study design to explore the associations between parents' perceptions on environmental autonomy support, BPN expressions, and subjective well-being (i.e., core concepts within SDT) in their child with severe or profound intellectual and multiple disabilities in the context of transitions (N = 40). Finally, Chapter 5 summarizes, integrates, and discusses the findings of the studies. The overall strengths and limitations are considered followed by suggestions for future research and exploration of the practical implications.

Chapter 2

Satisfying basic psychological needs among people with complex support needs: A self-determination theory-guided analysis of primary relatives' perspectives

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Abstract

Background. The fulfilment of basic psychological needs (BPNs) is seen as an integral part of human self-determination, subjective well-being, and overall quality of life. However, the meaning of these psychological constructs for individuals with the most extensive support needs remains elusive.

Method. Primary relatives of nine people diagnosed with severe or profound intellectual and multiple disabilities were interviewed about their perceptions of autonomy, competence, and relatedness regarding their family member with complex care needs, and about the ways in which they tried to support their family member in fulfilling specific BPNs. The interview analysis followed a grounded theory with the sensitizing concepts approach.

Results. The relatives assigned important meaning to the BPNs, providing insights into their subtle nature, their implicit drivers, and how they were experienced. The relatives also identified serious challenges in detecting, clarifying, and creating opportunities for BPNs.

Conclusion. The themes in the relatives' perspectives can be summarized into a conceptual framework that may contribute to better mutual understanding between people with complex care needs, their relatives, and healthcare providers.

Introduction

Supporting children in becoming individuals with a strong sense of direction who strive after desires relating to what they want in life can be challenging for caregivers, especially when communication is difficult and children require long-term support to meet their needs (Chu, 2018). In particular, caregivers of children with extensive and complex support needs repeatedly struggle with questions like "what is it that my child wants?" and "how do I get my child to achieve this?", which is reflected in their desire for greater knowledge about how to support their child's needs, development, and wellbeing (EMB TOP 10 Onderzoeksagenda, 2019). In the current paper, "complex support needs" refer to persons who have been described in the literature as having severe or profound intellectual and multiple disabilities (SPIMD) (Maes et al., 2021). This combination of severe or profound cognitive and additional impairments, such as motor, sensory, communication, and physical health problems, causes a permanent dependency on others in all aspects of daily life (Nakken & Vlaskamp, 2007). Taking care of and raising children with complex support needs thus has a huge impact on the lives of relatives, and as such potentially changes families' future prospects (Luijkx et al., 2017; Tadema & Vlaskamp, 2010; Vandesande et al., 2019). Understanding the perspectives of relatives regarding the psychological need satisfaction and motivation (i.e., self-determination) of their family member with complex support needs may therefore not only reveal unique insights but may also increase the relevance of theories on self-determination.

The use of the self-determination construct in the disability field started in the late twentieth century and expanded exponentially in the past few decades (Wehmeyer et al., 2017; Wehmeyer, 2020a). This increase in attention for self-determination in the care and education of children and adults with disabilities corresponds to the first principle of the Convention on the Rights of Persons with Disabilities, which defines universal respect for one's own autonomy (United Nations, 2006). Wehmeyer et al. (2017) argued that an action can be seen as self-determining when it is taken by a person who acts volitionally on the basis of his or her own desires. In addition, self-determination is not an inborn skill but rather develops and is maintained in interaction between the person and the environment (Ryan

& Deci, 2000b). Two major explanatory frameworks for the emergence of self-determination are Self-Determination Theory (SDT) and Causal Agency Theory (CAT). SDT is a widely known meta-theory on the interaction between social and environmental contexts, human action motivation, and psychological needs satisfaction (Adams et al., 2017). CAT focuses on the causal action sequence of how people eventually become self-determined (Shogren et al., 2017c). According to SDT, self-regulation and intrinsic motivation follow from opportunities to fulfill three innate basic psychological needs (BPNs): autonomy, competence, and relatedness (Deci & Ryan, 2000; Ryan & Deci, 2000a). In brief, the need for autonomy refers to people's desire to experience self-endorsed regulation (Ryan & Deci, 2006), the need for competence refers to people's desire to feel effective in what they do (White, 1959), and the need for relatedness refers to people's desire to seek connection with significant others (Baumeister, 1995).

The satisfaction of the three BPNs in combination with a supportive environment enhances subjective well-being and overall quality of life, while the thwarting of those needs accomplishes the opposite (Deci & Ryan, 2000; Ryan & Deci, 2000b; Vansteenkiste et al., 2020). Research with people with intellectual disabilities indicates similar links between self-determination and health-related outcomes to the general population. A study by Frielink et al. (2018) with adults with mild to borderline intellectual disabilities, for example, showed positive associations between perceived autonomy support, autonomous motivation, the satisfaction of the three BPNs, and psychological well-being. The Quality of Life model for people with intellectual disabilities by Schalock and Verdugo (2002) emphasizes the importance of "self-determination" or "self-determined behavior" as one of eight indicators of health-related quality of life. However, despite its importance, Wehmeyer (2020a) concluded from the available empirical evidence that persons with intellectual and developmental disabilities show less self-regulatory behavior compared to their peers. Vicente et al. (2019), for example, found that the level of support needs was negatively associated with self-determination, and Carter et al. (2009) concluded that people with severe intellectual disabilities had minimal self-determination capacity levels.

A lower level of self-determination in people with support needs is often attributed to limitations in their cognitive abilities. However, contextual factors may be important as well, such as living in a controlling environment, being dependent on others to create opportunities for self-regulated behavior, and a lack of adequate support (Wehmeyer et al., 2011a; Wehmeyer & Shogren, 2017). It is possible, for example, that the quality of care is negatively influenced by the presence of stigmatizing perceptions of support staff about people with high support needs (Pelleboer-Gunnink, 2021a). Martínez-Tur et al. (2015) found that the positive attitudes of relatives towards self-determination were associated with higher frequencies of self-determined behaviors of family members with intellectual disabilities. Thus, in order to understand how the social environment facilitates or hampers the self-determination of people with complex support needs, it may be helpful to clarify and describe the perspectives of those most involved regarding this elusive concept.

There are currently few studies on self-determination specifically in people with the most extensive support needs. One explanation could be that self-determination is often misinterpreted as "having independent control" over one's own life or being capable of making considered and informed decisions, when in fact it refers to "acting volitionally" (Wehmeyer, 2005). Another explanation may be the lack of suitable and reliable measures of self-determination for people with low-level cognitive functioning (Maes et al., 2021). Furthermore, most of the studies in this population that do focus on self-determination are mainly intervention-oriented and aimed at improving specific aspects. Examples are studies on decision-making regarding everyday issues (Lifshitz, 2010), independent living and leisure skills (Dollar et al., 2012), metacognition and self-regulation (Moreno & Saldaña, 2005), and assisted acts of self-determination using microswitch technology (Roche et al., 2015). There is little literature on person-specific interpretations of BPN satisfaction and motivation that go along with self-determination.

The limited scientific understanding of the perceived meaning of constructs within SDT for people with the most extensive support needs may directly hamper effective professional support. It may also hamper support indirectly, as it complicates working with others (e.g., parents) who advocate on behalf of the person with the complex care needs (Kruithof et al., 2020). Studying the perspectives of relatives who act as a sounding board for those with the most extensive support needs may therefore serve the dual purpose of providing an important indication as to what self-determination might mean while also pointing towards opportunities for support. Therefore, one study aim was to explore the meaning that primary relatives ascribe to satisfaction and motivation for the three BPNs (i.e., autonomy, competence, and relatedness) for their family member with complex support needs. The other aim was to identify what relatives see as necessary for supporting self-determination.

Method

Design

The SDT claims that need fulfilment leads to autonomous motivation, laying the foundation for self-determination (Deci & Ryan, 2000; Deci & Ryan, 2002). Consistent with this theory, the current qualitative study explored primary relatives' perceptions regarding the BPN satisfaction and motivation of their family member with complex support needs using semi-structured interviews. The study was designed according to a grounded theory and sensitizing concepts approach in which specific constructs or interests guide qualitative data collection and analysis (Bowen, 2006; Charmaz, 2006). The sensitizing concepts were the basic psychological needs of "autonomy," "competence," and "relatedness" (Deci & Ryan, 2000).

Data sources and participants

The participants were primary relatives of people diagnosed with severe or profound intellectual and multiple disabilities. Parents were recruited because of their unique, experiential, and crucial knowledge about the care and support of their child with special needs (Kruithof et al., 2020). Siblings were recruited because they also play a significant role in the life of their family member with extensive support needs, especially when parents become older, have disabilities themselves, or pass away (Hall & Rossetti, 2018). In order to be included, the participants had to have a family member at least 3 years old, diagnosed with severe or profound intellectual disability (i.e., IQ score < 35–40 points or a developmental age < 5 years) in combination with additional disabilities such as motor, sensory, communication, physical health problems. They themselves had to fulfil an active role in the life of this family member (e.g., as their parent or legal representative), speak Dutch, and be at least 18 years old. Family members with complex support needs were included whether they lived with participants or in a care facility.

The participants were recruited through several Dutch care and client advocacy organizations that support people with disabilities and their caregivers. These organizations shared information about the study in their newsletter, on their website, and through their support staff. In addition, conventional and social media were used. When interested, the relatives left their contact information on the study website, after which the researchers contacted them and fully explained the study, consent form, and measures taken to ensure confidentiality. In order to check if the participants met the inclusion criteria, the participants were asked about complex support needs in divergent domains, indicating dependency on others for all aspects of physical care, health, and safety (Maes et al., 2021). The participants also completed a paper-and-pencil survey prior to the interview on the demographic and additional characteristics of themselves and their family member with extensive support needs (e.g., aetiology, adaptive, communication, socialization, daily living, and motor behaviors). In case of doubt, the participants were contacted for more information. Primary relatives of nine people with extensive support needs were willing to participate, available, and met all of the inclusion criteria. After written consent was collected, practical considerations and participant availability determined the order of interviews, and the interview appointments were made. Finally, the researchers offered the participants the opportunity to have their family member present during the interview. Interviews were held with the mother only (n = 5), both parents (i.e., mother and father) simultaneously (n = 2), and a sister (n = 2). All of the participants knew their family member all their lives. The educational level of the participants varied from secondary education to doctorate. The mean age of the people with complex support needs was 27.17 years (SD = 3.49), ranging from

7 to 63 years old. Eight participants lived with their family member in the same household. The family member of one participating sister lived in a care facility. Four family members had visual impairments that could not be corrected by glasses or contact lenses. Three had auditory impairments that could not be corrected with a hearing aid. At the time of study entry, two family members received treatment for their behavioral and psychological problems, and six received medical treatment for specific physical health problems (see Table 2.1 for more details).

The research team consisted of five people from the fields of psychology, developmental psychopathology, child development, qualitative and quantitative research, intellectual and physical disability, policy, and nursing. One team member was also a parent of a child with complex support needs. Prior to the study, one member (i.e., the first author and interviewer) had significantly less work experience with people with complex support needs compared to all of the other team members, who had extensive professional experience in this field. This diversity in familiarity with the study population was valued by the research team as it hopefully reduced blind spots and preconceptions.

Procedures

Ethical approval was obtained from the Scientific and Ethical Review Committee of the Faculty of Behavioral and Movement Sciences, Vrije Universiteit Amsterdam, The Netherlands (registration number: VCWE-2018-003). The first author collected all of the data in a five-month period. All of the interviews were in-person and took place at locations preferred by the participant, which was at their home in all cases. The interviews were audio-recorded and lasted between 58 and 112 minutes, with an average duration of approximately 87 minutes. Each interview was transcribed verbatim and received a unique code.

Table 2.1 Demographic summary

Participants				Family Members with Complex Support Needs			
Participant pseudonym	Relationship	Primary caregiver(s) of family member with complex support needs	Primary caregiver(s) of others next to family member with complex support needs	Gender	Age group (years)	Other health issues [a]	Living arrangement
R1	Mother	√	√	Male	Middle childhood (6–12)	√	Family home
R2	Both parents	√	√	Male	Middle childhood (6–12)	√	Family home
R3	Mother	√	×	Female	Adult (21+)	√	Family home
R4	Mother	√	√	Female	Adolescence (13–21)	√	Family home
R4	Mother	√	√	Female	Adolescence (13–21)	√	Family home
R6	Both parents	√	√	Male	Middle childhood (6–12)	√	Family home
R7	Sister	×	-	Male	Adult (21+)	√	Group home
R8	Sister	√	×	Female	Adult (21+)	×	Family home
R9	Mother	√	√	Female	Adolescence (13–21)	×	Family home

[a] The presence of one or more severe additional health issues within the visual, auditory, behavioral/psychological, or physical health domain for which the family member was being treated at the time of study participation.

Confidentiality was assured by replacing all names with pseudonyms (i.e., R1, R2, R3, etc.) and by changing or removing all other identifying data (e.g., locale). The transcripts remained in Dutch throughout the whole analysis and writing process. Only the quotations used in this article were translated into English. This was achieved through a back-translation procedure performed by one native English and one native Dutch speaker, both independent of this study, until high congruence between the original and back-translated quotes was achieved.

Interview and pilot

The research team first constructed a semi-structured interview with broad and open-ended questions around the three BPNs: autonomy, competence, and relatedness. This interview was piloted with two fathers of young children with complex care needs. Feedback provided by the two fathers and their interview transcripts were discussed extensively within the research team, which eventually led to the formulation of several key questions for the final interview protocol. In this protocol, the participants were first asked to tell something about their relationship with their family member, for example how they communicated with each other, and how their family member enacted self-determined behavior. This was followed by three corresponding sets of questions, one for each BPN, which were administered sequentially. Each set addressed perceptions on the person-specific meanings of the BPN, the detection of (changes in) person-specific needs, recognition of (dis)satisfaction and motivation for person-specific needs, and the support and stimulation of person-specific needs (see Table 2.2 for the questions that guided each interview). Questions from the topic list were followed-up with prompts for elaboration and clarification. Because the abstract terms ‘autonomy,’ ‘competence,’ and ‘relatedness’ could be perceived as jargon by the participants, each question set started with an operational definition of the concept that was going to be discussed. Then, the participants were asked about the meaning of the need in their own lives, in order to facilitate the application of the concept to their family member with complex support needs. In order to encourage depth and detail, the interviewer provided extensive time for responses. In order to limit question-order bias, the interviewer alternated the order of the sets between interviews.

Table 2.2 Sample interview protocol

No.	Semi-Structured Interview Questions
1.	What does autonomy[a] mean to you/What do you understand by it/How would you describe it?
2.	What do you think autonomy means for (name family member)/What would (name family member) understand by this?
3.	Can you tell me what changes there have been in the need for autonomy from birth to now, and how did you notice that?
4.	How do you notice in (name family member) that he/she feels supported in his/her need for autonomy?
5.	How do you notice in (name family member) that he/she does not feel supported in his/her need for autonomy?
6.	How do you notice when (name family member) needs (more) autonomy?
7.	What do you do to support or stimulate the need for autonomy?
8.	What could healthcare professionals do to support or stimulate the need for autonomy/What possibilities do you see for this?

[a] The same key questions were asked for competence and relatedness

Data analysis

Field notes taken during the interviews, as well as reflections and discussions of the data, were described in a diary as memos to support data analysis and code development (Charmaz, 2006). All of the authors reflected on their own positionality and assumptions during all phases of the study with other team members and with outsiders. The interview transcripts were entered into NVivo 12 Pro software (Nvivo version 12, 2018), and significant statements of the participants were coded line by line. The exploratory data analysis followed grounded theory strategies with the sensitizing concepts of autonomy, competence, and relatedness as the conceptual framework (Bowen, 2006; Charmaz, 2006). This meant that although the three BPNs were the foundation for our conversations with the relatives, the coding was inductive and iterative. A constant comparative method was followed (Glaser & Strauss, 2008) in order to identify patterns and interrelationships in the perceptions of relatives, leading to the formation of the ultimate themes. As a result, these ultimate themes with the "thick description" of phenomena could include either one specific or multiple BPNs.

In the first phase of the data analysis, the first author assigned open codes to two interview transcripts by giving short descriptive terms to relevant statements that were used by the participants. The first author discussed these open codes with the third and second author individually, as well as with the entire research team together. These discussions led to the first clustering of codes in three categories: Interpretations of BPNs, Support options to find out BPNs, and Encountered obstacles. Then, the first and third author independently coded six interview transcripts, including the first two for a second time, through an iterative process of open and axial coding. Figure 2.1 illustrates this process of gradually creating related higher- and lower-level themes (Gorbin & Strauss, 2008).

Throughout this analysis process, the coders compared, discussed, and refined all of the interim coding categories until they reached consensus before starting to code a new interview. They also actively searched for perceptions and statements that confirmed or contradicted previous findings (i.e., negative case analysis). Finally, the first author single-handedly coded the remaining interviews as described above, and again discussed and refined the findings during frequent meetings with the entire research team. The data analysis was completed when it was no longer possible to develop new themes or merge developed themes (i.e., when data saturation had occurred). At that moment, the final themes were structured under two main categories: (I) Primary relatives' perceptions on what the BPNs of family members with complex support needs look like, and (II) Primary relatives' perceptions on how support processes for the BPNs of family members with complex support needs work. In addition, the researchers incorporated perceptions on support processes into a tentative conceptual model to illustrate how relatives attempt to clarify and respond to their family members' specific BPNs.

Results

The purpose of this study was to understand primary relatives' perspectives on the meaning of satisfaction and motivation for the three BPNs (i.e., self-determination) for their family members with extensive support needs, as well as on finding ways to support them. The two overarching categories and corresponding themes that emerged through the data analysis are discussed below.

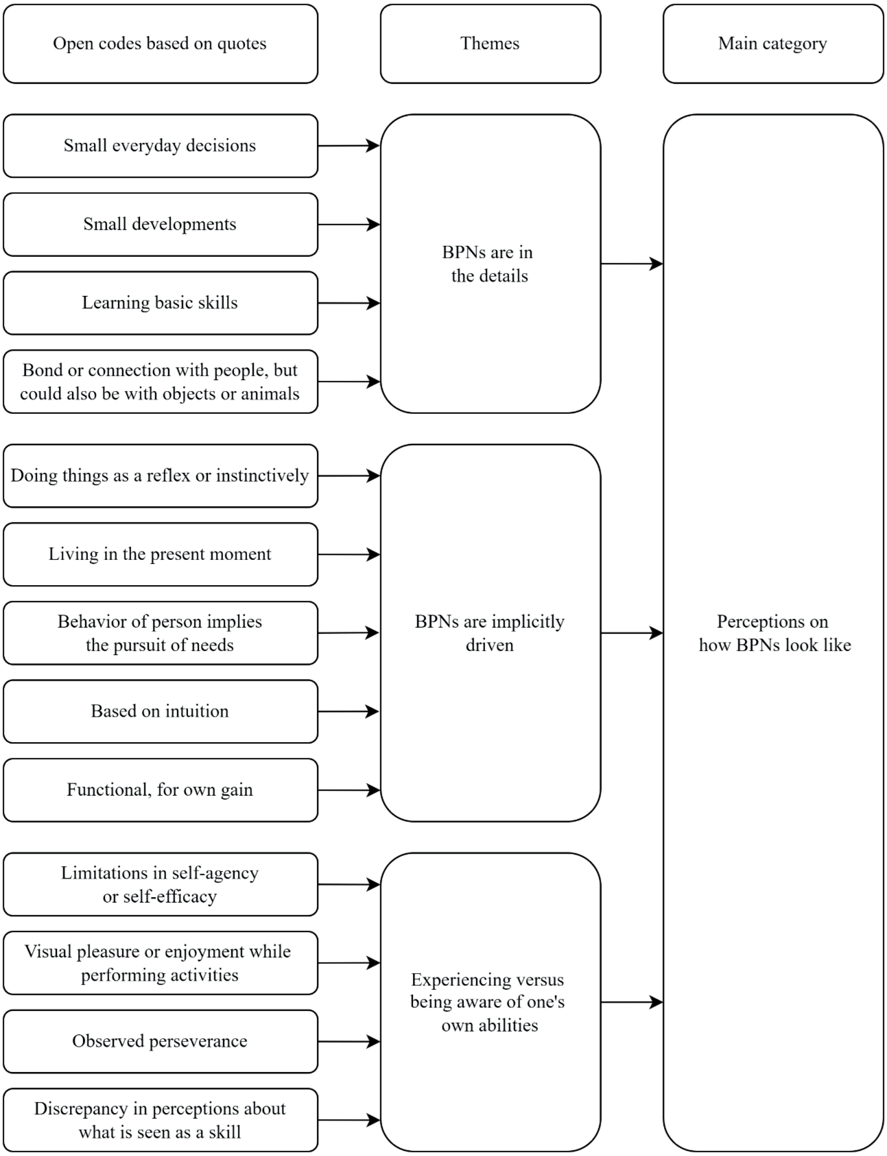

Figure 2.1. Open codes, themes, and categories reflecting the coding process of primary relatives' perceptions on what the BPNs of family members with complex support needs look like.

I. Primary relatives' perceptions on what the BPNs of family members with complex support needs look like

The participants' descriptions of the extent to which their family members with complex support needs were able to direct or determine things for themselves varied from "*he can determine very little . . . Actually, we [as parents] determine his life*" (R1) to "*she pretty much determines her daily schedule herself, insofar as that is possible*" (R4). From their interpretations of the meaning of the BPNs, three themes were synthesized; they will be explained below.

I. BPNs are all in the details

Most of the participants stated regarding the nature of their family members' BPNs that needs were often very discrete, subtle, and idiosyncratic. Autonomy, for example, could be paraphrased as "the things" that the family members liked, they felt comfortable with, made them happy, they wanted, they did not want, they wanted differently, or they could choose for themselves. However, these specific things mainly revolved around small everyday activities. R3, for example, said "*the bigger things in life, she cannot make decisions about those. But it is more about the small things in daily life . . . like when she does not want to get up, she will stay in bed.*" R7 mentioned: "*well if he is on holiday for example, I always let him choose what to wear. Those are often little things, but yeah, I do notice that he has clear preferences.*"

Regarding relatedness, some participants indicated that "the others" with whom their family members felt connected, comfortable, or safe, and whom they liked, preferred, or interacted with, did not necessarily have to be a person but could also be a thing, object, or animal. R2, for example, stated about his son "*I think that his feeling of connectedness is very broad, with everyone and everything, well, yeah, what moves . . . He is just really focused on other people and animals. Horses, dogs, it does not matter.*" Furthermore, this feeling of a connection with someone or something, or in a broader sense "belonging," was very noticeable, and could arise quickly in some family members, as in the aforementioned example of R2, while revealing itself less readily in others.

Competence was often explained as "the things" family members were able to do, were good at, were trying to do, or were learning to master. In this context, the participants spoke primarily about basic motor (e.g., holding an object or sitting up with(out) support), communication (e.g., using pictograms), cognitive skills (e.g., knowing how to use a specific object), and social skills (e.g., waving to others). R8 mentioned, for example, "*well then she helps me folding laundry, then I throw the washing from the dryer in the washing basket, I put it on the table and then she hands everything piece by piece*." R7 explained this as "*he really does have things in which he excels, but they are in general not skills that advance you in life or anything*." Some participants even indicated that, due to the limited capacities of their family member, they would rather not speak about it to outsiders, like R1 who said:

> *When people ask like "what can he do?" I say "he cannot do anything." Of course we know jolly well what he can do. But I do not need to say to a stranger, like "well he can stand in a standing-frame," because then they are like "right, he can take a few steps in a walking-frame, whatever," you know. I just say it very darkly like, "well he cannot do anything."*

II. BPNs are implicitly driven

The participants were often only able to infer the existence of specific BPNs rather than directly observing them. This meant that although certain behaviors implied that the family members were trying to express or pursue their BPNs, it often could not be determined why they had these specific needs, or in some cases even what exactly these specific needs entailed. For example, R2 described her son's drive to explore new skills (competence) as "*he surprises us too sometimes, suddenly he can do something. He watches and copies something, and then he knows at once how to open something*." According to the participants, BPNs were therefore mainly driven by instinct or primary drives, as R5 explained about her daughter's wishes (autonomy): "*she lives in the present, so she, in that sense it is instinctive . . . So just about feeling NOW*." R9 explained this as:

> *What other people think and if they want something too . . . It just is not there. It is not that she says "that is not important to me," she just does not see it like that. It just does not exist for her. In fact a tremendously autonomous person. Yeah, autonomous to the core.*

When R3 talked about her daughter's preferences for specific people (relatedness), she said: "*that is very intuitive by [name of daughter], no signs are needed, no gifts are needed, she is very selective, purely intuitive*." Another example was given by R9, who explained that her daughter "*hardly shows interest at all in other people, other than functional, because she wants something . . . She will sit next to you because she likes to be cuddled, but it is never reciprocal.*"

On the other hand, some participants emphasized that specifically for the formation of a close bond (relatedness), the intensity and frequency of the caring relationship also played an important role. In other words, these participants indicated that they only noticed a relationship arising with people who were closely involved with their family members and had invested a lot of time to get to know them. R6 described this as follows:

> *A relationship with his support workers, well there you see that it is kind of a family relationship. That he can just be himself (with them) and that they know him and that he has that attachment. That is, the more often he sees people, the more he can just be himself and find his own way in it.*

III. Experiencing versus being aware of one's own abilities

The participants indicated that, in most cases, they doubted whether their family members were conscious of the personal capacities they had developed (competence). Some described this as an absence of experiencing the fact that one has the skills to accomplish a particular task (self-efficacy), as in the case of R9, who stated: "*[I] wonder if* *she is aware of it [her abilities]. It is also at a level of abstraction that I wonder, does she have that? And even if she has it, is it visible to us?*" R7 mentioned that she could not notice any self-potential in her brother: "*he does not expand it [his skills] like 'oh that is a strength of mine, I can develop that' . . . It is totally meaningless to him 'oh I am good at something.'*"

Others even indicated that it often took a lot of effort to make family members aware that specific actions were self-generated (self-agency), and that these efforts were not always successful. R1, for example, described the importance of endless repetition in this process: "*at school they know exactly what to do to stimulate him and they put him in it [a walking-frame] every day, countless times, and then suddenly the penny drops and he starts doing it, and then he likes it.*"

This observation of pleasure or gratification while performing an activity in itself without the presence of a deeper meaning or goal came up frequently during the interviews, and corresponds to what the German psychologist Karl Bühler (1924) described as 'Funktionslust.' R9, for example, said that her daughter clearly enjoyed riding a horse without experiencing it herself as something she can do: "*the horse itself does not interest her either. Stroking or brushing or something like that, that is all boring. It is all about sitting on it.*"

On the other hand, some participants did report specific situations in which their family member with complex support needs appeared to be aware of personal capacities. As R4 described, "*well that is very funny actually, because the moment that she realizes that it is very important that she shows how well she can communicate with [her] speech computer, she starts doing her utmost.*" Some participants, including the latter, even spoke explicitly of the presence of perseverance, which may indicate a desire of the family members to feel effective in what they do. R4 said, in this regard, that her daughter had a "*very big drive to be able to keep walking,*" even when she had to relearn this after a scoliosis surgery "*where she got metal rods in* *her body that reached deep into her pelvis,"* which prevented her pelvis from tilting.

Nevertheless, when the participants were able to detect a degree of self-efficacy, it often also revealed the discrepancy between the family members' perceptions about their own skills and how others interpreted these skills as such. R2, for example, explained that his son is quite successful and persistent at "*opening things, climbing on things, or grabbing certain things he wants. So I think he feels, yeah, competent with that sort of things. However, it sounds crazy to me, as I would not think of it in that way myself.*" R5 illustrated this discrepancy as follows:

> *If you let (name of daughter) help you bake a cake or something . . . she is only able to put two or three things in a pan, but later she will tell someone else that she can bake, that she always does that, which is partly due to her getting a lot of positive feedback like "gosh how good of you (name of daughter)," you know? So (she thinks) "I can do that." But that does not touch reality.*

In addition, the participants indicated that in some cases this discrepancy could have negative or harmful consequences. R5, for example, said that even though she felt that her daughter deserved to experience the feeling of self-efficacy, "*you also have to protect her when she expresses this (feeling) to other people, that they do not interpret it as such.*"

II. Primary relatives' perceptions on how support processes for the BPNs of family members with complex support needs work

The participants experienced the process of figuring out how their family member with complex support needs could be supported in BPNs as complicated and time-consuming. R6 described this as "*you do not get a manual, you have to sense things, and keep an eye on how everything comes about and what affects what, the whole time.*" The participants' perceptions on how they attempted to support the BPNs were synthesized into three themes and a tentative conceptual framework, which will be explained below.

I. Detecting BPNs

BPN support started with noticing the person-specific expressions of their family members that represented their need for autonomy, competence, or relatedness. R2, for example, said "*well yeah I think he can indicate all the things he needs for his goal in great detail, we just do not notice it all.*" The participants further indicated that BPN expressions or signals could vary according to context, were often idiosyncratic in nature, and could be verbal or non-verbal (e.g., the presence or absence of certain sounds, behaviors, and other body language). In addition, expressions of BPNs were reactive in most situations. R1, for example, explained that on the rare occasions that her son expressed himself, he mainly did this by producing "*higher sounds, louder sounds, faster sounds, [or] more sounds*" in response to someone else's action or something happening at that moment that he liked or disliked (autonomy). R7 said about her brother:

> *You have to look carefully at his behavior because, for example, if he is at his care-organization performing daytime activities, and he is bored there, then he will start to show difficult behavior, so to speak. Then he will no longer participate, or then he is more difficult for this support workers to handle. Yes, then you can see from his behavior that he is not feeling comfortable in his own skin and that he actually does not agree with what is happening.*

On the other hand, a few participants indicated that signals could also be proactive. For example, the daughter of R9 took the initiative to express that she really wanted something (autonomy)—"*because she does grab her coat herself and then she does put her coat on. Sometimes upside down and very often also the right way. And that is like 'well, shouldn't we head outside?'*"—or that she liked specific social workers (relatedness) “*who no longer came because they were going to do something else, that she then came to me with a picture ‘where is she, he?’ ‘Sweet, sweet, sweet’ [through using hand gestures].*”

II. Clarifying BPNs

After signals of BPNs were noticed, the participants stressed the challenges and the importance of interpreting these signals correctly. This quandary is reflected in the statement by R4, who indicated that her daughter withdrew or fell asleep when she was dissatisfied, and that “*this is very difficult in a group setting and difficult for therapists [to interpret] because they then say ‘oh, she is tired,’ and I will say ‘no, she is bored.’*” R9 emphasized the importance as follows:

> *If she cannot make clear what she wants, yeah nice idea autonomy, but I do not think you can do anything with it then . . . she can then only influence the things she can directly reach herself, she can grab, she can organize . . . Everything for which she dependents on other people, and that is a lot considering her developmental age, she needs communication for that.*

In order to help clarify expressions regarding BPNs, the participants indicated that they often tried a wide variety of support resources and techniques, like using a “trial and error” method to rule different options out, calling in professional assistance, using supportive communication tools (e.g., speech computers, hand gestures, and pictograms), or relying on intuition and prior experiences with the family member. In this regard, R4 indicated that her understanding of her daughter’s BPN expressions used to be very limited, and consisted only of relying on what her daughter was looking at. However, this improved drastically when her daughter learned how to use an eye-operated speech computer that made her go from “*someone who cannot influence her own environment to someone who can.*” Nevertheless, some participants indicated that despite trying many different types of resources and techniques, signals often remained unclear to them, as in the situation illustrated by R1:

> *We are working with pictograms, but that is still too challenging for him, but we do offer it to him. I notice myself in practice that I hardly do it, and because it just, yeah, is a fair amount of work and you do not get a response back. So that is pretty difficult . . . Signs, I did do them in the beginning . . . When he was only nine months old he got a hearing aid so then I had to use sign language too, but yeah, you can also do sign language to a cat, but they also will not understand it and (name of son) does not understand it either . . . With [name of son], the level is just too low to use signs. And he would never be able to make a sign back because he does not have the motor skills at all.*

III. Creating opportunities

All of the participants discussed family members' high degree of dependence on others to express, develop, maintain, and fulfil their BPNs. Because of this dependency, the participants stressed the importance of creating opportunities in all of these areas for their family member with complex support needs. This meant continuously creating optimal contexts, always putting the interest of family members first, and always striving for growth, development, and new opportunities. Regarding expressing one's own choices (autonomy), R9, for example, stated about her daughter: "*[for me it is] extremely important, for the limited decisions she is able to make, that she is involved and has the right to say something about it.*" However, BPN expressions, as mentioned in the first theme, were usually reactive in nature, and therefore often only followed after another person's action or a change in the environment. Actively stimulating BPN expressions—for example, by offering options attuned to the family member (autonomy)—was therefore very important according to the participants. Similarly, the development of specific abilities (competence) was often only achieved by providing comprehensive learning opportunities over a long period of time, as R1 described:

> *I think he has had a walking-frame since he was three and he only now is starting to enjoy it and taking steps in it, but that is a matter of practice, practice, practice. Putting him in it every day at school . . . And well, yeah, he has his standing-frame, he stands in it every day at school, he practices with that, that is improving too, so yeah, he is developing in that. Just in teeny tiny steps.*

A caveat to this specific focus on learning opportunities was that such opportunities declined into adulthood, or as R3 explained about her 43-year-old daughter: "*it is not so much that you are busy with the development. Actually, now I think about it I have not for a long time.*" R8 said about her sister "*you know about that, she is done developing. She is 63 after all! Tried a lot and at a certain point, yeah, it is all done too . . . If it had been possible, it would have happened.*"

In the context of creating opportunities to fulfil clarified or well-known BPNs, such as facilitating what family members wanted (autonomy), the environment also played an important role. R4 shared, for example, that because of her daughter's well-known need to be around other people (relatedness), she deliberately took her to a reading hour for toddlers in the library and lets her visit a day-care facility for the elderly where she is seen as "the mascot." R1 explained the importance of her being the one who responds to her son's expressed need to be comforted (relatedness), relative to involved support workers:

> *If I sing a song when he cries, and I sing a certain song, then he is quiet, and if [name support worker] does that then he is not quiet. So that is well, then you just notice that he so to say, well, has a preference, does feel connected, right, to me, thankfully.*

The participants also elaborated on their challenges with creating opportunities and their inability to support expressed BPNs. Some participants indicated that because it was often impossible for them to notice or clarify current, new, or changes in BPNs, they often could only strive to make family members as comfortable as possible with their own life. R9 described this as follows:

> *I think the only thing we can go on is, is she acting happy, yes or no. And since she generally behaves as quite happy, shows happiness, we assume that apparently as far as she is concerned the world is okay. But what she would have wanted to do, other than what she is doing now, or how she would have wanted to live her life, I have no idea.*

Subsequently, when BPNs remained unclear, or were clear but unfeasible (e.g., because they were dangerous or inconvenient at the time), it was often difficult or even impossible for the participants to communicate this to their family member, or why this was the case, which could lead to dissatisfaction or frustration in both parties. R4 described this as follows:

> *There are also very difficult moments. For example, right before an operation and then say "I do not want to [through using her speech computer]." You know, she could not say that before. On one hand it is great, but now I have to do something with it.*

Tentative conceptual framework of BPN support

In order to integrate the themes and codes from the data, a schematic flowchart was constructed (see Figure 2.2). This chart depicts the interactive steps and challenges of supporting the personal BPNs of people with complex care needs. The initial steps represent the idiosyncratic **proactive** or **reactive** expressions of a **current BPN**, respectively from the persons themselves or **induced by someone or something from the environment.** On the one hand, these expressions can **go unnoticed**, reducing the chance of fulfillment and inducing the chance of dissatisfaction or frustration. On the other hand, these expressions can **be noticed**, after which they can

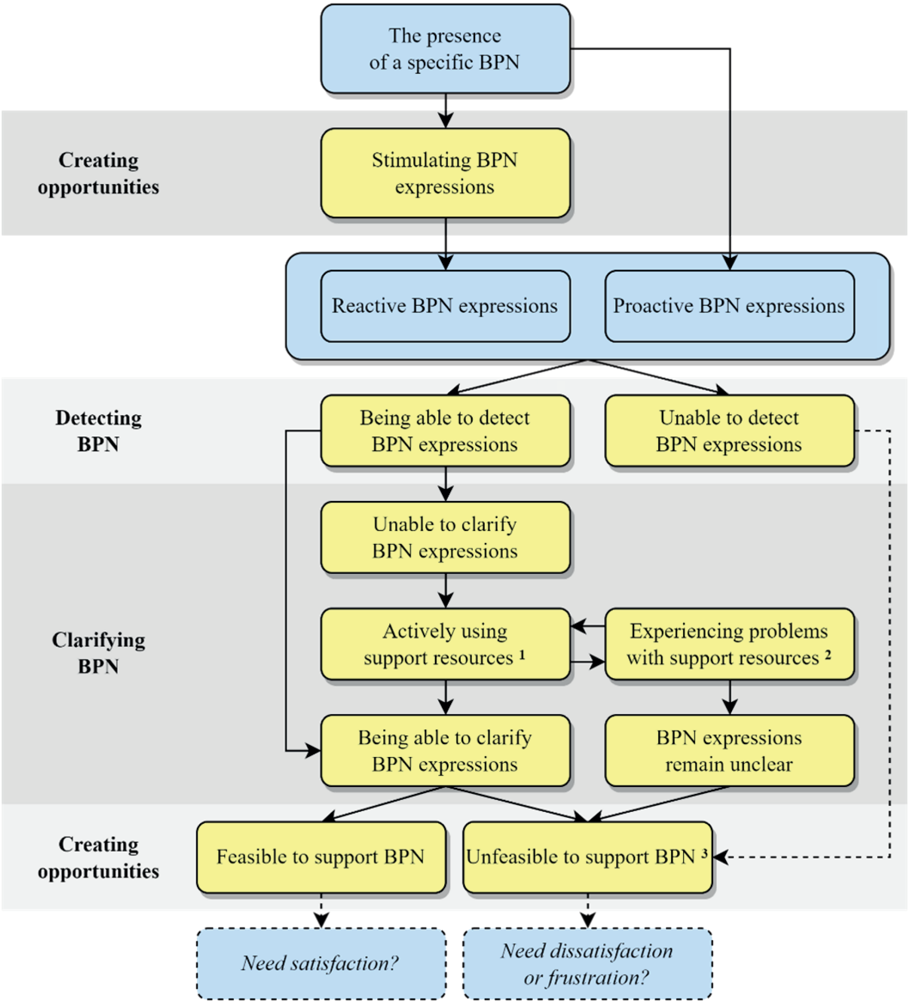

Figure 2.2. This figure represents a tentative theoretical flowchart of the steps and challenges of primary relatives in signaling and supporting the person-specific basic psychological needs of family members with complex support needs. The blue blocks represent the experiences and behaviors of the family members with complex support needs, while the yellow blocks represent the actions, experiences, and outcomes of the primary relatives. [1] Examples of types of support resources include therapy or training, time investment, trial and error, and communication tools (e.g., hand gestures, pictograms, and speech computers). [2] Examples of problems with support resources include the resources being too expensive, the resources having their own limitations, and regression when resources are not maintained. [3] Examples of the inability to create opportunities to support a need include the need being unclear, the need being dangerous, and the need not being executable.

either be **interpreted correctly or be unclear**. When needs are unclear, it often prompts the **use of various resources or techniques** to assist clarification. When these **support resources fail repeatedly** for whatever reason, those involved can get stuck in a loop in which the BPN ultimately **remains unclear**, again reducing the chance of fulfillment and inducing the chance of dissatisfaction or frustration. When those involved can correctly interpret the BPN, it is either **possible or impossible to support it**, increasing the chance of satisfaction with the former and the chance of dissatisfaction or frustration with the latter.

Discussion

In line with Self-Determination Theory (SDT), this study explored primary relatives' perspectives on what they think satisfaction and motivation for the three BPNs mean to their family member with extensive support needs. First, all of the participants acknowledged the importance of the BPNs for self-determined (i.e., intrinsically motivated) action, as they described these as the things their family members liked, felt comfortable with, or wanted (autonomy); were able to do, trying to do, or learning to master (competence); and the others to which they felt attached, they made contact with, or they felt safe with (relatedness). Second, the relatives elaborated on the subtle and idiosyncratic nature of the BPNs in their family members; BPNs were often related to small everyday activities (autonomy); were mainly basic motor, communication, cognitive, or social skills (competence); and could arise with people as well as with things (relatedness). Third, the participants often had to infer a specific BPN from behavioral clues, instead of having it communicated directly. Fourth, some participants indicated that although they could not detect self-efficacy or even self-agency in their family members regarding their personal capacities (competence), they often did notice pleasure or enjoyment while performing these skills. Among the participants who could detect a degree of self-efficacy, there was often a discrepancy between how family members perceived their own skills and how the participants or others in the environment viewed these skills as such.

As seen from the perspective of Causal Agency Theory (CAT), people with complex support needs may thus sometimes develop "beliefs about the link between the self and the goal (control expectancy beliefs; 'When I want to do ___, I can')" (Shogren et al., 2017c, p. 62). However, beliefs about one's own capabilities (i.e., capacity beliefs) and about factors that lead to goal attainment (i.e., causality beliefs), may be less apparent. In addition, people without disabilities, or with mild disabilities, are expected to strive towards their own needs (i.e., volitional action) and can ask for help when they experience problems doing so (Shogren et al., 2017c). The self-determined behavior of people with complex support needs, on the other hand, may be more complicated because the actions to meet their own specific BPNs are much less visible to the outer world and therefore often go unnoticed, and are much more dependent on the actions performed and opportunities created by others. According to Wehmeyer (2005), this increased reliance on others to perform certain behaviors is of minor importance in the ability to act volitionally. This dependency does, however, emphasize the importance of finding out what, when, and how people with extensive support needs perceive something as a desired outcome.

Based on the premise that self-determination develops and is maintained in interaction between the person and the environment (Ryan & Deci, 2000b), this study further identified how relatives' perspectives translated into support for the BPNs of their family member with complex support needs. The tentative model represented in Figure 2.2 describes how BPN-related signals, in interaction between relatives and their family members, in some occasions can lead to need fulfillment and thus self-determination. This complex process of relatives looking for, interpreting, and responding to BPN signals to the best of their abilities shows similarities with the concept of sensitive responsiveness from attachment theory, which indicates the extent to which a caregiver picks up on and adequately reacts to their infant's signals (Ainsworth, 1987). Specific for this population are the steps of the model in which relatives attempt to elicit expressions of BPNs and use diverse resources to clarify these expressions, and in which relatives need to deal with the fact that some of the BPNs will remain opaque to them. These steps will become easier over time for caregivers of typically developing children as their children develop increased capacities to properly identify and communicate their needs. However, they will remain challenging for the relatives of family members with complex support needs throughout the life course. Finally, these population-specific steps are in line with research by Vandesande et al. (2019) on the preconditions and challenges that parents of children with severe or profound intellectual disabilities encountered when trying to establish a secure attachment relationship with their child. Examples of corresponding findings are (difficulties in) learning how to read non-verbal, subtle, and idiosyncratic signals of their child; teaching them new things through patience and repetition; and using the help of professionals (Vandesande et al., 2019).

Implications for practice

The environment of people with extensive support needs mainly consists of parents and healthcare professionals. Embregts et al. (2019) showed that both parents and professionals are capable of taking the perspective of people with severe intellectual disabilities. However, De Geus-Neelen et al. (2014) indicated that parents in this population evaluated their child's self-determination more positively than support workers did. De Geus-Neelen et al. (2019) found significant discrepancies between relatives and support workers in their rating of the subjective well-being and internal needs of people with severe-to-profound intellectual disabilities. Furthermore, collaboration between relatives and support workers is hampered by the limited understanding of how the families of people with intellectual and developmental disabilities promote and support self-determination and its development in the home context (Dean et al., 2021).

The present study shows that BPNs, seen through the eyes of relatives, do not have a self-evident meaning for people with complex support needs, complicating support in realizing those needs. In order to support healthcare professionals in their knowledge about BPN satisfaction and motivation (i.e., self-determination), relatives may thus be involved more as equal partner in the client, caregiver, healthcare professional triad, as well as in education programs. In other words, healthcare professionals might accept the guidance of relatives and their family members in assigning meaning to their client's BPNs. Figure 2.2 can play a two-sided role in this. On the one hand, the figure may empower relatives to share what they know about how and what specific BPNs are communicated, how these expressions can be stimulated and recognized, what resources could be helpful for the clarification of expressions, and what optimal opportunities can be created to support specific BPNs. On the other hand, the figure can be used in conjunction with other tools, e.g., (Vandesande et al., 2021), to help relatives structure and articulate requests for assistance, such that professional support is more helpful. Furthermore, more structural awareness needs to be created among healthcare professionals that BPNs have different meanings compared to people without disabilities, and that support should always be in the best interest of the person with complex care needs, therefore requiring openness, sensitive responsiveness, dedication, and perseverance (Anderson et al., 2019; Skarsaune et al., 2021).

Limitations and future research

There are several limitations to this study. First, the task for relatives to discuss someone else's internal states is extremely challenging (Scott & Haverkamp, 2018). A study by Janssen et al. (2010), for example, found that the parents of children with cerebral palsy rated their child's health-related quality of life, including autonomy, more negatively than the children did themselves. Nevertheless, the fact that the perspectives of relatives on meanings for their family members with complex support needs were colored by interpretations of the concepts for themselves possibly made the results more valuable, precisely because relatives are so important in helping their family members meet BPNs. Second, the interviews in this study were the sole data source, making validation through data-triangulation impossible. Future research might collect observations during situations related to self-determination, as well as member checks or focus groups with interviewed and non-interviewed relatives to verify the emerging themes and processes. Third, this study derived its sensitizing concepts from SDT. Although this study did not exclude relatives' perceptions that fitted better with other concepts, the use of other sensitizing concepts as a starting point, for example, related to one of the other mini-theories under SDT or to CAT, could have led to additional insights. Fourth, the tentative theoretical model is based on the processes of self-determination support from one specific person (i.e., a primary relative). However, if the family member with complex support needs lives in a household with several people, support could also be, for example, a joint process of relatives together. Fifth, although the family members in this sample were relatively heterogeneous in their age and additional impairments (e.g., severity, type), their living situation was rather homogeneous, as the vast majority lived with the interviewed relative. It is possible that relatives like R7, whose family members mainly receive care from healthcare professionals, have different experiences and perceptions to relatives who are involved on a daily basis, like the others in this sample.

The purpose of this study was to investigate the perceptions of relatives, as they play an important role in the life of and have comprehensive knowledge of their relative with extensive and complex support needs (Hall & Rossetti, 2018; Kruithof et al., 2020). However, relatives tend to differ from healthcare professionals in their views about people within this population (De Geus-Neelen et al., 2014; De Geus-Neelen et al., 2019). Future research may therefore explore where these differences lie regarding the BPN satisfaction and motivation that go along with self-determination. Furthermore, inclusion was only based on the presence of a severe or profound intellectual disability. However, as people with complex support needs grow older, they build up life history and experiences. Accumulated experience, combined with the fact that relatives know their family members longer and thus probably better, could lead to changes or the crystallization of perceptions of the meanings of BPNs. Future research could look into how these changes develop over time (within people) and whether specific perceptions on meanings are tied to a specific age group or similar acquired experiences.

Additional findings showed that the three sensitizing concepts refer to needs that are highly intertwined. For example, learning to walk with a walking-frame (competence) can influence the family members' ability to determine whether, when, and where they want to go. Building a deep connection with someone (relatedness) can influence the family members' chance to be understood. An increase in competence or relatedness thus potentially facilitates autonomy satisfaction. Further research is needed into these associations between the three BPNs, in order to shed more light on how to create, increase, and extend a better supportive environment for people with complex support needs. Finally, the interviews also provided insights into a topic that went beyond the scope of this article, namely the specific meaning of autonomy, competence, and relatedness for relatives of family members with complex support needs themselves. Relatives, for example, indicated that they often felt limited or thwarted in their own BPNs due to the enormous burden of raising a family member with complex support needs. This aligns with other studies on caregiver burden for this specific group (Luijkx et al., 2017; Tadema & Vlaskamp, 2010), and underlines the relevance of not only taking care of people with complex support needs but also their special caregivers.

Conclusion

This study showed that BPNs are recognized as relevant to self-determined (i.e., intrinsically motivated) action in people with complex support needs. However, the meaning of self-determination goes further than "making one's own choices." Enjoying and experiencing the things to one likes and meaningful interactions with others are equally important aspects. As explained by their relatives, BPNs in people with complex support needs are in the details, implicitly driven, and not always consciously or self-consciously expressed.

Although the environment is of great importance, supporting BPNs turns out to be complex. Limitations in communication and sensorimotor skills hinder the identification and clarification of needs, trapping those involved in a loop in which BPNs ultimately remain unclear, reducing the likelihood of fulfillment and increasing the likelihood of dissatisfaction or frustration. Due to the dependence on others, the environment also has a role in creating opportunities to fulfill needs. Relatives of people with complex support needs can help other caregivers who are learning to understand and support BPN signals, preferences and wishes.

The frequently encountered methodological difficulties in research on people within this target group (Maes et al., 2021) will continue to challenge the understanding of constructs within SDT for people with complex care needs and the support for these constructs by their environment. Despite its limitations, however, the current study shows that relatives provide a unique insight into this quest. Based on the shared illustrative experiences of relatives and the resulting implications (e.g., involving relatives as equal partners, using the schematic flowchart, raising awareness that BPNs do not have self-evident meaning), we can now think more constructively about how to support people with complex support needs and their caregivers in promoting self-determination. Taken together, in order for people with complex support needs to have equal opportunities to act volitionally and to give them 'a stronger voice,' it is of great importance that researchers, service providers, policymakers, and all other parties involved not only value and take good note of the intimate knowledge of relatives but also make good use of it.

Chapter 3

Parent-perceived autonomy-supportive experiences and basic psychological needs of people with complex support needs: Development and preliminary psychometric evaluation of two questionnaires

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Abstract

Background. Understanding and supporting basic psychological needs of persons with complex support needs is important but difficult because of communicative challenges. We developed and tested questionnaires to obtain parents' perspectives on autonomy support and basic psychological needs of autonomy, competence, and relatedness.

Method. Two parent-informant questionnaires were developed, administered, and subjected to psychometric property analyses. Participants were 63 Dutch parents of persons diagnosed with severe or profound intellectual and multiple disabilities.

Results. Principal component analyses revealed a one-factor structure for the Parental Perceptions on Autonomy-Supportive Experiences questionnaire, while the Parental Perceptions on Basic Psychological Need Signals questionnaire yielded two-factors interpreted as Noticing Signals of Autonomy and Noticing Signals of Competence/Relatedness. Evidence for construct validity was found for both instruments.

Conclusion. Preliminary evaluation of the new questionnaires is encouraging, but further validation with a larger sample size is warranted.

Introduction

Attention for self-determination of persons with intellectual disabilities increased significantly in recent decades in the fields of education, health care, and research (Mumbardó-Adam et al., 2023; Wehmeyer et al., 2017, Wehmeyer, 2020a). However, it is still not clear how to apply this concept with persons with severe or profound intellectual and multiple disabilities (SPIMD). This population is characterized by a combination of cognitive limitations and additional motor, sensory, communication, and health problems that make them heavily dependent on others for everyday tasks (Nakken & Vlaskamp, 2007; Van Timmeren et al., 2017). Access to their subjective experiences and point of view is furthermore limited (Maes et al., 2021). Research on self-determination, like on other topics, often engages with closely involved caregivers, studying and describing their intimate understanding of the person with complex support needs within specific settings and feeding back those findings (Jacobs et al., 2018; Kruithof et al., 2020; Petry et al., 2005; Watson, 2012). To address the call for better understanding how self-determination may be related to interventions and outcomes (Kuld et al., 2023; Mumbardo-Adam et al., 2023), the current study sought to operationalize the psychological constructs of autonomy support and basic psychological needs as perceived by parents or other family carers of persons with complex support needs.

According to Basic Psychological Needs Theory (BPNT), a mini-theory under Self-Determination Theory (SDT), every person possesses three innate basic psychological needs (BPNs), the satisfaction of which are important for psychological health. The BPNs regard autonomy, competence, and relatedness (Deci & Ryan, 2012). Opportunities for fulfilling these BPNs contribute to the emergence of intrinsic motivation, self-regulation, and well-being (Deci & Ryan, 2000; Ryan & Deci, 2000a, 2000b). Material and especially social environmental circumstances may thwart or promote autonomous behaviour. Need satisfaction is linked to having an autonomy-supportive social context, in which the voluntariness of action is respected and encouraged, feedback on competent performance is informative, and the person is made to feel accepted and part of a group (Deci & Ryan, 2000; Soenens et al., 2007). Although cognitive and functional impairments may hamper one's ability to be a causal agent who creates and takes opportunities for need fulfillment (Fusinska-Korpik & Gacek, 2022; Shogren et al., 2017b; Wehmeyer, 2020a), associations between perceived autonomy support, BPN satisfaction, autonomous motivation, and well-being have been empirically demonstrated among persons with less severe intellectual disabilities (e.g., Behzadnia et al., 2022; Frielink et al., 2018). Regarding persons with the most complex support needs, Beadle-Brown et al. (2021) found positive associations between active (i.e., empowering) support and several quality-of-life domains. Thus, the relation between quality of support and quality of life may potentially be conceptualized in a self-determination framework for this latter group as well.

Skarsaune et al. (2021) argued for a relational understanding of the phenomenon of self-determination for persons with the most complex support needs. Self-determination would be facilitated in this population if others around the person look out for the many ways in which the person expresses desires, volition, and satisfaction, and are likewise aware that self-determination lies "not only in decisions about where to live or how to spend money, but also in ongoing processes of being understood—for instance, help with burping after eating or being met on the need for proximity" (Skarsaune et al., 2021: p. 324). Van Tuyll van Serooskerken et al. (2022) also explored what deeper meanings BPNs might have for persons with complex support needs through conversations with their primary relatives. Again, self-determination went beyond "making choices." While there appeared little to no self-awareness of one's abilities or actions (e.g., movements), gratification could occur when persons with complex support needs "just" did or experienced the things they liked. According to their relatives, BPNs could be found in both subtle, idiosyncratic proactive and reactive expressions of preferences regarding, for example, food, bedtime rituals, motor actions, and persons in the environment. In addition, support of BPNs resulted from complex interactions in which sensitive responsiveness was crucial.

Autonomy-supportive interactions imply intensive involvement of social partners, such as carers (Watson, 2012). A literature review by Hostyn and Maes (2009), for example, emphasized that high-quality interactions with parents and others (e.g., family members, healthcare professionals) would positively affect the quality of life of persons with complex support needs. However, providing helpful scientific insights to partners involved in their support is fraught with methodological challenges. This makes it difficult to assess support requirements for persons with extensive needs and evaluate support that may be given to carers (Kuld et al., 2023). Despite the risk for bias, one way to access inner experiences of persons with complex support needs in research and practice is to seek the perspectives of parents. Parents have a lifelong connection with their child and usually fulfill the role of crucial advocate for sharing knowledge about their child's needs with other involved parties (Kruithof et al, 2020). Mothers of children with complex support needs believed that their understanding of their children's needs added to what they believed that the perspectives of healthcare professionals were (Adams & Jahoda, 2019). The perspectives of parents on what their children may be thinking and feeling are thus valuable sources of information in their own right.

Taken together, the aim of the present study was to develop and test two questionnaires for parents of persons with complex support needs. One construct we sought to operationalize was parents' perceptions of autonomy-supportive experiences of their child with all key partners in the environment. The second construct regarded parents' perceptions of their children's signals reflecting BPNs. Both constructs were chosen because, according to SDT, autonomy support and signals of basic needs relate to quality of life and well-being but have not been studied in people with complex support needs. Currently available scales for mapping constructs related to self-determination are often designed on the basis of the concepts within causal agency theory (Vicente et al, 2020). However, these instruments seem less suitable for persons with extensive support needs as items assume higher cognitive functioning, like goal setting and having beliefs about achieving that goal. As a result, these instruments differentiate little between individuals (i.e., they all score low on all items) and yield little information other than the fact that persons with more severe intellectual disabilities show very limited self-determination capacity levels (Carter et al. 2009). Building on work on universal dimensions of autonomy support and BPNs, instrument development was based on existing instruments on both constructs, while informed by research into their meaning for parents (Van Tuyll van Serooskerken et al., 2022). We asked first what the most unambiguous and parsimonious internal structure was for each questionnaire within this sample. Second, we examined the internal consistencies of the found structures. Third, we examined evidence for construct validity by assessing conceptually related constructs (i.e., subjective well-being and quality of life of the person with complex support needs as perceived by the parent). The communication and influence domain of quality of life was chosen because of the conceptual overlap with self-determination which also underlies the constructs measured with both new questionnaires.

Method

Data resources and study participants

Participants were included when they were the parent of a person with complex support needs of at least 3 years old and spoke Dutch. If parents were not available, other relatives (e.g., family member or legal representative) could participate instead, but only if they were least 18 years old and fulfilled a long-term caring role in the person's life. Persons were considered to have complex support needs when they were diagnosed with severe or profound intellectual disabilities (i.e., IQ score < 35–40 points or a developmental age ≤ 5 years) in combination with additional disabilities such as motor, sensory, communication, and physical health problems (Nakken & Vlaskamp, 2007; Van Timmeren et al., 2017). Participants were asked about the complex support needs across domains, indicated by dependency on others for all aspects of care, health, and safety, prior to their participation (Maes et al., 2021). Mean age of persons with complex support needs was 21.47 (SD = 11.03 years), ranging from 3 to 55 years old. Other demographic information and additional characteristics of participants and persons with complex support needs is presented in Table 3.1.

Table 3.1 Demographic Information of Participants and Persons With Complex Support Needs

	n (%) [a]
Participant characteristics	
Gender	
Female	45 (71)
Male	17 (27)
Missing	1 (2)
Relationship to person with complex support needs	
Parent	59 (94)
Sibling	1 (2)
Legal representative	2 (3)
Missing	1 (2)
Education level (highest completed)	
Master's degree	18 (29)
Bachelor's degree	12 (19)
Vocational college	20 (32)
Secondary schoo	8 (13)
Missing	5 (8)
Migration background	
Non-immigrant	55 (87)
European immigration background	3 (5)
Non-European immigration background	1 (2)
Missing	4 (6)
Characteristics of persons with complex support needs	
Gender	
Male	29 (46)
Female	33 (52)
Missing	1 (2)
Age group	
Early childhood (< 6)	2 (3)
Middle childhood (6–12)	10 (16)
Adolescence (13–20)	20 (32)
Adult (≥ 21)	30 (48)
Missing	1 (2)
Living arrangement	
Family home (fully)	35 (56)
Family home (partially)	3 (5)
Adjacent to family home	2 (3)
Group home	22 (35)
Missing	1 (2)
Migration background	
Non-immigrant	60 (95)
Non-European immigration background	2 (3)
Missing	1 (2)

[a] Total *n* = 63 and rounding to integer percentages explains deviations from 100%.

Instrument development

The two new instruments were developed by six researchers from the field of child development who all had substantial work experience with persons with intellectual disabilities. One of the researchers is also a parent of a child with complex support needs. For each of the two key concepts (autonomy-supportive experiences and BPN signals), pre-existing measures were identified through literature search. Results of a qualitative study by Van Tuyll van Serooskerken et al. (2022) on primary relatives' perspectives about the meanings and support for the three BPNs in their family member with complex support needs guided the selection of base instruments and their further adaptation and expansion.

Parental perceptions on autonomy-supportive experiences.

The Perceptions of Parents Scale – College-Student Scale (POPS; Robbins, 1994) was used as a starting point for the development of the questionnaire on autonomy support for persons with complex support needs. This questionnaire was chosen because it operationalized domain-general autonomy support rather than domain-specific autonomy support, which regards support in domains in which persons with complex needs seldom participate (e.g., school, sports, paid work). Items were translated and adapted to suit parents reporting on the support they themselves provided as well as that of other caregivers closely involved (e.g., social workers) in their child's life. All items were therefore initially focused on the parent by starting with the phrase "To what extent do you notice that persons currently most involved in your child's environment …," with the instruction to answer the question from their child's perspective as much as possible. Example items that followed this phrase were "… involve him/her in matters that concern him/her?" or "… present him/her with suitable choices?" After leaving out 5 items that did not apply (e.g., "My mother/ father listens to my opinion or perspective when I've got a problem"), the 16 remaining adjusted items had to be rated on a 5-point Likert scale ranging from 1 (*not at all*) to 5 (*very much*). Because participants were not always parents, instruction was added to read "the person with complex support needs" if it said "my child" when applicable.

Parental perceptions on basic psychological need signals.

The initial aim was to adapt an existing questionnaire from the perspective of BPNT, in collaboration with experts (i.e., parents and professionals) in the field (n = 7), as a proxy version suitable for parents of persons with complex support needs. The Dutch Basic Psychological Need Satisfaction and Frustration Scale seemed most appropriate as it already was successfully adapted for self-report by persons with mild intellectual disability (BPNSFS-ID; Frielink et al., 2019). However, despite exhaustive modification attempts, it was impossible to create a meaningful version of the existing items that could potentially lead to variation within the target population. The experts did not perceive these aspects in their child or clients, but they did notice other things that they associated with the psychological basic needs (Van Tuyll van Serooskerken et al., 2022). Consequently, the approach changed towards generating new items within the dimensional space of the BPNSFS-ID (i.e., constructs related to satisfaction or frustration of autonomy, competence, and relatedness). Furthermore, the scope was changed to parents' perceptions about "reading" or noticing signals that they believe reflected BPNs, rather than trying to capture the actual experience of satisfaction or frustration of BPNs as experienced by the child, a task that according to the experts was virtually impossible.

During the generation process all items were continuously discussed and tested with the experts, based on which further adjustments were made. In total 36 new items were developed, six for each construct, which all had to be rated on a 5-point Likert scale ranging from 1 (*never*) to 5 (*always*). Subsequently, to optimize the number of items on relevance and burden for respondents, the draft questionnaire was subjected to item reduction. First, the distribution of item responses was inspected to check for variability within this target population. Because people with complex support needs are highly heterogeneous in their behaviors and expressions, variation in item responses were expected. Any item where more than 40% of participants answered "never" or "always" combined with less than 5% answering the other extreme was removed (i.e., 5 of 36 items, see Supplementary material, Table 3.A). These items were indicative of high skewness and kurtosis, and thus indicate low informational value. Second, participants' feedback on items was checked. An item was removed when at least two participants had substantial issues with it (e.g., it was not applicable or it was expressed differently than item described). This included further omitting 10 of 31 items. Third, item reduction was based on removing duplicate items. High inter-item correlations (r ≥ .50) along with high linguistic concurrence were therefore inspected (see Supplementary material, Table 3.B). To maintain a homogeneous set, the duplicate item that correlated least often above .30 with other items was removed. This included omitting item 7 (r = .78, with item 8), 10 (r = .54, with item 4), 12 (r = .61, with item 8), and 20 (r = -.50, with item 14). Finally, item 24 was the only item with no correlation above .30 and was therefore also removed, leaving 16 items for further analyses.

Measures for construct validity

Subjective well-being.

To test associations expected based on SDT, well-being as perceived by parents was assessed with the Dutch translation (Maes et al., 2016) of the Mood, Interest and Pleasure Questionnaire (MIPQ; Ross & Oliver, 2003). The questionnaire contains 23 items on a 5-point Likert scale ranging from 1 (*never*) to 5 (*always*). Each item had "not applicable" as additional response category. The total score reflected an overall indicator of positive mood. Specifically for persons with complex support needs, Petry et al. (2010) demonstrated evidence for construct validity, good internal consistency (i.e., Cronbach's alphas between 0.84 and 0.94), and good test-retest and inter-rater reliabilities (i.e., above 0.86 and 0.69 respectively) for the subscales and total scale. Reliability scores for the total subjective Well-Being scale in the current study was 0.88 (i.e., good).

Quality-of-life in the communication and influence domain.

Self-determination-related quality of life as perceived by parents was assessed using the Communication and Influence subscale of the Quality-of-Life of people with Profound Multiple Disabilities questionnaire (QOL-PMD; Petry et al., 2008). This 10-item subscale uses four response categories (i.e., agree, partly agree, disagree, and do not know). A higher score indicates better quality of life. A preliminary validation study of the overall QOL-PMD in persons with complex support needs showed promising construct validity and psychometric properties with a Cronbach's alpha of 0.82 and item-remainder correlation of 0.51 for family informants on the subscale Communication and Influence (Petry et al., 2009b). In the current study, the reliability score was 0.87 (i.e., good).

Procedures

Ethical approval was obtained from the Scientific and Ethical Review Committee of the Faculty of Behavioural and Movement Sciences, Vrije Universiteit Amsterdam, The Netherlands (registration number: VCWE-2019-047). Recruitment was done through social media, newsletters, website posts, and word-of-mouth by support staff of several Dutch care and client advocacy organizations that support persons with disabilities and their caregivers. When all inclusion criteria were met and the researchers received the consent form, a telephonic appointment was planned for the administration of the BPN Signals questionnaire and other questionnaires not included in the current study. Prior to this appointment, participants had to fill in a battery of measures online, including information on demographic, additional characteristics, and the Autonomy-Supportive Experiences, Well-Being, and Quality-of-Life questionnaires. Due to the outbreak of the COVID-19 pandemic, data collection was temporarily paused. On resumption of the study, burden for the final 15 participants was reduced by only letting them complete the Autonomy-Supportive experiences, BPN Signals, and Quality-of-Life questionnaires.

Analysis strategy

All data were analyzed using SPSS Statistics ((IBM Corp, 2020) Version 27). The first research question on the internal structure within this sample was answered using Principal Component Analyses (PCAs). The PCA method was chosen because it reduces the dimensionality of the data and is often used when the factor structure is unknown (Fokkema & Greiff, 2017). The first PCA for both questionnaires was done without rotation, after which the number of components (i.e., factors) was selected based on parsimonious descriptions given by eigenvalues above 1.00 or the scree plot point of inflexion (Cattell, 1966). All subsequent PCAs for solutions with more than one component were done with oblimin rotations and interpretability of components was assessed by strength of factor loadings. This process ended when the most unambiguous parsimonious solution had no more items loading below .30 on any component.

The second research question on the internal consistencies of components was answered by computing Cronbach's alpha. Specifically for a small sample size, internal consistency coefficients were considered sufficient (i.e., good or excellent) when these did not fall below 0.70 for scales with 6 or fewer items, below 0.75 for scales between 7 and 11 items, or below 0.80 for scales with 12 or more items (Ponterotto & Ruckdeschel, 2007).

The third research question on the construct validity of both new instruments was answered with bivariate correlation analysis, using Spearman's rho for ordinal variables. Missing data within the Well-Being and Quality-of-Life in the Communication and Influence Domain questionnaires were imputed as per the instrument manual (Maes et al., 2016; Petry et al., 2008). Bivariate correlations were computed for all found constructs of the two new questionnaires with the Well-Being and van Tuyll van Serooskerken et al. 7 Quality-of-Life questionnaires. Correlations above .20 were interpreted as supportive for construct validity (Swank & Mullen, 2017).

Results

I. Structure and validity of the Parental Perceptions on Autonomy-Supportive Experiences questionnaire

Missing data and data pre-treatment

In total, 61 of 63 participants completed this questionnaire. One participant stopped due to the COVID-19 pandemic, the other withdrew without giving a reason and could no longer be reached. Examination of item descriptives (see Supplementary material, Table 3.C) in the sample of completed questionnaires (16 items x 61 respondents = 976 values) showed a total of 2 (0.2%) missing item values. These two missing values were completely at random (MCAR), as these were the result of a computer error. In addition, the percentage of missing data was well below 5%, justifying a replacement of the missing values by the item average in further analyses (Eekhout et al., 2013).

Internal structure and internal consistency

A first PCA on the 16 items showed a large (.87) Kaiser–Meyer–Olkin (KMO; Kaiser, 1970) value for sampling adequacy and a significant ($\chi 2$ (120) = 622.16; $p < .001$) Bartlett's test of Sphericity, indicating that correlations between items were sufficiently large for the interpretation of robust factors (Bartlett, 1950). The PCA yielded a 4-factor solution explaining 73% of the total variance, with eigenvalues of 7.57 (47%), 1.79 (11%), 1.36 (8%), and 1.03 (6%) respectively. However, the single and clear point of inflexion on the scree plot at the second factor suggested a 1-factor solution. The pattern matrix further revealed that item 2 was the only item that barely loaded (.01) on the first component of the 4-factor solution. A second PCA without item 2 again yielded a 4-factor solution, now explaining 77% of the total variance, with eigenvalues of 7.57 (50%), 1.66 (11%), 1.29 (9%), and 1.01 (7%) respectively. The scree plot still showed a clear deflection of the line at the second factor. A final PCA with one component had 14 items loading above .40 and one (i.e., item 6) loading above .30. Given the sufficient percentage of explained variance, the 1-factor solution (see Table 3.2) was therefore selected as the most unambiguous and parsimonious solution. The internal consistency of the scale created on the basis of this component was .92 (excellent).

Construct validity

The association between Autonomy-Supportive Experiences and Well-Being was positive and statistically significant with Spearman's rho being .34 ($n = 41$; $p = .028$). The association with the communication and influence subscale of Quality-of-Life was not statistically significant ($n = 59$; Spearman's rho = .16, $p = .22$).

Table 3.2 Final Pattern Matrix After Principal Component Analysis of the Parental Perceptions on Autonomy-Supportive Experiences Questionnaire

Item [a]		**Component loading**
		1
Component 1		
8.	Put energy into helping	**.87**
7.	Feel engaged	**.83**
11.	Accept the person	**.82**
10.	Understand needs	**.81**
12.	Show their love	**.80**
1.	Help satisfy needs	**.77**
15.	Are happy to see person	**.74**
16. (R)	Are disappointed in person	**.73**
13.	Make person feel special	**.70**
3.	Make time	**.69**
9.	Present proper choices	**.65**
4.	Let person choose	**.63**
14. (R)	Disapprove of person	**.62**
5.	Involve with issues concerning person	**.49**
6. (R)	Are too busy	.31

Note. Factor loadings above .40 are in bold. Reversed-scored items are denoted with (R).
[a] Items listed above are translated abbreviations from the ones that were used.

II. Structure and validity of the parental perceptions on basic psychological need signals questionnaire

Missing data and data pre-treatment

In total, 58 of 63 participants completed the BPN Signals questionnaire. One participant dropped out due to personal reasons unrelated to the study, two withdrew because of the COVID-19 pandemic, and the other two withdrew without giving a reason and could no longer be reached. Examination of item descriptives (see Supplementary material, Table 3.D) of the 16 items (i.e., 16 x 58 = 928 values) indicated a total of 2 (0.22%) missing item values. Further analyses were done with imputed values for these two missing values (Eekhout et al., 2015).

Internal structure and internal consistency

The first PCA on the 16 items showed a good (.78) KMO and significant ($\chi 2$ (120) = 423.63; $p < .001$) Bartlett's test of Sphericity for robust factors. This

PCA yielded a 4-factor solution that explained 67% of the total variance, and indicated eigenvalues of 5.79 (36%), 2.59 (16%), 1.31 (8%), and 1.03 (6%), respectively. However, the scree plot showed a clear point of inflexion at the third factor whereas all items loaded above .40 on either the first or second component, suggesting a 2-factor solution. Therefore, a second PCA with an oblique rotated 2-factor solution was performed. The pattern matrix (see Table 3.3) showed that there were two items with a second loading above .40 and three items with a second loading between .30 and .40, of which all but one were in the opposite direction. Also, there was a distinct split of the items. Eight of the 10 items in the first component focused on the extent to which participants could observe signals that reflected autonomy. The other two items (i.e., 17 and 30) were initially designed to capture the perception of signals indicating competence and relatedness, respectively. However, items 17 and 30 loaded on both the first and second component. The six items in the second component all focused on the extent to which participants could observe signals that reflected either competence or relatedness. One of these items (i.e., 33) loaded on both components as well as in the opposite direction of the other items on the second component. Due to the small sample size it was decided, for now, to not remove the items that had notable loadings on both components. The correlation between the two components was weak (r = -.20). This final 2-factor solution explained 52% of the total variance with eigenvalues of 5.79 (36%) and 2.59 (16%), respectively. Internal consistency of the two subscales created on the basis of the two components were .87 (excellent) and .78 (excellent), respectively.

Construct validity

The associations between the two BPN Signals subscales and both Well-Being and Quality of Life were all statistically significant. The subscale interpreted as Noticing Signals of Autonomy correlated moderately with Well-Being (n = 37; Spearman's rho = 0.36, p = .030) and strongly with Quality-of-Life (n = 54; Spearman's rho = 0.64, p < .001). The subscale interpreted as Noticing Signals of Competence/Relatedness correlated strongly with Well-Being (n = 37; Spearman's rho = 0.55, p < .001) and moderately with Quality of Life (n = 54; Spearman's rho = 0.32, p = .018).

Table 3.3 Final Pattern Matrix After Principal Component Analysis of the Parental Perceptions on Basic Psychological Need Signals Questionnaire

Item [a]		Component loading	
		1	2
Component 1: Noticing Signals of Autonomy			
4.	Signals things one does not want	**.81**	.13
8.	Signals not getting what one wants	**.76**	-.06
11.	Signals desire to determine more for oneself	**.75**	-.12
3.	Signals things one wants	**.72**	.09
9.	Signals undergoing things one does not want	**.64**	.09
5.	Chooses from options offered	**.62**	-.32
2.	Signals things one dislikes	**.60**	.20
1.	Signals things one likes	**.50**	-.31
17.	Signals capabilities	**.48**	-.43
30.	Signals for more attention	**.43**	-.34
Component 2: Noticing Signals of Competence/Relatedness			
15.	Enjoys new things or activities	-.21	**-.81**
14.	Gets pleasure from capabilities	.23	**-.78**
29 .	Distinguishes between people	-.00	**-.69**
13 .	Enjoys things one does	.24	**-.68**
33.	Signals reluctance towards closeness or comfort	.50	**.59**
28.	Feels comfortable around animals or things	.29	**-.57**

Note. Factor loadings above .40 are in bold.
[a] Items listed above are translated abbreviations from the ones that were used.

Discussion

In this study, two parent-informant questionnaires were developed, one about autonomy-supportive experiences by their child with complex support needs and one about noticing signals that reflect BPNs in this target population. Regarding the first research question, the most unambiguous and parsimonious structure for the 15 remaining items of the Autonomy-Supportive Experiences questionnaire was a one-dimensional model. Although the autonomy-supportive experiences items were derived from the three subscales of the POPS questionnaire (i.e., Autonomy Support, Involvement, Warmth), these subscales could not be distinguished as separate factors in the PCA. Setting aside the limited sample size, the limited set of items that were deemed applicable and the extent of their revisions may have obscured finer nuances in ways in which carers may support autonomy in persons with complex support needs. It may also indicate that the various aspects of autonomy support are highly integrated in interactions with persons with more complex support needs. This corresponds to the complex process of understanding and supporting the needs of people with complex support needs as described by Van Tuyll van Serooskerken et al. (2022). However, without directly testing the variance in the structure of the new Autonomy-Supportive experiences questionnaire across populations, this remains speculative.

The 16 remaining items of the BPN Signals questionnaire fell alongside two dimensions. One component reflected noticing signals of autonomy and the other reflected noticing signals of both competence and relatedness. These components encompassed the extent to which caregivers noticed need expressions (e.g., signals things one wants), manifestations of need-related behaviours (e.g., chooses from options offered), and expressions of need satisfaction (e.g., enjoys things one does). However, this degree of at least noticing needs and need fulfillment is a necessary but not sufficient condition to actually guarantee effective support and satisfaction of BPNs.

Because virtually no frustration-related items of competence and relatedness resulted from the item construction and social validation stage, those constructs also did not emerge in the final item set. Negative affective states in persons with complex care needs have been found to be expressed in a more diffuse and sometimes paradoxical way compared to positive states and to people without disabilities (Vos et al., 2013a; Vos et al., 2013b). This aligns with the difficulties we encountered when attempting to create a proxy questionnaire based on the BPNSFS-ID (Frielink et al., 2019). It must be noted, also, that the validity of the basic psychological needs frustration scale has recently come under scrutiny and may need to be reconceptualized (Murphy et al., 2023). Yet, due to the small sample size, the results should be interpreted with caution. Conclusions about the structure found therefore only concern this sample for the time being. Nevertheless, being able to detect and interpret BPN signals of persons with complex support needs is an important step in creating effective possibilities for self-determination (Van Tuyll van Serooskerken et al., 2022).

The internal consistency coefficients for the Autonomy-Supportive Experiences questionnaire and the BPN Signals questionnaire were considered sufficient as the lowest alpha was 0.78. Furthermore, the medium to large correlations between the two questionnaires and Well-Being and Quality of Life are a first indication of construct validity and applicability of the BPNT and SDT in persons with complex support needs (Deci & Ryan, 2000; Soenens et al., 2007), and point to their potential contribution to understanding the mechanisms that link self-determination to quality of life (Mumbardo-Adam et al., 2023). The strong correlation between the factor interpreted as Noticing Signals of Autonomy and self-determination-related quality-of-life might indicate that parents' attentiveness towards signs of, for example, preferences and volition is related to the ability of persons with complex support needs to influence their environment (Mumbardo-Adam et al., 2023). The strong correlation between the factor interpreted as Noticing Signals of Competence/ Relatedness and well-being might indicate that parents' attentiveness towards signals of, for example, experiencing activities and comfort with regard to others is related to the positive mood of persons with complex support needs. An unexpected finding was the absence of a statistically significant association between autonomy-supportive experiences and self-determination-related quality of life, which is often found in typically developing persons (Ryan et al., 2008). A possible explanation for this absence might be that there is no direct but indirect relationship between the two concepts. Frielink et al. (2018), for example, showed that the link between autonomy support and health-related quality of life was mediated by BPN satisfaction. Another explanation might be that because the Autonomy-Supportive Experiences questionnaire does not distinguish between different aspects of autonomy support, associations with the more specific concept of Communication and Influence domain of quality of life may have been attenuated. It is also possible that the association between autonomy support and self-determination-related quality of life manifests itself differently within this target group compared to persons without (severe) disabilities. Further research is warranted into the association between autonomy-supportive experiences and other Quality of Life domains such as personal development, activities, social relationships, physical health, and material well-being (Flanagan, 1978; Petry et al., 2009a).

Limitations and future research

In line with other research on this population (Maes et al., 2021), given the low prevalence and the demands of their time which were compounded by the COVID pandemic, the sample size was small for factor analytic work. While any factor analytic work requires cross-validation, solutions based on small samples may need to be considered extra carefully and might not reveal finer nuances in the conceptual space covered by these instruments.

Options to increase sample sizes for studies such as the current one include collaborating with relatives in the initiation of research and building of research infrastructure. This may take the form of registries where parents voluntarily enroll for scientific research (e.g., Conners et al., 2014). Another option is to increase national and international coordination and collaboration, for example, using harmonized measures or minimal datasets and by asking participants for permission to share their data with other researchers (Maes et al., 2021; Ras et al., 2020).

Response set such as social desirability bias (Paulhus, 2002; 2017) may also act as a confounder. Although Autonomy-Supportive Experiences items concerned the support from all key partners in the environment, the extent of the participants' own role was not clear. It is possible that participants who mainly related the items to themselves filled out the questionnaire differently than participants who included other key partners in their evaluation.

An important limitation is that parents' perceptions cannot be equated with the thoughts and experiences of the persons with complex support needs themselves. Although Embregts et al. (2019) showed that family members were able to differentiate between their own perspectives and that of the person with complex support needs, Olsman et al. (2021) argued that key individuals in the environment of persons with complex support needs are not assessors but witnesses who, when they share experiences and knowledge about the person, should constantly remain critical and receptive.

Conclusion and implications for practice

In the current study, two questionnaires were developed and tested to measure parent-perceived autonomy-supportive experiences and BPN signals in persons with complex support needs. Both questionnaires appeared internally consistent and showed the expected associations with other constructs in the nomological network around self-determination. Although further research is needed, the development and preliminary evaluation of these questionnaires is a first step in understanding the processes of autonomy support and BPN satisfaction, which may ultimately increase the understanding of self-determination in this group (Kuld et al., 2023; Mumbardo-Adam et al., 2023). In addition to the potential empirical value of psychometric tools, questionnaires aimed at parents and other caregivers may also contribute to the introspection and reflective skills of the informant, which might indirectly benefit the person of interest. Subsequently, the questionnaires could contribute to a shared frame of reference between parents and healthcare professionals if these also prove to be valid for support staff. In turn, a shared frame of reference will ensure that their support from both sides becomes complementary and more effective. Ultimately, this will improve the quality of life of individuals with complex support needs.

Supplementary material

Table 3.A Distribution of Item Responses on Parental Perceptions on Basic Psychological Need Signals Questionnaire

Item[a]	% Never	% Always
Autonomy items		
1. Signals things one likes	0	25.9
2. Signals things one dislikes	0	29.3
3. Signals things one wants	8.6	13.8
4. Signals things one does not want	3.4	19
5. Chooses from options offered	15.5	22.4
6. Enjoys to define things	24.1	19
7. Signals not getting pleasurable things	20.7	10.3
8. Signals not getting what one wants	20.7	13.8
9. Signals undergoing things one does not want	3.4	32.8
10. Signals dissatisfaction with what is offered	12.1	8.6
11. Signals desire to determine more for oneself	34.5	6.9
12. Signals frustration when not being understood	20.7	17.2
Competence items		
13. Enjoys things one does	3.4	20.7
14. Gets pleasure from capabilities	3.4	25.9
15. Enjoys new things or activities	10.3	5.2
16. Enjoys own growth and development	32.8	13.8
17. Signals capabilities	39.7	22.4
18. Signals desire to learn new things	**48.3**	**3.4**
19. Enjoys little of things one does	22.4	0
20. Gets little pleasure from capabilities	25.9	3.4
21. Withdraws in response to new things or activities	19	6.9
22. Signals frustration when something does not work out	24.1	12.1
23. Would like to be able to do or learn more	31	8.6
24. Withdraws when one is not challenged	31	10.3
Relatedness items		
25. Enjoys attention	**3.4**	**46.6**
26. Enjoys social interaction	**3.4**	**41.4**
27. Finds comfort in others	10.3	17.2
28. Feels comfortable around animals or things	22.4	17.2
29. Distinguishes between people	6.9	36.2
30. Signals for more attention	8.6	36.2
31. Enjoys the closeness of others little	31	3.4
32. Takes little pleasure from social interaction	32.8	1.7
33. Rejects proximity or comfort	34.5	3.4
34. Signals anger or sadness when one is alone	**41.4**	**1.7**
35. Signals anger or sadness when one misses people, animals, or things	39.7	3.4
36. Signals anger when one does not get attention	**43.1**	**3.4**

Note. Items in bold represent items with too low variability.
[a] Items listed above are translated abbreviations from the ones that were used.

Table 3.B Inter-item Correlations for Parental Perceptions on Basic Psychological Need Signals Questionnaire

Item[a]	1	2	3	4	5	7	8	9
1. Signals things one likes	-	.59**	.35**	.27*	.38**	.24	.33*	.23
2. Signals things one dislikes	-	-	.21	.47**	.22	.14	.25	.31*
3. Signals things one wants	-	-	-	.48**	.50**	.46**	.60**	.35**
4. Signals things one does not want	-	-	-	-	.56**	.34**	.47**	.34**
5. Chooses from options offered	-	-	-	-	-	.48**	.53**	.22
7. Signals not getting pleasurable things	-	-	-	-	-	-	.78**	.25
8. Signals not getting what one wants	-	-	-	-	-	-	-	.42**
9. Signals undergoing things one does not want	-	-	-	-	-	-	-	-
10. Signals dissatisfaction with what is offered	-	-	-	-	-	-	-	-
11. Signals desire to determine more for oneself	-	-	-	-	-	-	-	-
12. Signals frustration when not being understood	-	-	-	-	-	-	-	-
13. Enjoys things one does	-	-	-	-	-	-	-	-
14. Gets pleasure from capabilities	-	-	-	-	-	-	-	-
15. Enjoys new things or activities	-	-	-	-	-	-	-	-
17. Signals capabilities	-	-	-	-	-	-	-	-
20. Gets little pleasure from capabilities	-	-	-	-	-	-	-	-
24. Withdraws when one is not challenged	-	-	-	-	-	-	-	-
28. Feels comfortable around animals or things	-	-	-	-	-	-	-	-
29. Distinguishes between people	-	-	-	-	-	-	-	-
30. Signals for more attention	-	-	-	-	-	-	-	-
33. Rejects proximity or comfort	-	-	-	-	-	-	-	-

[a] Items listed above are translated abbreviations from the ones that were used.
* $p < .05$. ** $p < .01$.

10	11	12	13	14	15	17	20	24	28	29	30	33
.26*	.41**	.10	.47**	.34**	.18	.31*	-.37**	.04	.48**	.38**	.35**	-.01
.48**	.29*	.33*	.13	-.05	-.18	.12	-.01	.01	.23	.10	.27*	.16
.40**	.54**	.23	.24	.30*	.03	.38**	-.16	.29*	.22	.05	.34**	-.01
.54**	.55**	.55**	.25	.14	-.19*	.38**	-.08	.08	.31*	.04	.09	.31*
.39**	.56**	.42**	.41**	.39**	.16	.57**	-.18	.09	.33*	.22	.26*	.07
.30*	.56**	.49**	.10	.30*	.14	.44**	-.14	.16	.15	.20	.55**	.05
.52**	.57**	.61**	.12	.22	.14	.42**	-.08	.16	.30*	.16	.41**	.21
.48**	.47**	.39**	.18	.21	-.05	.19	-.18	.03	.22	.09	.35**	.26*
-	.47**	.49**	.12	.12	.03	.24	-.06	.28	.19	.11	.22	.27*
-	-	.37**	.28*	.39**	.12	.59**	-.27*	.22	.36**	.19	.38**	.12
-	-	-	.03	-.01	-.06	.30*	.15	-.03	.08	.23	.30*	.42**
-	-	-	-	.58**	.36**	.22	-.56**	.04	.49**	.41**	.17	-.19
-	-	-	-	-	.56**	.51**	-.50**	.16	.46**	.42**	.31*	-.25
-	-	-	-	-	-	.26	-.30*	.15	.41**	.39**	.03	-.31*
-	-	-	-	-	-	-	-.25	.23	.46**	.36**	.35**	-.02
-	-	-	-	-	-	-	-	.03	-.42**	-.57**	-.34**	.39**
-	-	-	-	-	-	-	-	-	.03	-.07	-.06	-.06
-	-	-	-	-	-	-	-	-	-	.33*	.24	-.14
-	-	-	-	-	-	-	-	-	-	-	.43**	-.16
-	-	-	-	-	-	-	-	-	-	-	-	-.20
-	-	-	-	-	-	-	-	-	-	-	-	.

Table 3.C Means, Standard Deviations, Range, and Missing Values for the Parental Perception on Autonomy-Supportive Experiences Questionnaire Items

Item [a]		M (SD)	Min. – Max. (1–5)	Missing values
1.	Help satisfy needs	4.00 (.78)	(2–5)	-
2. (R)	Not take person's wishes into account	2.87 (1.14)	(1–5)	1
3.	Make time	3.64 (1.05)	(1–5)	-
4.	Let person choose	2.25 (.87)	(2–5)	-
5.	Involve with issues concerning person	3.31 (1.12)	(1–5)	-
6. (R)	Are too busy	2.77 (1.16)	(1–5)	-
7.	Feel engaged	4.16 (.86)	(2–5)	-
8.	Put energy into helping	3.89 (.99)	(1–5)	-
9.	Present proper choices	3.48 (.92)	(1–5)	-
10.	Understand needs	3.77 (.82)	(1–5)	-
11.	Accept the person	4.28 (.80)	(2–5)	-
12.	Show their love	4.30 (.76)	(2–5)	-
13.	Make person feel special	4.08 (.78)	(2–5)	-
14. (R)	Disapprove of person	4.20 (.96)	(1–5)	-
15.	Are happy to see person	4.13 (.83)	(1–5)	1
16. (R)	Are disappointed in person	4.34 (.75)	(3–5)	-

Note. Reversed-scored items are denoted with (R).
[a] Items listed above are translated abbreviations from the ones that were used.

Table 3.D Means, Standard Deviations, Range, and Missing Values for the Psychological Need Signals Questionnaire Items

Item [a]		M (SD)	Min. – Max. (1–5)	Missing values
1.	Signals things one likes	3.97 (.75)	(3–5)	-
2.	Signals things one dislikes	3.98 (.78)	(3–5)	-
3.	Signals things one wants	3.47 (1.06)	(1–5)	-
4.	Signals things one does not want	3.71 (.94)	(1–5)	-
5.	Chooses from options offered	3.41 (1.35)	(1–5)	-
8.	Signals not getting what one wants	3.05 (1.32)	(1–5)	-
9.	Signals undergoing things one does not want	3.88 (1.06)	(1–5)	-
11.	Signals desire to determine more for oneself	2.50 (1.32)	(1–5)	-
13.	Enjoys things one does	3.90 (.87)	(1–5)	-
14.	Gets pleasure from capabilities	3.79 (1.00)	(1–5)	1
15.	Enjoys new things or activities	3.04 (1.05)	(1–5)	1
17.	Signals capabilities	2.33 (1.22)	(1–5)	-
28.	Feels comfortable around animals or things	3.14 (1.42)	(1–5)	-
29.	Distinguishes between people	3.98 (1.11)	(1–5)	-
30.	Signals for more attention	3.67 (1.33)	(1–5)	-
33.	Signals reluctance towards closeness or comfort	2.22 (1.11)	(1–5)	-

[a] Items listed above are translated abbreviations from the ones that were used.

Chapter 4

Change in self-determination-related constructs in persons with severe or profound intellectual and multiple disabilities in the context of transitions

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Abstract

Background. This study explored the changes in self-determination-related constructs during transitions in the lives of persons with severe or profound intellectual and multiple disabilities.

Method. Questionnaires about autonomy support, basic psychological need expressions, and subjective well-being were filled out twice by family caregivers who foresaw an important transition in the near future (N = 40; pre-post design).

Results. Average changes in outcomes across a period of 6–13 months were not statistically significant. Reliable change was observed for 5.6 to 24% of individuals, depending on the outcome variable. Caregiver engagement in and period of impact of the transition, as well as prior expectations, were not associated with these changes.

Conclusion. Self-determination-related constructs appear robust against life transitions for most persons with complex support needs. From the caregivers' perspective, improvements and deteriorations were unexpected, underscoring the need for a better understanding of the role of context for self-determination in this population.

Introduction

Acting volitionally according to one's own desires (i.e., self-determination) contributes to subjective well-being and quality of life (Deci & Ryan, 2000; Ryan & Deci, 2000b). Self-determination is thought to go along with satisfaction of three universal and innate basic psychological needs (BPNs), namely autonomy, competence, and relatedness (Deci & Ryan, 2000) including in persons with mild intellectual disabilities (Frielink et al., 2018). Life transitions may sometimes create new opportunities for supporting and achieving self-determination, but may also make it harder (Audet et al., 2021; Kins et al., 2009; Oliveira et al., 2014). Normative life transitions, for example, foster self-determination and quality of life in neurotypical children (e.g., Gillison et al., 2008). In social and health sciences, transition is a psychological process of adapting to change that involves an inner reorientation with distinct phases (Bridges, 2004). Transitions denote both shifts from one developmental stage to another and events that mark changes or disruptions in physical or mental health, education, work, daytime activities, finances, housing, relationships, or social circumstances (Kralik et al., 2006). The current longitudinal study aimed to explore how transitions may go along with changes in self-determination in persons with severe or profound intellectual and multiple disabilities and what role caregivers play during such transitions.

Individuals diagnosed with severe or profound intellectual and multiple disabilities experience comprehensive cognitive impairments that are accompanied by serious motor, sensory, communicative, and other health problems (van der Putten et al., 2017; van Timmeren et al., 2017). Consequently, they rely on extensive assistance from other people for daily functioning (Nakken & Vlaskamp, 2007). Given the focus of this study on the friction between this dependency and support for autonomy, we refer to this population as having complex support needs. People with intellectual and physical disabilities generally require significant accommodation to experience autonomy (Wehmeyer & Shogren, 2016; Wehmeyer & Shogren, 2017). From a self-determination theory (SDT; Deci & Ryan, 2000) perspective, autonomy support includes acknowledging and respecting one's perspectives, feelings, and choices. Additionally, it entails creating a climate rich in encouragement, empathy, and provision of practical information, while remaining free of coercion (Reeve, 2002; Ryan et al., 2015; Soenens et al., 2007). Transitions may offer persons with complex support needs new possibilities to reorganize life according to one's wishes and desires. For example, transitioning from living with parents to moving into a group home may stimulate the development of new competencies, such as engaging with peers. However, Bigby et al. (2011) and Taylor et al. (2019) emphasized that successful outcomes of transitions largely depend on the adequacy of support. For instance, autonomy-supportive interventions for adolescents with intellectual or other disabilities in transition planning improved self-determination and quality of life compared to control groups (Nadig et al., 2018; Seong et al., 2015; Wehmeyer et al., 2011b). It is therefore important to also explore how autonomy support during transitions may foster self-determination for persons with complex support needs.

Persons with complex support needs communicate their needs in idiosyncratic, unconventional, and pre-symbolic ways. Their methods may vary across physical contexts or interaction partners and are often delayed or reactive (Dhondt et al., 2021; Dhondt et al., 2023; van Tuyll van Serooskerken et al., 2022). Self-determination and autonomy support may result from socially mediated meaning-making, in which every effort is made to elicit, pick up, understand, and fulfill the person's need expressions (Skarsaune et al., 2021; Skarsaune et al., 2023; van Tuyll van Serooskerken et al., 2022). Parents play a key role because of their unique and experiential knowledge through the lifelong and intensive connection with their child with complex support needs (de Geeter et al., 2002; Kruithof et al., 2020). Beyond parents, an autonomy-supportive context is fostered by other social partners involved in the care and upbringing, including other family members and healthcare professionals (Hostyn & Maes, 2009).

The outcomes of transitions may depend not only on support but also on the nature of the transition itself. Meleis et al. (2000) identified, among others, engagement in the transition process, temporal aspects, and expectations and attributions regarding the transition. Regarding engagement in children from the general population, for instance, a positive association was found between student involvement in transition planning and self-determination (Williams-Diehm et al., 2008). The impact of a transition can further vary depending on when it was completed. A recent transition may have different consequences than one completed some time ago, which may have allowed the effects on daily life time to develop for longer. Additionally, teachers' expectations for students without disabilities have been linked to self-determination-related outcomes, such as student motivation and engagement (Hornstra et al., 2018). Outcomes of transitions may differ according to the possibilities that people involved see for achieving self-determination, which does not necessarily align with why a transition occurs (i.e., a blessing in disguise). Together, these perceived transition characteristics may shed light on changes in self-determination in persons with complex support needs.

Following SDT, this study focused on environmental autonomy support, BPN expressions, and subjective well-being as core constructs experienced by people with complex support needs according to their parents (Ryan & Deci, 2000b; Lachapelle et al., 2005; Wehmeyer, 2020b). The following research questions were formulated: I. To what extent did changes occur in a) the autonomy support for persons with complex support needs received from all key partners involved, b) the persons' BPN expressions, and c) the persons' subjective well-being, within the context of a relevant life transition (see Figure 4.1)? II. To what extent were the changes over time in these three self-determination-related concepts interrelated (see Figure 4.2)? III. To what extent were caregivers' prior expectations of the impact of the transition on a) possibilities for BPN support and b) the persons' BPN Expressions related to actual changes in BPN expressions (see Figure 4.3)? And IV. To what extent were a) the degree of "Caregiver engagement" in working towards the transition and b) the "Period of impact" after transition completion, associated with actual changes in the three self-determination-related concepts (see Figure 4.4)?

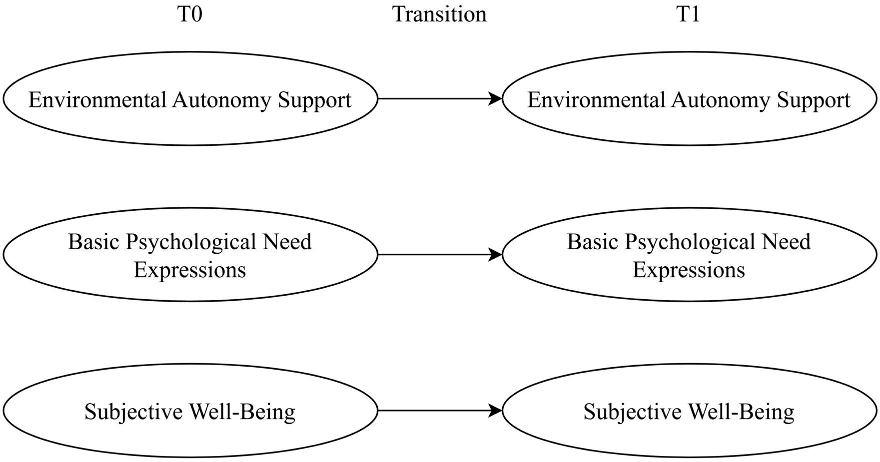

Figure 4.1. Research question 1. To what extent did changes occur in self-determination-related concepts, within the context of a relevant life transition (visual representation)?

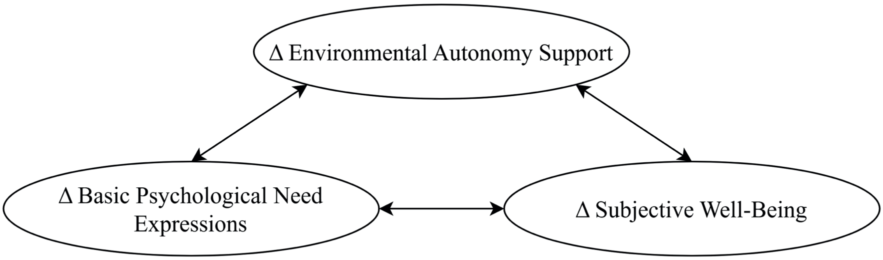

Figure 4.2. Research question 2. To what extent were the changes in self-determination-related concepts interrelated (visual representation)?

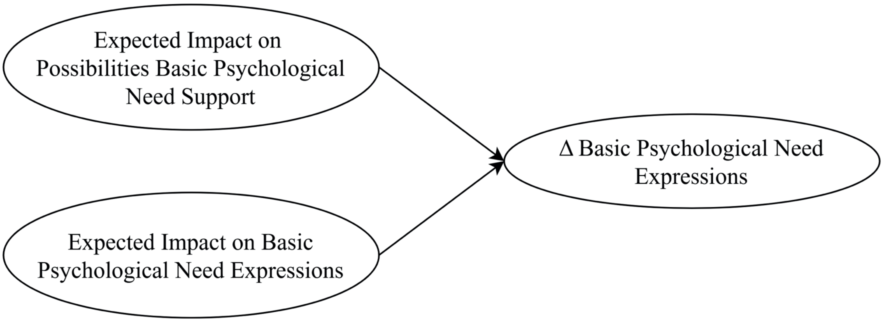

Figure 4.3. Research question 3. To what extent were caregiver expectations prior to the transition (i.e., transition characteristics) related to actual changes in BPN expressions (visual representation)?

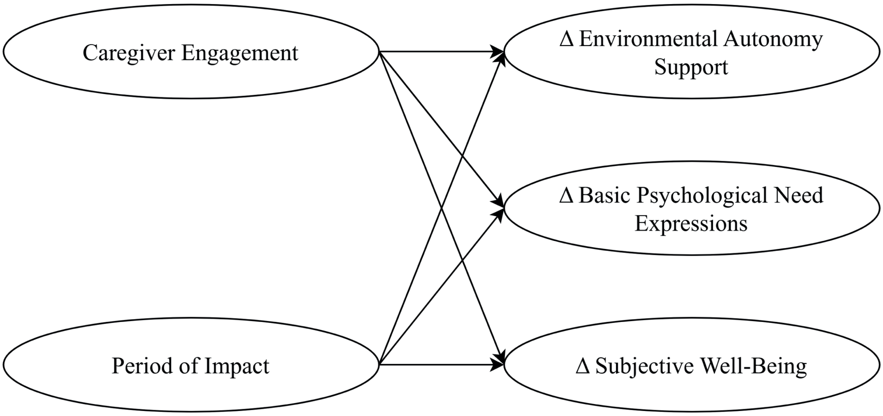

Figure 4.4. Research question 4. To what extent were caregiver engagement and period of impact (i.e., transition characteristics) associated with changes in self-determination-related concepts (visual representation)?

Method

Sample

Based on the severe impairments in various domains, subjective experiences of persons with complex support needs often need to be collected indirectly by asking closely involved caregivers to share their intimate knowledge about the person (Maes et al., 2021; Nieuwenhuijse et al., 2023). Participants were Dutch-speaking parents of a person with complex support needs of at least 3 years old. Other relatives (e.g., family members or legal representatives) of at least 18 years old who played an active role in the person's life could also participate when parents were not available. Participants were eligible when they expected a life transition in their child's life, such as the living situation, care and support, education, or daytime activities, within the next 12 months (see Table 4.1 for an overview). Persons were considered to have complex support needs when they were diagnosed with severe or profound intellectual disability (i.e., IQ score < 35–40 points or a developmental age ≤ 5 years) in combination with additional disabilities such as motor, sensory, communication, and physical health problems (van Timmeren et al., 2017; Nakken & Vlaskamp, 2007). To check if inclusion criteria were met, participants were asked

Table 4.1 Information About Expected Transition (N = 40)

	N (%)
Transition categories	
Care and support	14 (35.0)
Living and sleeping situation	11 (27.5)
Education and work[a]	6 (15)
Leisure and daytime activities	2 (5.0)
Family and upbringing	2 (5.0)
Relationships and sexuality	1 (2.5)
Own finances	1 (2.5)
Other	3 (7.5)
Expected transition occurred at T1	
Yes	21 (52.5)
No	15 (37.5)
Takes place at the moment/will take place in the near future	14 (35.0)
Will no longer take place	1 (2.5)
Missing	4 (10.0)

[a] By work we mean special day service centers that resemble school or work tasks to accommodate and stimulate the possibilities of persons with disabilities.

about complex support needs, indicating dependency on others for all aspects of physical care, health, and safety (Maes et al., 2021). A total of 85 participants registered, of which 8 participants did not meet inclusion criteria and 30 did not respond to contact attempts or eventually did not have time to participate. After 10 months of recruitment, the Netherlands took extensive measures against COVID-19 that severely impacted the daily lives of persons with complex support needs. Recruitment was first paused and then stopped as pre-COVID-19 care and support resumption remained unclear in the foreseeable term (Embregts et al., 2021). Therefore, 47 participants started the study. Three participants dropped out during baseline measurement (T0): two without giving a reason and one due to personal circumstances. Their data were removed from further analyses. For four participants, COVID-19 started halfway through collecting T0 measures, their participation was therefore ceased and data collected up to that point was also removed from further analyses. The final dataset at T0 included 40 participants. At T1, four participants dropped out, one of whom stopped responding, one due to time constraints, and two due to personal circumstances. Mean age of persons with complex support needs was 22.32 years (*SD* = 12.26), ranging from 5 to 55 years old. Table 4.2 provides demographics and additional characteristics of participants and persons with complex support needs.

Table 4.2 Demographic Information of Participants and Persons with Complex Support Needs (N = 40)

	N (%)
Participant characteristics	
Gender	
Female	29 (72.5)
Male	11 (27.5)
Relationship to person with complex support needs	
Parent	37 (92.5)
Sibling	1 (2.5)
Legal representative	2 (5.0)
Education level (highest completed)	
Master's degree	12 (30.0)
Bachelor's degree	7 (17.5)
Vocational school	13 (32.5)
Secondary education	5 (12.5)
Missing	3 (7.5)
Migration background	
Non-immigrant	34 (85.0)
European immigration background	3 (7.5)
Non-European immigration background	-
Missing	3 (7.5)
Characteristics of persons with complex support needs	
Gender	
Male	18 (45.0)
Female	22 (55.0)
Years of age	
Early childhood (< 6)	1 (2.5)
Middle childhood (6–12)	8 (20.0)
Adolescence (13–20)	10 (25.0)
Adult (≥ 21)	21 (52.5)
Living arrangement	
Family home (fully)	21 (52.5)
Family home (partially)	4 (10.0)
Adjacent to family home	1 (2.5)
Group home	14 (35.0)
Migration background	
Non-immigrant	39 (97.5)
Non-European immigration background	1 (2.5)

Procedures

Recruitment was done through a variety of methods, using social media, newsletters, website posts, and word-of-mouth by support staff of several Dutch care and client advocacy organizations. Participants gave written consent before participation. Two measurement waves were planned for assessing independent, dependent, and background variables. T0 took place right after inclusion and thus prior to the expected transition in the life of the person with complex support needs. The second measurement (i.e., T1) took place around 6 months after T0 (*M* = 7.04, min = 4.91, max = 13.39 months, of which all measurements with more than 8 months apart were caused by the onset of COVID-19 in between). This period was chosen to create variability in characteristics of the transition in terms of caregiver engagement and period of impact. The same participant completed T0 and T1. An online questionnaire included questionnaires on perceived environmental autonomy support and subjective well-being of persons with complex support needs. A phone interview covered their BPN expressions and transition characteristics. When approximately half of the participants had completed the full study (*n* = 25) and the other half had only completed T0 (*n* = 15), data collection was put on hold for approximately 4.5 months due to the start of COVID-19. Upon restarting, the questionnaires were adapted to reflect and assess the impact of the pandemic on the care situation as well (e.g., Embregts et al., 2021). For 14 out of 15 persons with complex support needs, the living situation did not change due to the onset of COVID-19. One person had moved from sheltered care to living with the caregiver during the lockdown period. Five out of 15 participants saw their child as often during the pandemic as before, two participants saw their child more during, and eight participants were temporarily unable to see their child due to the lockdown measures, this period ranged between 4 weeks to 3.5 months. At the restart of T1, these eight latter participants had seen their child again for at least 1 month. Ethical approval was obtained from the Scientific and Ethical Review Committee of the Faculty of Behavioral and Movement Sciences, Vrije Universiteit Amsterdam, The Netherlands (registration number: VCWE-2019-047). For the COVID-19-related adjustments, an amendment was granted.

Materials

Environmental autonomy support.

Autonomy support was measured with a questionnaire developed and preliminary validated for this target group (van Tuyll van Serooskerken et al., 2024). The basis for this questionnaire was the Perceptions of Parents Scale – College-Student Scale (POPS; Robbins, 1994). The translated and adapted version contains 15 items designed to assess environmental autonomy support for persons with complex support needs, from all key people currently involved in their lives (e.g., parents, relatives, and support staff). Each item starts with "To what extent do you see that important people in your child's environment …" and is followed by, for example, "… understand his/her feelings?" or "… have enough time for him/her?" Participants rated each item on a Likert scale that ranged from 1 (*absolutely disagree*) to 5 (*absolutely agree*). Participants were instructed to answer the question from their child's perspective as much as possible. After reversing the negatively phrased statements, a higher total score reflected higher autonomy support from the environment. Van Tuyll van Serooskerken et al., (2024) demonstrated preliminary evidence for construct validity and excellent internal consistency (i.e., α = .92). Internal consistency in the current study was .91 at T0 and .91 at T1.

Basic psychological need expressions.

The extent to which persons with complex support needs exhibited expressions of self-determination as reported by participants, was assessed using another specially developed and preliminarily validated questionnaire for this target group (van Tuyll van Serooskerken et al., 2024). The instrument has 16 items divided over two subscales (i.e., Noticing signals of Autonomy and Noticing signals of Competence/Relatedness), which were rated on a Likert scale that ranged from 1 (*never*) to 5 (*always*). Example items are "my child expresses him/herself when he/she wants something" and "my child enjoys the things he/she can do." To reduce redundancy and the number of statistical analyses, the total score was used instead of the two separate subscale scores, with a higher score indicating more noticeable behaviors to communicate BPNs. Van Tuyll van Serooskerken et al. (2024) demonstrated preliminary evidence for construct validity and excellent internal consistencies for both subscales (i.e., α = .88 and .84, respectively). Internal consistencies of the total scores in the current study were .69 at T0 and .77 at T1.

Transition characteristics.

Participants were asked about four different transition-related features (i.e., expected impact on possibilities for BPN support, expected impact on BPN expressions, caregiver engagement, and period of impact). Parents' expectations regarding the potential of transitions to enhance BPNs were assessed using two variables. First, the expected impact on possibilities for BPN support was measured with three questions, based on the work of Verhage et al. (2013). For instance, participants were asked "Working towards the transition, how well do you expect to be able to respond to what your child likes and dislikes?" and moved a sliding bar between 0 (*not at all*) and 100 (*completely*). The expected impact on BPN expressions was assessed by adapting three items from the BPN Expressions questionnaire (i.e., one for autonomy, one for competence, and one for relatedness). Participants were asked whether they expected the transition to have *a lot of positive* = 5, *a little positive* = 4, *none* = 3, *a little negative* = 2, or *a lot of negative* = 1 influence on this. A total score was calculated for both expected impact variables, by summing the three answers. For caregiver engagement, participants were asked at T1 to estimate the amount of time spent on activities such as searching for information, planning ahead, and making preparations during the period leading up to the transition. This resulted in a subjective indication of caregiver engagement starting from T0 (in months). In addition, participants were asked whether and, if so, how long ago the transition had taken place to indicate the period of impact. This was also converted to time in months.

Subjective well-being.

Well-being was assessed with the Dutch translation (Maes et al., 2016) of the Mood, Interest and Pleasure Questionnaire (MIPQ; Ross & Oliver, 2003). This questionnaire contains 23 items on a Likert scale that ranged from 1 (*never*) to 5 (*always*) over the past two weeks. Each item had "not applicable" as an additional response category. The total score reflects an overall indicator of positive mood. Petry et al. (2010) demonstrated evidence for construct validity, good internal consistency (i.e., Cronbach's alphas between .84 and .94), and good test-retest and inter-rater reliabilities (i.e., above .86 and

.69 respectively) for all subscales and the total scale when used in this target population. Internal consistencies of the total scores in the current study were .88 at T0 and .92 at T1.

Analysis strategy

Data were analyzed using IBM SPSS Statistics (Version 27). Missing items scores at T0 and T1 within the Environmental Autonomy Support and BPN Expressions questionnaires were replaced when the total percentage of missing items within these questionnaires was well below 5% through single imputation with the participant's scale average (Eekhout et al., 2015). Missing item scores within the Well-Being questionnaire were imputed as per instrument manual (Maes et al., 2016). Multiple imputation was used to estimate the missing data of the four participants who dropped out at T1 (Sterne et al., 2009). Ten iterated datasets were created (White et al., 2011). Analyses were performed on these datasets and outcomes were pooled.
To assess change during the transition (research question 1), three paired-samples t tests were performed, one for each construct. In addition, the absolute change score was computed for each construct following the methodology outlined by Evans et al. (1998), to evaluate whether a statistically significant number of participants exhibited individual-level alterations, irrespective of its direction. It was checked whether the start of COVID-19 between T0 and T1 was related to the magnitude of change from T0 to T1. Three repeated measures analyses of variance were performed with time as within-subject factor and group (i.e., pre versus peri COVID-19) as between-subject factor. Because the group variable could not be imputed for the 4 participants with a missing T1, these four participants were excluded from this analysis.

To examine associations between changes over time (research question 2), bivariate correlation coefficients were computed. Difference scores were calculated for all three self-determination-related concepts (i.e., T1–T0), with positive scores indicating an increase.

The associations between the two a priori estimations of the impact of the transition and BPN expressions (research question 3) were examined with linear regression. The difference score for BPN expressions calculated by the subtraction of T0 from T1, represented the dependent variable. The two perceived impact scores were added as independent variables in two separate analyses.

Associations between caregiver engagement or period of impact and changes in the self-determination-related concepts (research question 4) were also explored with three linear regression analyses, separately for both predictive variables. The T1 measure of each self-determination-related concept was entered as a dependent variable. Its T0 measure plus caregiver engagement or period of impact were entered in the same step as independent (i.e., control) variables. All statistical tests used an alpha level of .05.

Results

Missing data and data pre-treatment

Examination of items in the sample of completed Environmental Autonomy Support questionnaires (15 items x 40 respondents = 600 values) showed a total of 1 (0.17%) missing item values at T0 and 0 at T1. The BPN Expressions questionnaire (16 items x 40 respondents = 640 values) showed a total of 2 (0.31%) missing item values at T0 and 3 (0.47%) at T1. Based on the MIPQ manual, 36 of 40 total scale scores could be calculated for T0 and 25 of 36 for T1. A Missing Value Analysis of the four participants with missing T1 data showed no statistical differences for Environmental Autonomy Support, $t(3.6) = .91$, $p = .42$; BPN Expressions, $t(3.7) = -.28$, $p = .79$; and Well-Being, $t(4.4) = -1.64$, $p = .17$ at T0, justifying multiple imputation. As the Relative Efficiency for all pooled imputations was around 1 (i.e., 0.99 - 1.00), ten iterations were considered sufficient (see Table 4.3 for an overview). See supplementary material (Table 4.A) for correlations between all variables.

Changes in self-determination-related concepts

On average, there was no statistically significant change between both measurement points for Environmental Autonomy Support ($t(318) = 0.66$, $p = .51$, Cohen's $d = 0.12$ (CI –0.18 – 0.45)), BPN Expressions ($t(713) = 0.15$, $p = .89$, Cohen's $d = 0.04$ (CI –0.27 – 0.35)), and Well-Being ($t(284) = –0.06$, $p = .95$, Cohen's $d = 0.04$ (CI –0.33 – 0.40)). However, the percentage of participants exceeding the absolute change score was 22.2% for Environmental Autonomy

Support, 5.6% for BPN Expressions, and 24% for Well-Being. This indicated that there was a large variation in the difference scores, with increases and decreases in all self-determination-related constructs balancing out. Furthermore, there was no statistical between x within effect of COVID-19 on the change in all three self-determination-related constructs, indicating that the change from T0 to T1 was not statistically different for the pre and peri COVID-19 participants: $F(1, 34) = 1.11$, $p = .30$, $\eta_p^2 = .03$ for Environmental Autonomy Support, $F(1, 34) = 0.66$, $p = .42$, $\eta_p^2 = .02$ for BPN Expressions, and $F(1, 23) = 1.16$, $p = .29$, $\eta_p^2 = .05$ for Well-Being.

Table 4.3 Descriptive Statistics of Original and Pooled Imputations Dataset for Study Variables

	Original dataset						Pooled imputations dataset		
	N	M (SD)	Min.	Max.	SE	SEM	N	M	SEM
T0 Measures									
Environmental Autonomy Support	40	58.05 (8.96)	-	-		1.42	-	-	-
BPN Expressions	40	58.06 (7.13)	-	-		1.13	-	-	-
Well-Being	36	55,97 (10.89)	-	-		1.81	-	-	-
Exp. Impact BPN Expressions	40	9.65 (3.37)	-	-		0.53	-	-	-
Exp. Impact Possibilities BPN Support	40	228.83 (50.58)	-	-		8.00	-	-	-
T1 Measures									
Environmental Autonomy Support	36	59.28 (8.44)	-	-		1.41	40	58.88	1.44
BPN Expressions	36	58.07 (7.64)	-	-		1.27	40	58.18	1.22
Well-Being	25	56.23 (13.47)	-	-		2.69	29	56.86	2.59
Caregiver Engagement	36	3.44 (2.99)	-	-		0.50	40	3.53	0.52
Period of Impact	36	2.22 (3.20)	-	-		0.53	40	2.37	0.52
T1−T0 Measures									
∆ Environmental Autonomy Support	36	0.78 (7.30)	-22.00	19.00	3.78	1.22	40	0.83	1.25
∆ BPN Expressions	36	0.12 (5.37)	-13.00	14.00	5.61	0.89	40	0.13	0.88
∆ Well-Being	25	0.16 (11.09)	-27.58	27.00	5.27	2.22	29	-0.13	2.16

Note. SE = Standard Error; SEM = Standard Error of the Mean; BPN = Basic Psychological Needs.

Interrelated changes in self-determination-related concepts

There were no statistically significant correlations between the change in Environmental Autonomy Support and change in BPN Expressions, $r = .31$, p (two-tailed) = .06, between the change in Environmental Autonomy Support and change in Well-Being, $r = .03$, p (two-tailed) = .88, and between the change in BPN Expressions and change in Well-Being, *r* = .07, *p* (two-tailed) = .74.

Caregiver expectations and actual changes in BPN expressions

The change in BPN expressions between T0 and T1 of persons with complex support needs was not statistically related to the expected impact on possibilities to support BPNs at T0, as well as to the expected impact of the transition on BPN expressions at T0 (see Table 4.4).

Table 4.4 Linear Regression Results for Change in Basic Psychological Need Expressions

	B	*SE B*	*95% CI B*	*p*
Step 1				
Exp. Impact Possibilities BPN Support T0	−0.00	0.02	−0.04 – 0.03	.97
Step 1				
Exp. Impact BPN Expressions T0	−0.13	0.27	−0.66 – 0.40	.63

Note. BPN = Basic Psychological Needs. Because SPSS does not provide a pooled version of the explained variance of steps 1 and 2, the range of the ten imputations was: $R^2 = .00$ for Step 1 Exp. Impact Possibilities BPN Support T0, $R^2 = .00 – .02$ for Step 1 Exp. Impact BPN Expressions T0.

Caregiver engagement and period of impact and actual changes in self-determination-related concepts

For all three self-determination-related constructs, scores at T0 were statistically associated with T1 for each corresponding construct. However, caregiver engagement before the transition, as well as period of impact were not statistically related to Environmental Autonomy Support at T1, BPN Expressions at T1, and Well-Being at T1 (see Tables 4.5, 4.6, and 4.7 respectively).

Table 4.5 Multiple Regression Results for Dependent Variable Environmental Autonomy Support T1

	B	*SE B*	*95% CI B*	*p*
Step 1				
Environmental Autonomy Support T0	0.62	0.13	0.37 – 0.88	< .001
Step 2				
Environmental Autonomy Support T0	0.61	0.13	0.36 – 0.87	< .001
Caregiver Engagement	−0.03	0.06	−0.14 – 0.08	.55
Step 2				
Environmental Autonomy Support T0	0.66	0.13	0.40 – 0.92	<.001
Period of Impact	−0.48	0.38	−1.21 – 0.26	.20

Note. Because SPSS does not provide a pooled version of the explained variance of steps 1 and 2, the range of the ten imputations was: $R^2 = .35 – .47$ for Step 1, $\Delta R^2 = .00 – .07$ for Step 2 Caregiver Engagement, $\Delta R^2 = .01 – .05$ for Step 2 Period of Impact.

Table 4.6 Multiple Regression Results for Dependent Variable Basic Psychological Need Expressions T1

	B	*SE B*	*95% CI B*	*p*
Step 1				
BPN Expressions T0	0.78	0.12	0.55 – 1.02	<.001
Step 2				
BPN Expressions T0	0.77	0.12	0.54 – 1.01	<.001
Caregiver Engagement	−0.04	0.04	−0.12 – 0.04	.32
Step 2				
BPN Expressions T0	0.77	0.13	0.51 –1.02	<.001
Period of Impact	−0.12	0.31	−0.73 – 0.48	.69

Note. BPN = Basic Psychological Needs. Because SPSS does not provide a pooled version of the explained variance of steps 1 and 2, the range of the ten imputations was: R^2 = .43 – .58 for Step 1, ΔR^2 = .00 – .03 for Step 2 Caregiver Engagement, ΔR^2 = .00 – .01 for Step 2 Period of Impact.

Table 4.7 Multiple Regression Results for Dependent Variable Well-Being T1

	B	*SE B*	*95% CI B*	*p*
Step 1				
Well-Being T0	0.73	0.18	0.37 –1.08	<.001
Step 2				
Well-Being T0	0.70	0.18	0.34 –1.06	<.001
Caregiver Engagement	−0.06	0.09	−0.23 – 0.11	.49
Step 2				
Well-Being T0	0.73	0.19	0.36 – 1.09	<.001
Period of Impact	−0.03	0.75	−1.51 – 1.45	.97

Note. Because SPSS does not provide a pooled version of the explained variance of steps 1 and 2, the range of the ten imputations was: R^2 = .32 – .43 for Step 1, ΔR^2 = .01 – .09 for Step 2 Caregiver Engagement, ΔR^2 = .00 – .01 for Step 2 Period of Impact.

Discussion

Self-determination-related concepts remained stable on average during transition but sizeable subgroups went to reliable increases or decreases. Whether participants expected possibilities for BPN support or the person's BPN expressions to increase or decrease was not associated with the actual direction of change. Caregiver engagement in preparing for the transition, as well as the time elapsed since the transition occurred, showed no association with observed changes either.

Extant studies suggest that self-determination and the support thereof are interrelated over time in persons with and without intellectual or other disabilities (Audet et al., 2021; Kins et al., 2009; Oliveira et al., 2014; Gillison et al., 2008; Nadig et al., 2018; Seong et al., 2015; Wehmeyer et al., 2011b). However, these studies did not focus on people with complex support needs. Given that intellectual disabilities hamper opportunities to express and fulfill preferences and desires (Wehmeyer & Shogren, 2017; Wehmeyer & Abery, 2013), the outcomes of transitions may be more difficult to control, despite everyone's best efforts.

The importance of further conceptual work to understand self-determination in the face of transitions in this population is highlighted by the fact the percentage of participants exceeding the absolute change score surpassed the 5% benchmark in all three constructs. Importantly, changes could not be predicted by caregivers, which in itself is noteworthy and in need of replication as it may have implications for supporting families. Research designs like case studies or within-person designs might track the often idiosyncratic and person-specific characteristics associated with these changes more accurately. Complementing this study with qualitative research methods to further explore what could make it so difficult for caregivers to predict the course of transitions might also be interesting. Another suggestion for further research would be to extend the duration between measurement points, which might reveal more pronounced changes, although this proposition remains speculative. Comprehensive investigations into the long-term impact of caregiver or environmental factors on changes in various domains remain underexplored within this population (Van keer & Maes, 2018).

Limitations and future research

In general, recruiting participants from this population for scientific research is challenging due to the low prevalence of individuals with complex support needs (Maes et al., 2021). Although recruitment was conducted through multiple channels, each of these channels had a limited reach. Reaching individuals without social media or a connection to parent organizations proved more challenging, potentially limiting the generalizability of the results. Both recruitment and data collection within this study were also severely limited by the sudden emergence of the pandemic. The resulting small sample size undeniably raises methodological issues (e.g., generalizability and statistical power), meaning that results should be interpreted with caution (Faber & Fonseca, 2014). In addition, participants with various different life transitions were included, rather than opting for inclusion based on one type of transition. Different transitions may present distinct opportunities for self-determination, which could have biased the results. Future studies with larger samples could explore subgroup differences to address this issue. Additionally, focusing on one specific type of transition such as moving from family home to sheltered care (e.g., Vereijken et al., 2024) could help reduce this bias, although it would limit the generalizability of the results to other transitions. Subgroup analyses based on living arrangements would also be valuable, considering that 35% of individuals with complex support needs did not reside in the family home. Parents of these individuals may be involved differently in transitions compared to parents of those living at home. Another factor to consider in follow-up research may be the age of persons with complex support needs. In typically developing children, autonomy support from parents differs across age groups (Grolnick, 2009; Vrolijk et al., 2022). Caregivers might see more opportunities for self-determination support during transitions for younger persons (e.g., adolescents) than for older persons with complex support needs (van Tuyll van Serooskerken et al., 2022). Finally, the BPN expressions questionnaire identifies observable signals in persons with complex support needs, but it may not fully reflect their actual expressions of BPNs or whether those needs are genuinely satisfied or unsatisfied. Also, changes in BPN expressions may be challenging to discern when caregivers, serving as informants in this study, are the only source of information. Including others, such as support staff, could enhance the precision of representing the subjective experiences of BPN satisfaction of persons with complex support needs. Nevertheless, proxy informants often struggle to accurately recognize and define internal states, such as psychological needs and subjective well-being, in individuals with intellectual disabilities, leading to variability in their assessments (De Geus-Neelen et al., 2014, 2019; Scott & Havercamp, 2018; Webb et al., 2024). Additionally, objectively measuring the construct of environmental autonomy support is challenging, as parents are inherently part of this environment. Therefore, individual change trajectories might be confounded with measurement error. Nonetheless, the degree to which the environment may be sensitive and empathic to signals could potentially influence the degree to which persons with complex support needs express them, and the reverse might also hold true (Hostyn & Maes, 2009; Skarsaune, 2024). In conclusion, it is imperative to exercise prudence when interpreting findings derived from proxy research, as they inherently represent an interpretation of reality, despite its origin from individuals intimately acquainted with the person under study (Nieuwenhuijse et al., 2023). It therefore remains crucial to develop innovative methods to capture the experiences of individuals within this target population, such as utilizing physiological data (Hammann et al., 2022) or modern Information and Communication Technologies (ICT; Kosiedowski et al., 2019).

Conclusion

This is a first longitudinal exploration of self-determination-related constructs in persons diagnosed with severe or profound intellectual and multiple disabilities. Previous research in the disability field on autonomy support, basic psychological needs, and quality of life has primarily focused on individuals with mild intellectual disability (e.g., Frielink et al., 2018; Shogren & Broussard, 2011). This study delved into the dynamics of self-determination during transitions, finding relative stability in self-determination-related constructs at the group level, even amidst disruptions like the COVID-19 lockdown. Neither pre-transition expectations, engagement levels during the transition, nor the time elapsed after the transition, significantly influenced these constructs. However, significant individual-level changes highlight the need for a more personalized approach to understanding these trajectories. Given that self-determination-related constructs changed in ways unexpected for caregivers and unrelated to their engagement in these transitions, there is a need for deeper insight into how context influences self-determination in this population. By incorporating a contextual perspective, this study reveals the potential for these variables to enhance research and address complex challenges in caring for individuals with complex support needs. The longitudinal approach adopted here offers valuable insights into the developmental aspects of self-determination, with the potential to inform future research and interventions, ultimately improving care for people with more severe intellectual disabilities.

Supplementary material

Table 4.A Mutual Bivariate Correlations Between Study Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. T0 Environmental Autonomy Support	-	.09	.27	.18	47**	.64**	-.13	.18	-.18	.23	-.45**	-.30	-.02
2. T0 BPN Expressions	-	-	.49**	.15	.08	.02	.74**	.63**	.18	-.31	-.08	-.29	.24
3. T0 Well-Being	-	-	-	.15	.16	.16	.43*	.62**	-.21	.24	-.15	-.14	-.29
4. T0 Exp. Impact BPN expressions	-	-	-	-	.31*	.15	.08	.51**	.09	.00	-.05	-.08	.37
5. T0 Exp. Impact Possibilities BPN Support	-	-	-	-	-	.33*	.07	.16	-.23	.21	-.17	-.01	.04
6. T1 Environmental Autonomy Support	-	-	-	-	-	-	-.01	.13	-.25	-.02	.40*	-.04	.00
7. T1 BPN Expressions	-	-	-	-	-	-	-	.67**	.18	-.28	.14	.44**	.31
8. T1 Well-Being	-	-	-	-	-	-	-	-	.00	.13	-.05	.00	.57**
9. T1 Caregiver Engagement	-	-	-	-	-	-	-	-	-	-.44*	-.08	.01	.31
10. T1 Period of Impact	-	-	-	-	-	-	-	-	-	-	-.29	.03	-.07
11. Δ Environmental Autonomy Support	-	-	-	-	-	-	-	-	-	-	-	.31	.03
12. Δ BPN Expressions	-	-	-	-	-	-	-	-	-	-	-	-	.07
13. Δ Well-Being	-	-	-	-	-	-	-	-	-	-	-	.-	-

Note. BPN = Basic Psychological Needs. Sample sizes range from *n* = 25 – 40. * $p < .05$, ** $p < .01$.

Chapter 5

General discussion

This dissertation was aimed towards understanding and measuring the abstract concept of self-determination and its support for people with severe or profound intellectual and multiple disabilities. In addition, this dissertation focused on exploring the coherence of specific elements of the Self-Determination Theory (SDT; Deci & Ryan, 2000) in this population during an important change in life (i.e., a transition). According to SDT, fulfilling three BPNs: autonomy, competence, and relatedness leads to autonomous motivation, serving as the foundation for self-determination (Deci & Ryan, 2000; Deci & Ryan, 2002). In combination with an autonomy-supportive environment, fulfillment of BPNs makes people thrive in their daily lives, contributing to the quality of their life by enhancing well-being, intrinsic motivation, and personal growth (Ryan & Deci, 2000a; 2000b). BPNs are considered innate and universal. Similar as in the general population, beneficial associations between BPN fulfillment and other SDT-related concepts (e.g., autonomy support, motivation, and well-being) were found in people with mild intellectual disability (Frielink et al., 2018). BPNs and their support may therefore present a promising starting point for exploring self-determination in persons with severe or profound intellectual and multiple disabilities as well.

At the start of this dissertation, research on BPNs and their support in individuals with severe or profound intellectual and multiple disabilities was limited. The three studies presented in this dissertation collectively contributed to filling this research gap. This final chapter summarizes and integrates their key findings and interpretations. In short, Chapter 2 qualitatively explored the meaning of the three BPNs (i.e., autonomy, competence, and relatedness) for people with severe or profound intellectual and multiple disabilities, according to their family caregivers (i.e., parents and siblings). This study also aimed to map family caregivers' support for BPNs. The findings of Chapter 2 guided the development and preliminary validation of two parent-informant questionnaires described in Chapter 3. Chapter 4 tested the tenets of SDT in people with severe or profound intellectual and multiple disabilities in a longitudinal design during a transition, using the questionnaires developed in Chapter 3. This final chapter considers the strengths and limitations of this set of studies, followed by suggestions for future research and exploration of the practical implications. The chapter concludes with a general reflection.

Summary of main findings

Family caregivers' perspectives on basic psychological needs among people with severe or profound intellectual and multiple disabilities

People with severe or profound intellectual and multiple disabilities experience lifelong and complex support needs regarding their development, medical care, education, and general upbringing that arise from difficulties in cognition, motor and sensory functioning, communication, and physical health (Nakken & Vlaskamp, 2007; Van der Putten et al., 2017). This group thus relies on others such as parents, family members, and healthcare professionals) for all daily functioning, including achieving the satisfaction of BPNs and experiencing self-determination. However, little is known about what BPNs exactly mean for this population. Chapter 2 therefore focused on gaining more understanding of how the BPNs of people with severe or profound intellectual and multiple disabilities are interpreted, experienced, and supported by their family caregivers (i.e., parents and siblings).

Using semi-structured, in-depth interviews with questions about the three BPNs and a qualitative analytic approach, the perspectives of 9 family caregivers (i.e., 5 mothers, 2 couples, and 2 sisters) with intensive caregiving responsibilities for a child, adolescent, or adult diagnosed with severe or profound intellectual and multiple disabilities were explored. The study outcomes presented in Chapter 2 revealed two overarching categories: I. Perceptions of what the BPNs look like, and II. Perceptions of how support processes for the BPNs work, with corresponding sub-themes.

For the first category, the sub-themes were: I. BPNs are in the detail, II. BPNs are implicitly driven, and III. Experiencing versus being aware of one's abilities. Participants indicated that autonomy concerned *the things* their family member with severe or profound intellectual and multiple disabilities liked, felt comfortable with, made them feel happy, and wanted, did not want, or wanted differently. Moreover, these things were mostly small, day-to-day activities. According to participants, relatedness was associated with feelings of comfort and security towards other people, but could also emerge towards animals, objects, or other things. These feelings arose quickly in some family members, while in others they were more subtle or varied depending on the intensity and frequency of interactions. Competence concerned *the things* a family member tried to do, was learning to master, or already could do. Again, these things primarily involved enhancing small motor, communication, cognitive, or social skills. Participants further pointed out that others who did not know their family member very well often did not see these as real, noteworthy skills.

Participants further indicated that BPNs were mostly expressed instinctively or intuitively, making it difficult to understand why certain needs were there or what they exactly entailed. In addition, participants doubted whether their family members were aware of their capabilities (i.e., self-efficacy), or even whether specific actions were self-generated (i.e., self-agency). Nevertheless, this absence of a deeper sense of one's agency did not prevent some family members from visibly enjoying the activities they engaged in or could experience. These results show that self-determination goes beyond merely making or facilitating individual choices, which is often viewed as the most critical parameter in research on supporting self-determination within this population, particularly through interventions (Kúld et al., 2023).

Participants were also asked how they supported BPNs. For the second category, thematic coding resulted in three sub-themes: I. Detecting BPNs, II. Clarifying BPNs, and III. Creating opportunities. Participants indicated that they could not always recognize or pick up on all BPN expressions of their family member with severe or profound intellectual and multiple disabilities. Moreover, expressions for the same BPN could vary depending on the context or appear only in response to external triggers, which underscores the important role of the context in creating opportunities for the expression of self-determination. Regularly, participants tried various support resources (e.g., therapy or training, time investment, trial and error, and communication tools like hand gestures, pictograms, or speech computer) to understand or clarify signals.

Despite these efforts, participants frequently questioned whether they had interpreted signals correctly. Signals could also remain completely unclear. Finally, based on the sub-themes a tentative theoretical flow chart was created to visualize the interactive steps and challenges participants experience in supporting person-specific BPNs of family members with severe or profound intellectual and multiple disabilities.

These results thus show that participants saw an important role for themselves in creating optimal conditions and opportunities in which BPNs of their family member could be expressed, grow, be developed, and fulfilled. Participants further indicated that this dependency required them and others involved in the care and support of their family member to exhibit high sensitivity and responsiveness. Moreover, participants acknowledged that they were not always certain about what was happening in their child's mind or how to facilitate opportunities. The flow chart helped visualize that this gap in understanding could lead to various ongoing cycles of undetected, unclear, and unmet needs. The challenges that family caregivers face while working with limited information are further discussed in Chapter 4, highlighting the difficulty in accurately predicting changes in their child's BPNs during an expected transition.

Development and preliminary psychometric evaluation of two questionnaires for family caregivers of persons with severe or profound intellectual and multiple disabilities

There currently is a scarcity of suitable and valid instruments specifically developed for people with severe or profound intellectual and multiple disabilities. In general, most available instruments are self-report-based or contain situations that do not match the unique experiences of persons within this population, making them unsuitable (Maes et al., 2021). Instruments that quantitatively summarize experiences of BPNs and an autonomy-supportive environment in this specific population did not exist at the start of this thesis, which limited the possibilities for research on this topic. One way to capture these essential experiences is by including family caregivers' perceptions, as their lifelong and intimate connection highlights the value of their insights and warrants attention in its own right. Moreover, Chapter 2 emphasized that recognizing and appropriately responding to signals is a crucial aspect of creating an environment that promotes self-determination; an often challenging task that usually requires the involvement of those who know the individual best. The questionnaires created in Chapter 3 therefore focused on two main aspects: I. The extent to which family caregivers perceive that all key partners in the environment provide autonomy-supportive experiences, and II. The extent to which family caregivers perceive or notice their child's expressions of BPNs.

The development of both questionnaires took place across the following stages. First, existing instruments related to concepts within SDT were analyzed to see if they were adaptable for people with severe or profound intellectual and multiple disabilities. The Perceptions of Parents Scale – College-Student Scale (POPS; Robbins, 1994) was used as the foundation for the questionnaire on autonomy-supportive experiences, and 16 of the 21 items were reformulated. Regarding the questionnaire on BPN expressions, it was not possible to create a meaningful version of an existing questionnaire. Subsequently, the scope was changed from capturing actual experiences of BPN satisfaction or frustration of the family member with severe or profound intellectual and multiple disabilities to family caregivers' perceptions about reading or noticing signals that they believe reflected BPNs. This led to the development of 36 new items, guided by the family caregivers' experiences in Chapter 2. A draft version of this questionnaire was piloted in a small, separate group of parents to evaluate the comprehensibility and applicability of the questions. During the item test phase, the questionnaire was shortened to optimize the number of items on relevance and burden. This resulted in 16 items used in further analyses (*N* = 63, of which 93.6% were parents).

Principal component analyses on the Autonomy-Supportive Experiences questionnaire suggested removing one item and yielded an optimal 1-factor solution for the remaining items. Principal component analyses on the BPN Expressions questionnaire yielded an optimal 2-factor solution that could be interpreted as "Noticing signals of autonomy" and "Noticing signals of competence/relatedness." However, three items had ambiguous loadings. Furthermore, the two components of the BPN Expressions questionnaire encompassed the extent to which family caregivers noticed: I. Need expressions (e.g., signals things one wants), II. Manifestations of need-related behaviors (e.g., choosing from options offered), and III. Expressions of need satisfaction (e.g., enjoying things one does). Internal consistencies for both questionnaires were excellent (i.e., .78 – .92) and evidence for construct validity was found. Taken together, this indicates that items within the same component appeared to measure the same general construct and showed expected associations with other constructs in the nominal network around self-determination. These preliminary results are a first step in measuring the processes of environmental autonomy support and BPN expressions by people with severe or profound intellectual and multiple disabilities, which may ultimately increase the understanding of self-determination in this group (Kúld et al., 2023; Mumbardo-Adam et al., 2023).

Change in self-determination-related constructs during transitions

In this Chapter, transitions were taken as a framework that may offer persons with severe or profound intellectual and multiple disabilities new possibilities to reorganize life according to one's wishes and desires when accompanied by adequate support. Kralik et al. (2006) describe that transitions denote a change or disruption in the developmental stage, physical or mental health, education, work, daytime activities, finances, housing, relationships, or social circumstances. Chapter 4 explored the changes and interrelations in self-determination-related constructs (i.e., autonomy-support experiences, BPN expressions, and subjective well-being) in individuals with severe or profound intellectual and multiple disabilities during an expected transition. It also explored the potential influence of some transition characteristics and how well family caregivers could predict self-determination-related outcomes.

Participants (*N* = 40) were mostly parents (i.e., 92.5%). Average changes during a transition in Autonomy-Supportive Experiences, BPN Expressions, and Subjective Well-Being were not statistically significant. However, reliable change was observed for 5.6% to 24% of individuals, depending on the outcome variable. Analyses also revealed no significant interrelation between the changes in these three concepts over time. Family caregiver expectations, engagement (i.e., the amount of preparation time), and the period of impact (i.e., how long ago the transition had taken place) were not associated with these changes. These findings indicate relative stability in self-determination-related constructs at a group level, even amidst disruptions like the COVID-19 lockdown.

This first longitudinal exploration of self-determination-related constructs in persons with severe or profound intellectual and multiple disabilities offers valuable insights into the potential developmental aspects of self-determination during transitions that may be unknown to family caregivers. More specifically, Chapter 4 revealed that transitions did not always unfold as family caregivers anticipated in advance, which is in line with findings in Chapter 2 that highlighted family caregivers' feelings of uncertainty about eliciting, recognizing, and interpreting signals. The significant individual-level changes highlight the need for a more personalized approach to understanding these trajectories. Finally, the finding that changes in self-determination-related outcomes were not related to the family caregivers' engagement further emphasizes the need for a deeper understanding of how the context influences self-determination in people with severe or profound intellectual and multiple disabilities.

Strengths and limitations

This dissertation addresses concerns that parents and caregivers have expressed regarding the meaning and support for self-determination of their child with severe or profound intellectual and multiple disabilities. The aims of this dissertation were shaped through close collaboration with parents, professionals, and other stakeholders, as outlined in Chapter 1. Doing so promoted alignment between the research agenda and the priorities and needs of those most directly involved. Despite the methodological challenges in conducting research among people within this often hard-to-reach target population (Maes et al., 2021), we managed to compile several samples. To gain insight into their experiences through the perceptions of their family caregivers, multiple methods (i.e., qualitative and quantitative) were used, in accordance with the type of question in each study. Moreover, using a longitudinal design to measure changes in self-determination-related constructs in this population is innovative. Furthermore, this dissertation has been produced with great attention to family caregivers and has attempted to be inclusive, involving the target population when possible. Nevertheless, several chapter-specific and dissertation-transcending limitations are important to mention.

First, Chapter 2 focused on BPNs as sensitizing concepts, rather than other theories related to self-determination and motivation such as Causal Agency Theory (CAT; Shogren et al., 2015; 2017c), Choice Theory (Glasser, 1998), and Self-efficacy Theory (Bandura, 1977). These other theories seemed less appropriate because they focus on achieving personal goals through goal-directed actions and skills, internal factors and control, and the role of confidence in one's capabilities, respectively, indicating the use of higher-level cognitive functions that are affected in people with intellectual disabilities (e.g., Spaniol & Danielsson, 2022). However, the narrow focus on one theoretical framework may have limited the insights that could be gained.

Second, the small sample sizes (i.e., primarily due to halting participant recruitment at the onset of COVID-19) in Chapters 3 and 4 further necessitates a cautious interpretation of the results. Conclusions about both questionnaire structures found in Chapter 3 only concern our sample for the time being, and do not contain specific recommendations for items with anomalous loadings. For example, about items 17 (i.e., signals capabilities) and 30 (i.e., signals for more attention) of the BPN Expressions questionnaire that were originally developed for a construct related to competence and relatedness respectively. Both items, however, loaded higher on the component Noticing Signals of Autonomy than on the component Noticing Signals of Competence/Relatedness. Within Chapter 4, the small sample size prevented the exploration of more complex theoretical models with additional variables, subgroup analyses (e.g., living situation), and associations between subscales.

Third, evaluating subjective constructs such as self-determination and quality of life through the perspectives of family caregivers has potential benefits and limitations (Gruber-Baldini et al., 2012; Lynn Snow et al., 2005). For example, the literature emphasizes the importance of including this group as experts on their child with severe or profound intellectual and multiple disabilities and facilitating the development and transfer of their intimate knowledge to support workers, medical professionals, and researchers (e.g., Bredewold & van der Weele, 2024; Dorsman et al., 2023; Goldbart, 2023; Hoogsteyns et al., 2023; Kruithof et al., 2020; Zaal-Schuller et al., 2024). Nieuwenhuijse et al. (2024) substantiate this view and advocate for “accept[ing the] interpretation of signals and signs by proxies in the assessment of QoL in persons with PIMD and do not value this as second best” (p. 4). Nevertheless, while some insights gained through intensive and prolonged personal experiences can be codified and shared with others, as demonstrated by participants in our study, other insights often referred to as tacit knowledge cannot easily be expressed verbally, making them more difficult to transfer (Hoogsteyns et al., 2023; Kruithof et al., 2024; Polanyi, 2009). Subsequently, participants in Chapter 2 acknowledged that their knowledge, whether tacit or not, was certainly not always adequate, indicating that they were not always certain about what was going on in their child’s mind or how to facilitate opportunities. The other studies in this dissertation also illustrated how little information family caregivers of a person with severe or profound intellectual and multiple disabilities had to work with. This underlines the importance of being prudent when relying on a single group of informants as the primary source of information, even when they are presumed to know the individual best (Olsman et al., 2021). Moreover, when attempting to approximate the subjective perspectives of individuals with disabilities through the views of others, it is essential to consider the beliefs, expectations, norms, and values that may influence these informants (Emerson et al., 2013; Flynn et al., 2017; Olsman et al., 2021).

Fourth, in line with positions taken in the disability rights movement, the concept of self-determination, and respect for one’s autonomy, it can be argued that we could have done more towards integrating an inclusive research environment with associated research methods in this dissertation. This includes involving the target population not just as subjects but as fully engaged co-researchers, actively participating in every phase of the research process from design to conclusion to ensure that their perspectives are integral and valued (Frankena et al., 2018; Frankena, 2019). Inclusive research has been shown to benefit the research process and outcomes on multiple levels (O'Brien et al., 2022). However, it has been predominantly applied to individuals with mild to moderate intellectual disabilities (Hewitt et al., 2023). As in this dissertation, involvement of people with severe or profound intellectual and multiple disabilities often mainly consists of participatory approaches where family members and caregivers actively contribute to shaping the research agenda and methodology, ensuring the inclusion of the perspectives of their loved ones (de Haas et al., 2022). To improve inclusive research for this target group, Gjermestad et al. (2022) emphasize the essence of sensory and dialogic interactions. Grace et al. (2024) advocate for decolonizing research by challenging traditional power dynamics and adopting more collaborative and participatory approaches through "locating a space of 'being with' in which to do research with people [in this target population]" (p. 3). This approach does require recognition that including the 'voices' of individuals with severe or profound intellectual and multiple disabilities in relevant areas is a time-consuming process.

Fifth, this dissertation did not distinguish between severe and profound intellectual disability, adaptive skills, or comorbidity. However, focus was placed on an estimated developmental age of 5 or lower in combination with additional disabilities causing a high degree of support needs across domains (e.g., care, health, and safety). One reason for this decision was that the distinction, especially in borderline cases, is difficult to make because valid instruments to determine IQ, cognitive, and adaptive functioning are lacking (Colmar et al., 2006; Ludwig et al., 2024). Another consideration was that findings could be relevant for both groups, as impairments in domains such as communication often lead to overlapping support needs. Nevertheless, significant variability in abilities and challenges within and between the two groups (Forster et al., 2011) warrants caution in interpreting and generalizing results.

Sixth, a person's interest in being involved in a study may say something about how that person views the research topic (Gucciardi et al., 2010). For example, Kim et al. (2022) found an association between dispositional optimism and willingness to participate. During the recruitment phases for our studies, we tried our best to reach a diverse group of family caregivers, for example, by describing the study in neutral terms and by indicating that all opinions (i.e., positive, neutral, and negative towards self-determination by their child with severe or profound intellectual and multiple disabilities) were welcome. However, along the way, we noticed that most family caregivers held a positive view of self-determination. This may limit the generalizability of the findings to populations that include caregivers with a more skeptical perspective.

Finally, cultural diversity of participants was limited. This may have implications. For example, within individualistic cultures, autonomous decisions are based on personal preferences, while in collectivist cultures autonomy is seen as a relational construct in which decisions are tailored to the needs of a group (Rudy et al., 2007). Nevertheless, the development of autonomy also has corresponding characteristics between cultures (Helwig, 2006) and the positive association between internalized or relative autonomy and well-being seems universal (Chirkov et al., 2003). The underrepresentation of families from non-Western racial and ethnic backgrounds was also highlighted in the scoping review on burnout among parents of children with complex care needs by Patty et al. (2024). In addition to alternative perspectives on the construct under study, these families may have different views on having a child with disabilities (e.g., experiencing feelings of shame) and involving support from others (e.g., admitting that caring for one's child is hard may evoke feelings of guilt), making them less likely to sign up for participation. To better engage these groups in future research, it is essential to make study material (e.g., information about the study and instruments) more culturally inclusive and accessible.

Scientific and practical implications

Implications for future research

The findings within this dissertation have several implications for current understanding and future research. First, in Chapter 2, family caregivers indicated that people with severe or profound intellectual and multiple disabilities do express their BPNs (e.g., by showing new or changes in existing preferences or exercising specific (new) abilities). Recognizing the presence of BPNs implies that family caregivers take steps to create an environment where these needs can be met. Moreover, family caregivers emphasized the importance of creating learning opportunities, although this focus seemed to decline later in adulthood. These findings suggest that BPNs and self-determination may be differently interpreted and supported per developmental stage. Exploring these discrepancies in future qualitative and quantitative research could offer deeper insights into potential individual developmental pathways of BPNs and contribute to more tailored guidance at each stage the person is in.

Regarding the instruments developed in Chapter 3, some suggestions for improvement could be made based on today's knowledge. While perceptions on the meaning of BPNs from Chapter 2 guided the development of the instruments, the development of the questionnaires ran parallel to the thematic analysis. This was due to time constraints surrounding the project that required the longitudinal study to start within a fixed timeline. Furthermore, existing questionnaires (i.e., the POPS and BPNSFS-ID) were adapted or used as a starting point to ensure that both instruments had the greatest chance of loading on universal dimensions identified in current theories, possibly limiting the inclusion of constructs specific for this population. The findings from Chapter 2, suggest that the questionnaires in Chapter 3 capture only part of the meaning of self-determination as it applies to individuals with severe or profound intellectual and multiple disabilities. For instance, in the case of the Autonomy-Supportive Experiences questionnaire, the elicitation of signals is not included in this construct, while in Chapter 2, this appeared a crucial step, one that according to parents is often overlooked. Explicit focus on elicitation of signals appears unique to this population and is not typically addressed in frameworks for other groups. Adding items that focus on support for eliciting and interpreting signals, but also on, for example, the use of support resources, could enhance the questionnaire's alignment with the unique needs of this population and challenges faced by their environment. Such refinements could also help clarify where in the process family caregivers may require additional support, providing a basis for more targeted assistance in critical areas.

It was further decided to have family caregivers estimate the autonomy support from all key partners closely involved in their family member's life, rather than just the support they provided themselves. However, family caregivers were not asked *how many* other key partners they included in their answers nor did they have to specify *who* these key partners were. For family caregivers who primarily focused on their own support, social desirability bias might have influenced their responses (Paulhus, 2002; 2017). For family caregivers who included multiple key partners in their answers, scores may be less comparable as each informant may add up the support of involved key partners differently. For example, some family caregivers may average the support from all key partners while others may assign different weights to their own support and that of others. In the future, it may be recommended to identify all key partners (i.e., how many and their role) that are included in the answers. The questionnaire could also be completed separately for specific key partners or a specific group of key partners (e.g., support workers), making comparisons more feasible. In the long term, when specific model steps (Chapter 2) may be operationalized, an option can be added within each step to identify which key partners are involved, what their roles are, and how the level of support from each partner is perceived individually.

In addition to the social context, family caregivers in Chapter 2 also addressed possible influences from the physical context on the ability to express and fulfill BPNs. For example, exterior conditions such as sunlight could interfere with the functioning of an eye-controlled speech computer, preventing a person from communicating their needs. The literature further indicates that the physical context may impact the mood, sensory stimulus processing, and behavior of individuals with severe or profound intellectual and multiple disabilities (Fava & Strauss, 2010; van den Bosch et al., 2017). Examples include the layout of spaces, the presence of preferred, stimulating, or calming elements such as colors, lights, and sounds, and changes within environments or location shifts (e.g., moving from indoors to outdoors or vice versa). In addition, familiar environments may provide predictability, comfort, and safety, while unfamiliar locations may be confusing or cause stress. Research on the role of the physical environment on specifically BPNs and quality of life in people with intellectual disabilities is still very limited (Roos et al., 2022). Research in people with dementia, for example, did show that modifications of the physical environment such as specially designed spaces or use of technology have a positive impact on their experiences of autonomy and social interaction (e.g., Bouman et al., 2019; Namazi & Johnson, 1992; Woodbridge et al., 2018). It would therefore be valuable to map information about specific environmental factors that either promote or obstruct the expression and fulfillment of BPNs. This information would allow for more precisely tailored support strategies about optimizing the physical environment, contributing to the daily functioning and well-being of persons with severe or profound intellectual and multiple disabilities.

Regarding the BPN Expressions questionnaire, one striking point was that almost none of the items about expressions of BPN frustration made it to the final item set. This was mostly due to feedback from participants on these items which indicated that the family members' frustration expressions deviated substantially from the intended description. Ambiguous expressions are generally more prevalent in this target population. For instance, Nicholson's (2021) study highlighted the challenges in understanding the diverse behaviors of persons with severe or profound intellectual disabilities that may indicate resistance. Furthermore, negative affective states were also found to be expressed more diffusely or sometimes even paradoxically by people within this population compared to positive states (Doodeman et al., 2022; Vos et al., 2013a; Vos et al., 2013b). Expressing frustration thus seems to vary extensively per person, which impedes the development of items that represent frustration in a way that is perceived as truthful according to caregivers. Future research should address this issue systematically and explore potential solutions, for example, using case studies or within-person designs and formulating better fitting descriptions.

Implications for care practice

The findings presented in the studies within this dissertation are also relevant for care practice. First, the findings emphasize that family caregivers possessed valuable insights about the idiosyncratic and subtle cues of their family members with severe or profound intellectual and multiple disabilities that represented specific BPNs. This indicates the importance of recognizing the expertise of family caregivers in understanding their child's unique needs and preferences. Subsequently, understanding the dynamics and mapping the obstacles that family caregivers face in the process of BPN support may contribute to the development of better support strategies, interventions, and policies that can ultimately improve the quality of life of this target population. The theoretical flow chart from Chapter 2 may play a role in this and serve as an eye-opener for professionals and be included in their training.

The first part of the flow chart shows that difficulties were encountered not only in the presence of signals but also at an earlier stage of creating opportunities to prompt signals when they were, or appeared to be, absent. This led to questions such as, "*When* exactly should I do *what* to stimulate or elicit BPN expressions," and "*Which* contextual factors influence the expression of BPNs in *what* way?" This is consistent with research by Dhondt et al. (2021, 2022) in which they argue that opportunities for communication and interaction for people with severe or profound intellectual and multiple disabilities depend strongly on the behavior of interaction partners and contextual-related information, as signals rarely emerge spontaneously. The social environment should therefore not only focus on learning to interpret observable signals but also on proactively creating opportunities accommodated to the person's abilities to facilitate effective communication (i.e., stimulation of BPN expressions). Nevertheless, the studies within this dissertation show that family caregivers may have prior knowledge about what the person finds interesting or enjoyable, which could provide input for finding suitable elicitors and stimuli.

The recognition and correct interpretation of signals from people with severe or profound intellectual and multiple disabilities, the middle part of the flowchart, also often proved to be challenging for family caregivers. One reason could be that there can be a delay between a stimulus and response (Haishi et al., 2011; Wilder et al., 2015), which makes it difficult to understand signals correctly. Another reason could be that the meaning of expressions by individuals in this population can differ substantially from the typical interpretations assigned to more conventional expressions by individuals without such severe disabilities (Doodeman et al., 2022). For example, does falling asleep indicate fatigue or is it a sign of boredom or under-stimulation, as a mother in Chapter 2 pointed out about her daughter? Another example is that a minimal or visibly absent pain response does not necessarily imply a higher pain threshold, as shown in people with Down syndrome (De Knegt et al., 2017). Moreover, in individuals with severe or profound intellectual and multiple disabilities pain behaviors are often unique and non-verbal (Goodall et al., 2023). The resources used by family caregivers to support the interpretation of signals, also displayed in the middle part of the flowchart from Chapter 2, such as training, therapy, extensive time investment to get to know the person well, trial and error, and communication tools (e.g., hand gestures, pictograms, or speech computer) were often subject to disruptions and limitations. Besides resources simply not working or being unsuitable for the person's abilities, resources were often too expensive or less effective as regression occurred when they were not maintained. In addition, not all expressed BPNs, whether clear for the caregiver or not, could be met immediately, easily, or at all, indicating that the support for self-determination in this population also involves value-laden choices within a system that has its limitations. Consider, for example, needs that may pose a threat to the person's physical or mental health such as a need for sensory stimulation and wanting to put unsuitable or non-edible things in the mouth, or a need for stability (e.g., regarding professional caregivers or daily routines) when inevitable changes need to occur. These could be examples of the struggles of family caregivers with the knowledge of what their family member desires, accounting for the family member's health and safety, and doing what is within the realm of opportunities (e.g., relating to time and financial resources). Furthermore, these situations place significant demands on family caregivers' availability regarding their abilities to manage their children's feelings of dissatisfaction or frustration stemming from unmet BPNs.

Taken together, these results emphasize that the perspectives of parents on their child's self-determination are relevant and may help professionals to improve the quality of care. On the one hand, this means that family caregivers should get the opportunity to help professionals in assigning meaning to the person's expressions (i.e., sharing what is already known about how and what specific needs are communicated, how these expressions can be stimulated and recognized, what resources could be helpful for clarification, and what optimal opportunities could be created them). On the other hand, this means that family caregivers may need help with structuring and articulating their knowledge and experiences when professionals have specific requests.

These results regarding the support for autonomy, competence, and relatedness align with the four key strategies for self-determination support found by Kúld et al. (2024). These strategies were: *Communication and choice making (facilitated by aids)*, which indicates a focus on enabling and actively stimulating the expression of needs using communication tools and manners appropriate to the person's functioning, physical limitations, and health status; *Sensitivity*, which indicates a focus on increasing the ability of key partners to notice and effectively respond to subtle signals; *Familiarity*, which indicates a focus on building and maintaining a network of people who know the person well; and *Equivalent collaboration among involved parties* to create an environment conducive to self-determination. The interpretation of these strategies did differ, however, among parents of person living at home, parents of person in residential facilities, professionals working within residential care, and professionals working in person's home (Kúld et al., 2024). Clarifying individual interpretations of roles and responsibilities when using support strategies or the flow chart, could help increase mutual understanding between key partners.

All chapters reflected the complexity of mapping subjective constructs such as BPNs in people with severe or profound intellectual and multiple disabilities who cannot communicate them verbally. Although family caregivers naturally know their child best (Kruithof et al., 2020), they also acknowledge, as described earlier, that their abilities fell short sometimes. This indicates that the introspective and reflective abilities of caregivers can fluctuate. A possible way to increase the practical use of an instrument such as the BPN Expressions questionnaire is to ask informants about the level of confidence in their responses. This may help identify which topics are challenging and may need more attention. In addition, the current version of the questionnaire does not provide insights into person-specific needs for autonomy, competence, and relatedness of individuals with severe or profound intellectual and multiple disabilities, nor does it capture the unique, idiosyncratic ways in which they were expressed. It is therefore recommended to explore how these individualized needs and their signals can be incorporated, allowing for a more tailored and person-centered approach to support.

General conclusion

The findings in the current dissertation addressed the meaning and support for self-determination, viewed in terms of the three basic psychological needs autonomy, competence, and relatedness of people with severe or profound intellectual and multiple disabilities as perceived by their family caregivers.

The three studies are a step towards improving self-determination-related care and support for people within this population, focusing on the unique challenges they and their family caregivers experience. In Chapter 2, family caregivers were interviewed about their perceptions of the meaning and support for BPNs regarding their family member with severe or profound intellectual and multiple disabilities. This provided insights into the subtle nature of BPNs, the implicit drivers behind BPNs, and how BPNs were experienced. Aligning with Skarsaune et al. (2021) who argue for a relational understanding of self-determination, the importance of the environment was deeply intertwined with the meanings attributed to the BPNs. For instance, a sense of competence did not seem to emerge from being skilled at something, but rather from being provided with meaningful opportunities to engage, grow, and experience a sense of competence through social interactions. Family caregivers played a crucial role in creating an environment where BPNs could be expressed as well as fulfilled. Findings also identified serious challenges that caregivers experienced in detecting, clarifying, and creating opportunities for BPNs. Conclusions emphasize the need to raise greater awareness that self-determination does not have self-evident meaning. Furthermore, supporting BPNs of persons with severe or profound intellectual and multiple disabilities relies on knowledge from those who know the individual best, reinforcing the importance of involving family caregivers' perspectives in the care practice.

The results of Chapter 2 guided the development of two parent-informant questionnaires in Chapter 3. One on Autonomy-Supportive Experiences and one on BPN Expressions. The primary explorations of psychometric properties showed promising results. Both questionnaires appeared internally consistent and showed the expected associations with other constructs in the nomological network around self-determination, although further research is needed.

In Chapter 4 a longitudinal study design was used to explore the associations between environmental autonomy support, BPN expressions, and subjective well-being of persons with severe or profound intellectual and multiple disabilities in the context of transitions. The absence of significant associations indicated relative stability in self-determination-related constructs at the group level. However, significant individual-level changes highlighted the need for a more personalized approach to understanding these trajectories.

In conclusion, creating an environment that optimally supports BPNs, and thus self-determination, of individuals with severe or profound intellectual and multiple disabilities is more than just working towards a continuous infallible understanding of needs. Working towards an environment rich in autonomy-supportive interactions, constructive challenges, and warm social relationships is possibly even more important (Vansteenkiste et al., 2020). As a result, all fundamental, significant, and legal decisions made on behalf of individuals with severe or profound intellectual and multiple disabilities create opportunities for self-determination. However, until society can objectively identify the actual inner voices of this population, it is essential to establish a network of key partners who are closely and long-term involved with the person, collectively possessing greater knowledge than any single individual in that network. This requires fostering equality in collaboration among all these partners and promoting mutual understanding of diverse perspectives to enhance outcomes.

Chapter 6

I. Summary

Chapter 1 – General introduction

The general principles of the United Nations Convention on the Rights of Persons with Disabilities are designed to serve as guidelines to protect and promote, among other things, the autonomy and choices of all individuals with disabilities. Acting volitionally according to intrinsic motives (i.e., self-determination) contributes to subjective well-being and quality of life. Perceived autonomy support through a care environment that matches one's preferences and is full of relevant and motivating choices fosters feelings of autonomy and self-determination. However, opportunities for self-determination tend to diminish as intellectual disabilities are more severe. Individuals with the most severe intellectual disabilities additionally face unique situations, underscoring the need to better understand and assess self-determination and its related constructs in this specific population.

Persons with severe or profound intellectual and multiple disabilities

Persons with severe or profound intellectual and multiple disabilities are unique in personality and behavior. They share lifelong, complex support needs arising from limitations in cognitive, communication, motor skills, sensory, and physical health domains. The wide variation in challenges across individuals makes this population highly heterogeneous. Communication is often severely impaired, occurring non-verbally, idiosyncratically, and at a pre-symbolic level. Signals can be difficult to notice, fluctuate, and vary by communication partner and context. Less familiar caregivers may infer or guess meanings of signals, while experienced ones rely on their intuitive understanding (i.e., tacit knowledge). The process of communication requires sensitive responsiveness, and continuous adaptation and reconciling of communication repertoires.

The importance of the social environment

Individuals with severe or profound intellectual and multiple disabilities depend entirely on others for all daily tasks. These others mostly include parents, family members, and healthcare professionals. Parents face unique physical and emotional challenges that may impose a significant burden, increasing the risk of burnout and negatively affecting their quality of life. Parents are crucial experts on their child with severe or profound intellectual and multiple disabilities, often serving as lifelong advocates in communicating wants and needs to others. This also applies to other relatives, such as siblings. Both parents and siblings need informational, practical, and emotional support throughout the child's lifespan, including medical care, social resources, and system-wide support. Healthcare professionals share care responsibilities, making comprehensive training and strong partnerships between individuals, family caregivers, and professionals essential for responsive, person-centered care.

Evolving perspectives on self-determination and its role in quality of life

Quality of life (QoL) is a multidimensional concept reflecting overall well-being and life satisfaction, directing efforts to enable individuals to live fulfilling and meaningful lives. Individuals with severe or profound intellectual and multiple disabilities are vulnerable to low QoL, and their environment faces challenges in assessing and promoting it. Communicative impairments often hinder the expression of needs and wishes in a way that is understandable to others, complicating the provision of adequate care. Additionally, environments often lack opportunities tailored to the person's abilities and preferences.

According to the Self-Determination Theory (SDT), self-determination involves having influence and freedom of choice over one's own life and decisions. In individuals with less severe intellectual disabilities, self-determination correlates positively with psychological well-being, social relationships, community participation, and overall QoL. However, research on self-determination by those with more severe intellectual disabilities remains limited, often focusing on specific components such as choice-making, independence, and problem-solving. Methodological problems (e.g., a lack of validated tools) contribute to this gap. Since direct questioning is not possible within this population, appealing to those closest to them (e.g., family caregivers) is a crucial first step in understanding self-determination for this population.

Basic psychological needs and autonomy support

Existing self-determination theories, such as SDT and Basic Psychological Needs Theory (BPNT), provide a starting point for studying self-determination in individuals with severe or profound intellectual and multiple disabilities. Central to these theories are three fundamental basic psychological needs (BPNs): autonomy, competence, and relatedness. BPNs are considered universal and essential for mental and emotional well-being.

Vansteenkiste et al. (2020) provided an overview of the three BPNs: autonomy refers to the desire for freedom to exercise one's own will without external constrains (e.g., coercion); competence refers to the desire to influence one's environment effectively, valuing growth as valuable as success; and relatedness refers to the desire for reciprocal love and acceptance. When BPNs are satisfied, people experience intrinsic motivation, personal growth, and greater well-being; when BPNs are unmet or frustrated, adverse outcomes arise.

An autonomy-supportive environment is crucial for BPN fulfillment and self-determination. Autonomy support is associated with positive outcomes in education, work, healthcare, and family contexts, and similar effects are found in persons with mild to borderline intellectual disabilities. Gaining more comprehensive understanding of BPNs and perceived autonomy support in individuals with severe or profound intellectual and multiple disabilities, through insights from their family caregivers, can enhance research and lead to the development of suitable instruments with promising psychometric properties to test their relation to QoL outcomes.

Transitions

Possible contexts for understanding how BPNs and environmental autonomy support are experienced by persons with severe or profound intellectual and multiple disabilities include transitions. Transitions are a psychological process of adapting to changes in key life stages or circumstances. Transitions can significantly impact individuals and their social environment but also offer opportunities for self-determination through arising new choices that influence the life course. Expanding our understanding of theoretical principles and practical applications related to BPNs, perceived environmental autonomy support, and QoL during transitions may positively influence transition experiences and outcomes.

Dissertation aims

The aims of this thesis were developed in cooperation with parents and other stakeholders (e.g., client and healthcare organizations, and knowledge institutions) to ensure that the research addressed the wishes and needs of those involved. The overall goal of this dissertation was to better understand and measure self-determination, viewed in terms of BPNs, and its support for people with severe or profound intellectual and multiple disabilities. This resulted in four main research aims. The first was to explore the meaning and expressions of satisfaction and motivation for autonomy, competence, and relatedness in this population. The second was to understand family caregivers' needs, challenges, and expectations regarding BPN support and identify key events and opportunities for experiencing BPN satisfaction. The third was to develop and adapt questionnaires to measure BPNs and perceived environmental autonomy support, and assess their psychometric properties. The fourth was to explore how transitions impact self-determination, including the role of family caregivers in this.

Chapter 2 – Satisfying basic psychological needs: Primary relatives' perspectives

Within SDT, the fulfillment of the three BPNs: autonomy, competence, and relatedness, is seen as an integral part of human self-determination, subjective well-being, and overall quality of life. However, the current knowledge gap regarding the meaning of these psychological constructs that go along with self-determination for individuals with severe or profound intellectual and multiple disabilities hampers effective support. The qualitative study in Chapter 2 therefore explored the meaning family caregivers (i.e., parents or siblings) ascribed to BPNs for their child with severe or profound intellectual and multiple disabilities and the processes necessary for their support, using semi-structured interviews. Data collection and analysis followed a grounded theory and sensitizing concepts approach. Family caregivers acknowledged the importance of the BPNs for self-determined action, as they described these as the things their family members liked, felt comfortable with, or wanted (autonomy); were able to do, trying to do, or learning to master (competence); and the others to which they felt attached, they made contact with, or they felt safe with (relatedness). They also elaborated on the subtle and idiosyncratic nature of the BPNs of their family members and the fact that they often had to infer a specific BPN from behavioral clues, instead of having it communicated directly. The presence of self-efficacy (i.e., the confidence in one's ability to successfully perform a specific task) or even self-agency (i.e., the attribution of an action to oneself) could often not be detected, but pleasure or enjoyment while performing activities or skills could. The tentative theoretical flowchart visualized the complex support processes that family caregivers experienced, such as looking for, interpreting, and responding to BPN signals to the best of their abilities. The flowchart also indicated some steps that appear to be specific for this population, such as actively eliciting signals of BPNs and dealing with the outcome that some BPN signals will remain opaque. To conclude, this study showed that the meaning of self-determination goes further than making one's own choices. Enjoying and experiencing the things one likes and meaningful interactions with others are equally important aspects.

Chapter 3 – Development and psychometric evaluation of two questionnaires

Autonomy-supportive interactions imply intensive involvement of social partners that respect and encourage voluntariness of action, give informative feedback on competent performance, and make the other feel accepted and part of the group. Having an autonomy-supportive social context is linked to BPN satisfaction. However, at the start of the study, suitable instruments to measure autonomy support and BPNs in the target population were lacking. This absence limits the ability to better understand how self-determination may be related to interventions and outcomes. Chapter 3 therefore sought to operationalize these psychological constructs as perceived by family caregivers (i.e., parents or siblings) of individuals with severe or profound intellectual and multiple disabilities. Two questionnaires were developed and tested with family caregivers of persons within the target population; one for perceptions of autonomy-supportive experiences of their child with all key partners in the environment and one for perceptions of their child's signals reflecting BPNs. The most unambiguous and parsimonious structure for the remaining 15 items of the Autonomy-Supportive Experiences questionnaire was a one-dimensional model. The remaining 16 items of the BPN Signals questionnaire fell alongside two dimensions. One component reflected noticing signals of autonomy and the other reflected noticing signals of both competence and relatedness. Both components encompassed the extent to which caregivers noticed need expressions (e.g., signals things one wants), manifestations of need-related behaviors (e.g., chooses from options offered), and expressions of need satisfaction (e.g., enjoys things one does). While this degree of noticing expressions of needs, need-related behaviors, and need fulfillment is a necessary condition, it is not sufficient to guarantee effective support and satisfaction of BPNs. Furthermore, virtually no frustration-related items remained after the social validation stage, as negative affective states were often expressed more diffusely or paradoxically compared to positive states. The internal consistency coefficients for both questionnaires were considered sufficient and evidence for construct validity was found. Although further research is needed, these results are a first indication of the applicability of the SDT and BPNT in persons with severe or profound intellectual and multiple disabilities.

Chapter 4 – Change in self-determination-related constructs during transitions

In social and health sciences, transition is a psychological process of adapting to change that involves an inner reorientation with distinct phases. Transitions denote both shifts from one developmental stage to another and events that mark changes or disruptions in physical or mental health, education, work, daytime activities, finances, housing, relationships, or social circumstances. Life transitions may sometimes create new opportunities for supporting and achieving self-determination, but may also make it harder. In neurotypical children, for example, normative life transitions foster self-determination and quality of life. For individuals with intellectual disabilities, successful outcomes of transitions largely depend on the adequacy of support. Other factors such as transition characteristics, engagement, and expectations for achieving self-determination may also be important. The longitudinal study in Chapter 4 explored how transitions may go along with changes in self-determination in persons with severe or profound intellectual and multiple disabilities and what role family caregivers play during such transitions. Results indicated relative stability in self-determination-related constructs at the group level, even amidst disruptions like the COVID-19 lockdown. Neither pre-transition expectations, engagement levels working towards the transition, nor the time elapsed after the transition significantly influenced these constructs, which may have implications for supporting families. Given that an intellectual disability hampers one's opportunities to express and fulfill preferences and desires, outcomes of transitions may be more difficult to control, despite everyone's best efforts. Moreover, significant individual-level changes highlighted the need for a more personalized approach to better understand these trajectories.

Chapter 5 – General discussion

This dissertation aimed to understand and measure the abstract concept of self-determination and its support for people with severe or profound intellectual and multiple disabilities. In addition, this dissertation focused on exploring the coherence of specific elements of the SDT in this population during an important change in life (i.e., a transition). At the start of this project, research on BPNs and their support in individuals with severe or profound intellectual and multiple disabilities was limited. The three studies presented in this dissertation collectively contributed to filling this research gap. Chapter 5 discusses and integrates their main findings.

Strengths and limitations

A strength of this dissertation is that despite the methodological challenges in conducting research among people with severe or profound intellectual and multiple disabilities, we managed to compile several samples from this often hard-to-reach target population. We also used multiple methods (i.e., qualitative and quantitative) to gain insight into their experiences through the perceptions of their family caregivers, in accordance with the type of question in each study. In addition, using a longitudinal design to measure changes in self-determination-related constructs in this population is innovative. Finally, this dissertation has been produced with great attention to family caregivers and has attempted to be inclusive, involving the target population when possible.

Despite these strengths, it is important to acknowledge several limitations when interpreting findings. First, the use of SDT and BPNT as a starting point to explore the meaning of its associated constructs in Chapter 2, rather than other theories related to self-determination and motivation, may have limited the finding of additional insights. Second, the small sample sizes (i.e., primarily due to halting participant recruitment at the onset of COVID-19) in Chapters 3 and 4 further necessitates a cautious interpretation of the results. Third, including family caregivers' perspectives when evaluating subjective constructs such as self-determination and quality of life has potential benefits and limitations. On the one hand, family caregivers are seen as the experts on their child with severe or profound intellectual and multiple disabilities, possessing intimate knowledge through intensive and prolonged personal experiences. On the other hand, some of their knowledge is more intuitive and difficult to put into words, complicating transfer. Family caregivers also mentioned experiencing difficulties in noticing and understanding signals. This underlines the need for caution when relying on a single group of informants as the primary source of information, even if they are presumed to know the individual best.

Fourth, more effort could have been made to establish a more inclusive research environment (i.e., not only involving family caregivers but also persons with severe or profound intellectual and multiple disabilities themselves), especially given the evidence that inclusivity benefits the research process and outcomes on multiple levels. Including the voices of individuals in this population throughout all stages of research, however, demands a shift in perspective and methodology. This area remains in its infancy, particularly when compared to, for example, the more advanced inclusive studies involving individuals with mild intellectual disabilities. Fifth, this dissertation did not distinguish between severe and profound intellectual disability, adaptive skills, or comorbidity. Significant variability in abilities and challenges within and between the two groups thus warrants caution in generalizing results. Sixth, a person's interest and willingness in being involved in a study may say something about how that person views the research topic. As we noticed that most caregivers held a positive view of self-determination by their child with severe or profound intellectual and multiple disabilities, results may be less reflective of caregivers with a more skeptical perspective. Finally, the diversity of participants regarding culture and religion was narrow, which may have implications for the interpretation of constructs.

Implications for future research

The findings within this dissertation have several implications for current understanding and future research. First, family caregivers indicated that people with severe or profound intellectual and multiple disabilities express their BPNs, such as through new or changing preferences and abilities. Furthermore, findings suggest that self-determination may be differently interpreted and supported depending on the developmental stage of the person. Future qualitative and quantitative research is encouraged to explore these intrapersonal differences and internal inconsistencies. Second, some suggestions for improving the instruments developed in Chapter 3 are illustrated. For example, the findings from Chapter 2 suggest that the items of the Autonomy-Supportive Experiences questionnaire only partially capture self-determination for individuals with severe or profound intellectual and multiple disabilities as it overlooks the crucial step of eliciting signals. Refining the questionnaire to include support for eliciting and interpreting signals, as well as other relevant, population-specific aspects, could better address the unique needs of this population and guide more targeted caregiver support. Further identification could be made of the other key partners included in the responses of informants, as well as how they perceive the level of support provided by each key partner individually or by a specific group of key partners. Mapping information on specific environmental factors that either promote or obstruct the expression and fulfillment of BPNs can also be a valuable addition. Finally, regarding the

BPN Expressions questionnaire, the expression of frustration seemed diffuse and sometimes even paradoxical, resulting in most of these items being deleted. Exploring potential solutions to formulate more universal descriptions for frustration-related items is recommended.

Implications for care practice

The findings presented in the studies within this dissertation are also relevant for care practice. First, the findings emphasize that family caregivers possessed valuable insights about the idiosyncratic and subtle cues of their family members with severe or profound intellectual and multiple disabilities that represented specific BPNs. Professionals may want to acknowledge the expertise of family caregivers in understanding their child’s unique needs and preferences and empower them to advocate confidently for their child’s best interests. This suggests that family caregivers could be given the opportunity to assist professionals in assigning meaning to the person’s expressions (i.e., sharing what is already known about how and which specific needs are communicated, how these expressions could be stimulated and recognized, what resources could be helpful for clarification, and how optimal opportunities could be created for them). Nevertheless, family caregivers also struggled with recognizing and correctly interpreting signals. This indicates that they may need help with structuring and articulating their knowledge and experiences when professionals have specific requests. Subsequently, understanding the dynamics and mapping the obstacles that family caregivers face in the process of BPN support can contribute to the development of better support strategies, interventions, and policies that can ultimately improve the quality of life of this target population. The theoretical flowchart from Chapter 2 may play a role in this and serve as an eye-opener for professionals.

General conclusion

To conclude, the findings in the current dissertation addressed the meaning and support for self-determination, viewed in terms of the three basic psychological needs of autonomy, competence, and relatedness of people with severe or profound intellectual and multiple disabilities as perceived by their family caregivers. The studies are a first step towards improving self-determination-related care and support for people within this population, focusing on the unique challenges they and their family caregivers experience. The results highlight the importance of fostering environments characterized by autonomy-supportive interactions, opportunities for constructive challenges, and warm, nurturing relationships. To prioritize self-determination in all fundamental, significant, and legal decisions made on behalf of individuals with severe or profound intellectual and multiple disabilities, it is essential to establish a strong network of key partners. This network should consist of individuals closely and long-term involved with the person, collectively bringing a broader and deeper understanding than any individual could possess.

II. Samenvatting

Hoofdstuk 1 – Algemene inleiding

De algemene principes van het VN-Verdrag inzake de Rechten van Personen met een Handicap (Engels: United Nations Convention on the Rights of Persons with Disabilities) zijn ontwikkeld als richtlijnen om onder andere de autonomie en keuzes van alle personen met een beperking te beschermen en te bevorderen. Handelen uit vrije wil en volgens intrinsieke motieven (ook wel zelfdeterminatie of zelfbepaling genoemd) draagt bij aan subjectief welzijn en kwaliteit van leven. Autonomie-ondersteunende zorgervaringen die inspelen op persoonlijke voorkeuren en betekenisvolle en motiverende keuzes mogelijk maken, dragen bij aan een sterker gevoel van autonomie en zelfbepaling. Mogelijkheden voor zelfbepaling neigen echter af te nemen naarmate een verstandelijke beperking ernstiger is. Individuen met de meest ernstige verstandelijke beperkingen worden bovendien geconfronteerd met unieke situaties, wat de noodzaak onderstreept om zelfbepaling en daaraan gerelateerde constructen in deze specifieke populatie beter te begrijpen en in kaart te brengen.

Personen met (zeer) ernstige verstandelijke en meervoudige beperkingen

Personen met (zeer) ernstige verstandelijke en meervoudige beperkingen zijn uniek in persoonlijkheid en gedrag. Ze hebben levenslange, complexe ondersteuningsbehoeften die voortkomen uit beperkingen in cognitieve, communicatieve, motorische, zintuiglijke en fysieke gezondheidsdomeinen. De grote variatie in uitdagingen tussen individuen maakt deze populatie zeer heterogeen. Communicatie is vaak ernstig verstoord, gebeurt non-verbaal, idiosyncratisch en op een pre-symbolisch niveau. Signalen kunnen moeilijk op te merken zijn, fluctueren en variëren per communicatiepartner en context. Minder vertrouwde zorgverleners zullen de betekenis van signalen mogelijk afleiden of gissen, terwijl ervaren zorgverleners vertrouwen op hun intuïtieve kennis (Engels: tacit knowledge). Effectieve interactie vereist sensitieve responsiviteit, flexibiliteit en het op elkaar afstemmen van communicatiestijlen.

Het belang van de sociale omgeving

Mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen zijn voor alle dagelijkse taken volledig afhankelijk van anderen. Deze anderen omvatten grotendeels ouders, familieleden en zorgverleners. Ouders worden geconfronteerd met unieke fysieke en emotionele uitdagingen die een aanzienlijke belasting kunnen vormen, wat het risico op een burn-out vergroot en hun kwaliteit van leven negatief beïnvloedt. Ouders zijn cruciale experts op het gebied van hun kind met (zeer) ernstige verstandelijke en meervoudige beperkingen en spelen vaak een levenslange rol bij het communiceren van wensen en behoeften naar anderen. Dit geldt ook voor andere verwanten, zoals broers en zussen. Zowel ouders als verwanten hebben behoefte aan informatieve, praktische en emotionele ondersteuning gedurende het hele leven van hun naaste, zoals medische zorg, sociale voorzieningen en systeemgerichte ondersteuning. Zorgprofessionals dragen bij aan deze zorgverantwoordelijkheden, wat uitgebreide scholing en hechte samenwerking tussen personen, ouders en verwanten, en professionals onmisbaar maakt voor responsieve, persoonsgerichte zorg.

Veranderende perspectieven op zelfbepaling en de relatie met kwaliteit van leven

Kwaliteit van leven is een multidimensionaal concept dat het algehele welzijn en tevredenheid over het leven weerspiegelt, en een voorwaarde is voor een vervuld en betekenisvol leven. Personen met (zeer) ernstige verstandelijke en meervoudige beperkingen behoren tot een kwetsbare groep met een verhoogd risico op een verminderde kwaliteit van leven, en hun omgeving wordt geconfronteerd met uitdagingen bij het evalueren en bevorderen daarvan. Communicatieve beperkingen maken het vaak lastig om behoeften en wensen op een begrijpelijke manier te uiten, waardoor het voor betrokkenen moeilijker wordt om adequate zorg te verlenen. Bovendien ontbreekt het de omgeving vaak aan mogelijkheden die zijn afgestemd op de capaciteiten en voorkeuren van de persoon.

Volgens de Zelf-Determinatie Theorie (ZDT) houdt zelfbepaling in dat men invloed en keuzevrijheid heeft over het eigen leven en beslissingen. Bij mensen met een lichte verstandelijke beperking hangt zelfbepaling positief samen met psychologisch welzijn, sociale relaties, participatie in de gemeenschap en algeheel kwaliteit van leven. Onderzoek naar zelfbepaling bij mensen met ernstigere verstandelijke beperkingen is echter nog beperkt en richt zich vaak op specifieke componenten zoals het maken van keuzes, zelfstandigheid en het oplossen van problemen. Methodologische problemen, zoals een gebrek aan gevalideerde instrumenten, dragen bij aan de beperkte kennis. Aangezien directe bevraging bij deze doelgroep niet mogelijk is, is het raadplegen van de mensen die het dichtst bij hen staan, zoals ouders en verwanten, een essentiële eerste stap om zelfbepaling binnen deze populatie te begrijpen.

Psychologische basisbehoeften en autonomie-ondersteuning

Bestaande theorieën rondom zelfbepaling, zoals ZDT en de Theorie van Psychologische Basisbehoeften, bieden een startpunt voor het bestuderen van zelfbepaling bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Centraal binnen deze theorieën staan drie fundamentele psychologische basisbehoeften: autonomie, competentie en verbondenheid. Psychologische basisbehoeften worden beschouwd als universeel en cruciaal voor mentaal en emotioneel welzijn.

Vansteenkiste et al. (2020) gaven een overzicht van de drie psychologische basisbehoeften: autonomie verwijst naar het verlangen naar vrijheid om je eigen wil uit te oefenen zonder externe beperkingen zoals dwang; competentie verwijst naar het verlangen om je eigen omgeving effectief te beïnvloeden, waarbij groei even waardevol wordt gevonden als succes; en verbondenheid verwijst naar het verlangen naar wederkerige liefde en acceptatie. Wanneer psychologische basisbehoeften worden vervuld, ervaren mensen intrinsieke motivatie, persoonlijke groei en een beter welzijn; wanneer deze behoeften niet worden vervuld of worden tegengewerkt, heeft dat ongunstige consequenties voor motivatie en welzijn.

Een autonomie-ondersteunende omgeving is cruciaal voor de vervulling van psychologische basisbehoeften en zelfbepaling. Ondersteuning van autonomie hangt samen met positieve uitkomsten in onderwijs, werk, gezondheidszorg en binnen gezinssituaties. Ook zijn vergelijkbare effecten gevonden bij mensen met een licht verstandelijke beperking of zwakbegaafdheid. Het betrekken van ouders en verwanten bij het verkennen van psychologische basisbehoeften en ervaren autonomie-ondersteuning bij personen met (zeer) ernstige verstandelijke en meervoudige beperkingen kan onderzoek verdiepen. Bovendien kunnen deze inzichten waardevol zijn voor de ontwikkeling van geschikte instrumenten met veelbelovende psychometrische eigenschappen, gericht op het meten van de relatie met kwaliteit van leven.

Transities

Transities kunnen een belangrijke context bieden om te begrijpen hoe psychologische basisbehoeften en autonomie-ondersteuning worden ervaren door mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Transities zijn een psychologisch proces van aanpassing aan veranderingen in belangrijke levensfasen of omstandigheden. Transities kunnen een sterke impact hebben op personen en hun sociale omgeving, maar bieden ook kansen voor zelfbepaling door het ontstaan van nieuwe keuzes die de levensloop beïnvloeden. Het vergroten van ons begrip van theoretische principes en praktische toepassingen rondom psychologische basisbehoeften, ervaren autonomie-ondersteuning en kwaliteit van leven tijdens transities kan een positieve invloed hebben op de ervaringen en uitkomsten van deze overgangen.

Doel van het proefschrift

De onderzoeksdoelen van dit proefschrift werden opgesteld in samenwerking met ouders en andere belangrijke betrokkenen, zoals cliëntorganisaties, zorgorganisaties en kennisinstellingen, om ervoor te zorgen dat het onderzoek aansloot bij de wensen en behoeften van deze betrokkenen. Het overstijgende doel van dit proefschrift was het beter begrijpen en meten van zelfbepaling, gezien vanuit de psychologische basisbehoeften, en de ondersteuning daarvan voor mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Dit resulteerde in vier belangrijke doelstellingen. De eerste was het onderzoeken van de betekenis en expressies van vervulling en motivatie voor autonomie, competentie en verbondenheid in deze populatie. De tweede was om de behoeften, uitdagingen en verwachtingen van ouders en verwanten met betrekking tot de ondersteuning van psychologische basisbehoeften te begrijpen en belangrijke gebeurtenissen en mogelijkheden voor het ervaren van de vervulling van psychologische basisbehoeften te identificeren. De derde was om vragenlijsten te ontwikkelen en aan te passen om psychologische basisbehoeften en ervaren autonomie-ondersteuning vanuit de omgeving te kunnen meten en hun psychometrische eigenschappen te beoordelen. De vierde was om te onderzoeken hoe transities zelfbepaling beïnvloeden, inclusief de rol van ouders en verwanten hierin.

Hoofdstuk 2 – Vervulling van psychologische basisbehoeften: Perspectieven van ouders en verwanten

Binnen ZDT wordt de vervulling van de drie psychologische basisbehoeften: autonomie, competentie en verbondenheid, gezien als een integraal onderdeel van menselijke zelfbepaling, subjectief welzijn en algehele kwaliteit van leven. Echter, de huidige kenniskloof met betrekking tot de betekenis van deze psychologische constructen die samengaan met zelfbepaling voor personen met (zeer) ernstige verstandelijke en meervoudige beperkingen belemmert effectieve ondersteuning. De kwalitatieve studie in hoofdstuk 2 onderzocht daarom de betekenis die familieleden (ouders of verwanten) toekenden aan psychologische basisbehoeften voor hun naaste met (zeer) ernstige verstandelijke en meervoudige beperkingen en de ondersteuningsprocessen die zij nodig achtten voor de ondersteuning ervan, door middel van semigestructureerde interviews. De dataverzameling en analyse volgden een gefundeerde theorie en sensibiliserende concepten (Engels: grounded theory and sensitizing concepts) benadering. Ouders en verwanten erkenden het belang van de psychologische basisbehoeften voor zelfbepaald handelen, omdat ze deze beschreven als de dingen die hun familieleden leuk vonden, waar ze zich prettig bij voelden, of die ze wilden (autonomie); die ze konden, probeerden te doen, of leerden te beheersen (competentie); en als de anderen waarmee ze zich verbonden voelden, waar ze contact mee maakten, of waar ze zich veilig bij voelden (verbondenheid). Ze gingen ook dieper in op de subtiele en eigenzinnige aard van de psychologische basisbehoeften van hun naaste en het feit dat ze een specifieke psychologische basisbehoefte vaak moesten afleiden uit gedragssignalen, in plaats van dat deze rechtstreeks werd gecommuniceerd. De aanwezigheid van zelfeffectiviteit (het vertrouwen dat je in staat bent om een bepaalde taak succesvol uit te voeren) of zelfs zelf-agentschap (het toeschrijven van een handeling aan jezelf) kon dikwijls niet gedetecteerd worden, maar plezier of genot tijdens het uitvoeren van activiteiten of vaardigheden wel. Het voorlopige theoretische stroomdiagram (Engels: flowchart) visualiseerde de complexe ondersteuningsprocessen die ouders en verwanten ondervonden, zoals het zo goed mogelijk zoeken naar, interpreteren van en reageren op signalen van psychologische basisbehoeften. Het stroomdiagram gaf ook enkele stappen aan die specifiek lijken te zijn voor deze populatie, zoals het actief ontlokken van psychologische basisbehoefte-signalen en het omgaan met de uitkomst dat sommige signalen van psychologische basisbehoeften onduidelijk zullen blijven. Concluderend liet dit onderzoek zien dat de betekenis van zelfbepaling verder gaat dan het maken van eigen keuzes. Genieten en ervaren van de dingen die je leuk vindt en zinvolle interacties met anderen zijn even belangrijke aspecten.

Hoofdstuk 3 – Ontwikkeling en psychometrische evaluatie van twee vragenlijsten

Autonomie-ondersteunende interacties impliceren intensieve betrokkenheid van sociale partners die de vrijwilligheid van iemands handelen respecteren en aanmoedigen, informatieve feedback geven over competente prestaties en ervoor zorgen dat de ander zich geaccepteerd en onderdeel van de groep voelt. Het hebben van een autonomie-ondersteunende sociale context hangt samen met de vervulling van psychologische basisbehoeften. Echter, bij aanvang van het onderzoek ontbraken geschikte meetinstrumenten om autonomie-ondersteuning en psychologische basisbehoeften in de doelgroep te meten. Deze afwezigheid beperkt de mogelijkheid om beter te begrijpen hoe zelfbepaling gerelateerd zou kunnen zijn aan interventies en uitkomsten. In hoofdstuk 3 werd daarom getracht deze psychologische constructen te operationaliseren zoals zij worden waargenomen door familieleden (ouders of verwanten) van personen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Er werden twee vragenlijsten ontwikkeld met en getest bij ouders en verwanten van personen binnen de doelgroep; één voor percepties van autonomie-ondersteunende ervaringen van hun naaste met alle belangrijke partners uit de omgeving en één voor percepties van de signalen van hun naaste die psychologische basisbehoeften weerspiegelen. De meest eenduidige en spaarzame structuur voor de resterende 15 items van de vragenlijst Autonomie-Ondersteunende Ervaringen was een één-dimensionaal model. De resterende 16 items van de vragenlijst Signalen van Psychologische Basisbehoeften clusterden rondom twee dimensies. Eén component weerspiegelde het opmerken van signalen van autonomie en het andere component weerspiegelde het opmerken van signalen van zowel competentie als verbondenheid. Beide componenten omvatten de mate waarin ouders en verwanten in staat waren om: expressies van behoeften op te merken, zoals signalen van wat iemand wil; gedragingen te herkennen die verband houden met behoeften, zoals kiezen uit aangeboden opties; en uitingen van behoeftebevrediging te signaleren, zoals genieten van een activiteit. Hoewel het opmerken van behoefte-expressies, behoefte-gerelateerd gedrag en signalen van behoeftebevrediging essentieel is, vormt dit slechts een eerste stap om psychologische basisbehoeften daadwerkelijk effectief te kunnen ondersteunen. Bovendien bleven er na de sociale validatiefase vrijwel geen frustratie-gerelateerde items over, omdat negatieve affectieve toestanden vaak op een meer diffuse of meer paradoxale manier tot uiting kwamen dan positieve toestanden. De interne consistentiecoëfficiënten voor beide vragenlijsten werden als voldoende beoordeeld en er werd bewijs gevonden voor constructvaliditeit. Hoewel verder onderzoek nodig is, vormen deze resultaten een eerste indicatie van de toepasbaarheid van de ZDT en Theorie van Psychologische Basisbehoeften bij personen met (zeer) ernstige verstandelijke en meervoudige beperkingen.

Hoofdstuk 4 – Verandering in zelfbepaling-gerelateerde constructen tijdens transities

In de sociale en gezondheidswetenschappen wordt transitie gezien als een psychologisch proces van aanpassing aan verandering, dat gepaard gaat met een innerlijke heroriëntatie in verschillende fasen. Transities verwijzen zowel naar verschuivingen van de ene ontwikkelingsfase naar de andere, als naar gebeurtenissen die veranderingen of verstoringen teweegbrengen in lichamelijke of geestelijke gezondheid, onderwijs of opleiding, werk, dagbesteding, financiën, huisvesting, relaties of sociale omstandigheden. Transities tijdens de levensloop kunnen soms nieuwe mogelijkheden creëren om zelfbepaling te ondersteunen en te bereiken, maar kunnen dit ook moeilijker maken. Bijvoorbeeld bij neurotypische kinderen, dragen normatieve transities bij aan het versterken van zelfbepaling en kwaliteit van leven. Voor mensen met verstandelijke beperkingen hangen succesvolle resultaten van transities grotendeels af van de adequaatheid van de ondersteuning. Andere factoren zoals transitiekenmerken, betrokkenheid en verwachtingen rondom het bereiken van zelfbepaling kunnen ook belangrijk zijn. De longitudinale studie in hoofdstuk 4 onderzocht hoe transities kunnen samengaan met veranderingen in zelfbepaling bij personen met (zeer) ernstige verstandelijke en meervoudige beperkingen en welke rol ouders en verwanten spelen tijdens dergelijke overgangen. De resultaten wezen op een relatieve stabiliteit in zelfbepaling-gerelateerde constructen op groepsniveau, zelfs tijdens verstoringen zoals de COVID-19 lockdown. Noch de verwachtingen voorafgaand aan de transitie, noch de mate van betrokkenheid tijdens het toewerken naar de transitie, noch de verstreken tijd na de transitie had een significante samenhang met deze constructen, wat implicaties kan hebben voor de ondersteuning van gezinnen. Aangezien een verstandelijke beperking iemands mogelijkheden kan belemmeren om voorkeuren en wensen te uiten en te realiseren, kunnen de uitkomsten van transitie moeilijker te controleren zijn, zelfs wanneer alle betrokkenen zich maximaal inspannen. Bovendien benadrukten de significante veranderingen op individueel niveau de noodzaak van een meer gepersonaliseerde benadering om deze ontwikkelingspaden beter te begrijpen.

Hoofdstuk 5 – Algemene discussie

Dit proefschrift had als doel om het abstracte concept van zelfbepaling en de ondersteuning daarvan bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen te begrijpen en meetbaar te maken. Daarnaast richtte dit proefschrift zich op het onderzoeken van de samenhang tussen specifieke elementen van de ZDT binnen deze populatie tijdens een belangrijke verandering in hun leven, ook wel transitie genoemd. Aan het begin van dit project was onderzoek naar psychologische basisbehoeften en de ondersteuning daarvan bij personen met (zeer) ernstige verstandelijke en meervoudige beperkingen beperkt. De drie studies die in dit proefschrift worden gepresenteerd, hebben gezamenlijk bijgedragen aan het opvullen van deze kenniskloof. Hoofdstuk 5 bespreekt en integreert de belangrijkste bevindingen.

Sterke punten en beperkingen

Een sterk punt van dit proefschrift is dat we, ondanks de methodologische uitdagingen bij het uitvoeren van onderzoek bij mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen, erin zijn geslaagd om verschillende steekproeven samen te stellen uit deze vaak moeilijk te bereiken populatie. Daarnaast gebruikten we meerdere methoden (kwalitatief en kwantitatief) in overeenstemming met het type onderzoeksvraag van elke studie, om inzicht te krijgen in hun ervaringen via de percepties van hun ouders en verwanten. Ook is het gebruik van een longitudinaal onderzoeksdesign om veranderingen in zelfbepaling-gerelateerde constructen binnen deze populatie te meten, vernieuwend. Tot slot is dit proefschrift met veel aandacht voor ouders en verwanten tot stand gekomen en is er gestreefd naar inclusiviteit, waarbij de doelgroep waar mogelijk is betrokken.

Ondanks deze sterke punten is het belangrijk om bij de interpretatie van de bevindingen ook enkele beperkingen in acht te nemen. Ten eerste kan de keuze om in hoofdstuk 2 de ZDT en Theorie van Psychologische Basisbehoeften als uitgangspunt te nemen, in plaats van andere theorieën over zelfbepaling en motivatie, het verkrijgen van aanvullende inzichten hebben beperkt. Ten tweede maken de kleine steekproefgroottes in hoofdstukken 3 en 4 een voorzichtige interpretatie van de resultaten noodzakelijk. Deze beperkte omvang waren voornamelijk het gevolg van het vroegtijdig stopzetten van de werving van nieuwe deelnemers als gevolg van de uitbraak van COVID-19. Ten derde brengt het betrekken van perspectieven van ouders en verwanten bij het evalueren van subjectieve constructen zoals zelfbepaling en kwaliteit van leven zowel voordelen als beperkingen met zich mee. Enerzijds worden ouders gezien als de experts op het gebied van hun kind met (zeer) ernstige verstandelijke en meervoudige beperkingen, omdat ze intieme kennis bezitten door hun intensieve en langdurige persoonlijke ervaringen. Anderzijds is een deel van hun kennis meer intuïtief en moeilijk onder woorden te brengen, wat de overdracht bemoeilijkt. Bovendien gaven ouders en verwanten ook aan moeilijkheden te ondervinden bij het opmerken en interpreteren van signalen. Dit benadrukt het belang van voorzichtigheid bij het vertrouwen op één enkele groep informanten als primaire informatiebron, zelfs wanneer zij verondersteld worden de persoon het beste te kennen.

Ten vierde had er meer inspanning verricht kunnen worden om een meer inclusieve onderzoeksomgeving te creëren waarbij niet alleen familieleden worden betrokken, maar ook de personen met (zeer) ernstige verstandelijke en meervoudige beperkingen zelf. Dit is des te belangrijker gezien het toenemende bewijs dat inclusiviteit het onderzoeksproces en de uitkomsten op meerdere niveaus ten goede komt. Het meenemen van de perspectieven van personen binnen deze populatie in alle fasen van het onderzoek vereist echter een verschuiving in perspectief en methodologie. Dit onderzoeksgebied staat nog in de kinderschoenen, zeker in vergelijking met bijvoorbeeld de meer geavanceerde inclusieve studies bij mensen met een lichte verstandelijke beperking. Ten vijfde werd in dit proefschrift geen onderscheid gemaakt tussen een ernstige en zeer ernstige verstandelijke beperking, adaptieve vaardigheden, of comorbiditeit. De aanzienlijke variabiliteit in mogelijkheden en uitdagingen binnen en tussen deze twee groepen vraagt dus om voorzichtigheid bij het generaliseren van de resultaten. Ten zesde kan de interesse en bereidheid van een persoon om deel te nemen aan een onderzoek iets zeggen over hoe die persoon tegen het onderzoeksonderwerp aankijkt. Aangezien we merkten dat de meeste ouders en verwanten een positieve kijk hadden op zelfbepaling van hun naaste met (zeer) ernstige verstandelijke en meervoudige beperkingen, kunnen de resultaten minder representatief zijn voor ouders en verwanten met een meer sceptisch perspectief. Tot slot was de culturele en religieuze diversiteit onder de deelnemers beperkt, wat gevolgen kan hebben voor de interpretatie van constructen.

Implicaties voor toekomstig onderzoek

De bevindingen in dit proefschrift hebben verschillende implicaties voor de huidige inzichten en toekomstig onderzoek. Ten eerste gaven ouders en verwanten aan dat mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen hun psychologische basisbehoeften uiten, bijvoorbeeld door nieuwe of veranderingen in voorkeuren en vaardigheden. Daarnaast suggereren de resultaten dat zelfbepaling mogelijk verschillend geïnterpreteerd en ondersteund kan worden, afhankelijk van de ontwikkelingsfase van de persoon. Toekomstig kwalitatief en kwantitatief onderzoek wordt aangemoedigd om deze intra-persoonlijke verschillen en interne tegenstrijdigheden te onderzoeken. Ten tweede worden enkele suggesties geïllustreerd om de instrumenten die in hoofdstuk 3 zijn ontwikkeld te verbeteren. De bevindingen van hoofdstuk 2 impliceren bijvoorbeeld dat de items van de Autonomie-Ondersteunende Ervaringen vragenlijst slechts gedeeltelijk recht doen aan het concept zelfbepaling bij personen met (zeer) ernstige verstandelijke en meervoudige beperkingen, omdat de cruciale stap van het uitlokken van signalen niet wordt meegenomen. Het verfijnen van de vragenlijst door het meenemen van ondersteuning bij het uitlokken en interpreteren van signalen, evenals andere relevante, doelgroep-specifieke aspecten, zou kunnen zorgen voor betere aansluiting bij de unieke behoeften van deze populatie en een leidraad kunnen bieden voor meer gerichte ondersteuning door zorgverleners. Daarnaast kan verder geïdentificeerd worden wie de andere belangrijke ondersteuningspartners zijn die in de antwoorden van de informanten zijn opgenomen, evenals hoe zij het niveau van ondersteuning ervaren dat door elk van deze betrokken personen op individueel niveau of door een specifieke groep partners geboden wordt. Het in kaart brengen van informatie over specifieke omgevingsfactoren die de expressie en vervulling van psychologische basisbehoeften bevorderen of belemmeren, kan ook een waardevolle aanvulling zijn. Tot slot leken uitingen van frustratie bij de Signalen van Psychologische Basisbehoeften vragenlijst diffuus en soms zelfs paradoxaal, wat ertoe leidde dat deze items grotendeels werden verwijderd. Het wordt aanbevolen om mogelijke oplossingen te verkennen voor het formuleren van meer universele beschrijvingen van frustratie-gerelateerde items.

Implicaties voor de zorgpraktijk

De bevindingen uit de studies binnen dit proefschrift zijn ook relevant voor de zorgpraktijk. Ten eerste benadrukken de resultaten dat ouders en verwanten waardevolle inzichten hadden in de unieke en subtiele signalen van hun naaste met (zeer) ernstige verstandelijke en meervoudige beperkingen, die wezen op specifieke psychologische basisbehoeften. Professionals zouden de expertise van ouders en verwanten kunnen erkennen, zowel in het begrijpen van de unieke behoeften en voorkeuren van hun naaste, als in het versterken van hun vertrouwen in de rol van pleitbezorger voor diens belangen. Dit impliceert dat ouders en verwanten de gelegenheid zouden moeten krijgen om professionals te ondersteunen bij het duiden van signalen van hun naaste (bijvoorbeeld door te delen wat zij al weten over hoe en welke specifieke behoeften worden gecommuniceerd, hoe deze signalen gestimuleerd en herkend kunnen worden, welke hulpmiddelen daarbij zouden kunnen helpen en hoe optimale mogelijkheden voor het uiten van signalen gecreëerd kunnen worden). Tegelijkertijd gaven ouders en verwanten aan dat zij soms moeite hebben met het herkennen en correct interpreteren van signalen. Dit wijst erop dat zij mogelijk ondersteuning nodig hebben bij het structureren en verwoorden van hun kennis en ervaringen, bijvoorbeeld wanneer professionals specifieke vragen stellen. Het begrijpen van de dynamiek en het in kaart brengen van de obstakels die ouders en verwanten ervaren tijdens het proces van psychologische basisbehoefte-ondersteuning kan bijdragen aan de ontwikkeling van betere ondersteuningsstrategieën, interventies en beleidsmaatregelen die uiteindelijk de kwaliteit van leven van deze doelgroep kunnen verbeteren. Het theoretische stroomdiagram (Engels: flowchart) uit hoofdstuk 2 kan hierbij een rol spelen en nieuwe inzichten bieden aan professionals.

Algemene conclusie

Afsluitend kan gesteld worden dat de bevindingen in dit proefschrift ingaan op de betekenis en ondersteuning van zelfbepaling voor mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen zoals ervaren door hun ouders en verwanten, gezien vanuit de drie psychologische basisbehoeften: autonomie, competentie en verbondenheid. De studies vormen een eerste stap richting het verbeteren van zorg en ondersteuning met betrekking tot zelfbepaling binnen deze doelgroep, met aandacht voor de unieke uitdagingen die zowel deze personen zelf als hun ouders en verwanten ervaren. De resultaten onderstrepen het belang van het bewerkstelligen van omgevingen die gekenmerkt worden door autonomie-ondersteunende interacties, mogelijkheden voor constructieve uitdagingen en warme, zorgzame relaties. Om zelfbepaling centraal te stellen in alle fundamentele, betekenisvolle en juridische beslissingen die namens personen met (zeer) ernstige verstandelijke en meervoudige beperkingen worden genomen, is het essentieel om een sterk netwerk van belangrijke ondersteuningspartners op te zetten. Dit netwerk moet bestaan uit mensen die nauw en langdurig bij de persoon betrokken zijn en gezamenlijk een breder en dieper begrip van de persoon kunnen ontwikkelen dan één individu ooit alleen zou kunnen realiseren.

References

Adams, N., Little, T. D., & Ryan, R. M. (2017). Self-determination theory. In M. L. Wehmeyer, K. A. Shogren, T. D. Little, & S. J. Lopez (Eds.), *Development of self-determination through the life-course* (pp. 47–54). Springer: Dordrecht, The Netherlands.

Adams, T. M., & Jahoda, A. (2019). Listening to mothers: Experiences of mental health support and insights into adapting therapy for people with severe or profound intellectual disabilities. *International Journal of Developmental Disabilities, 65*(3), 135–142. https://doi.org/10.1080/20473869.2019.1609306

Ainsworth, M. D. S., Blehar, M. C., Waters, E., & Wall, S. (1978). *Patterns of attachment: Observations in the strange situation and at home.* Lawrence Erlbaum Associates: Hillsdale, MI, USA.

Akkerman, A., Kef, S., & Meininger, H. P. (2017). Job satisfaction of people with intellectual disabilities: the role of basic psychological need fulfillment and workplace participation. *Disability and Rehabilitation*, *40*(10), 1192–1199. https://doi.org/10.1080/09638288.2017.1294205

Alonso-Sardón, M., Iglesias-de-Sena, H., Fernández-Martín, L. C., & Mirón-Canelo, J. A. (2019). Do health and social support and personal autonomy have an influence on the health-related quality of life of individuals with intellectual disability? *BMC Health Services Research*, *19*(1). https://doi.org/10.1186/s12913-018-3856-5

Anderson, E. E., Boyd, B., Qureskhi, N. K., Stirling, J. M., McCarthy, V., & Kuczewski, M. G. (2019). Operation homefront: Meeting clerkship competencies with home visits to families of children with special needs. *Academic Pediatrics, 19*(2), 170–176. https://doi.org/10.1016/j.acap.2018.09.002

Arai, Y., Kadekaru, R., Okanishi, T., Tamasaki, A., & Maegaki, Y. (2024). Assessing the subjective happiness of parents of children with severe motor and intellectual disabilities receiving home care. *Cureus, 16*(7), e64562. https://doi.org/10.7759/cureus.64562

Audet É. C., Levine S. L., Holding A. C., Koestner R., & Powers T. A. (2021). A remarkable alliance: Sibling autonomy support and goal progress in emerging adulthood. *Family Relations, 70*(5), 1571–1582. https://doi.org/10.1111/fare.12562

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, *84*(2), 191–215. https://doi.org/10.1037/0033-295x.84.2.191

Bartlett, M. S. (1950). Tests of significance in factor analysis. *British Journal of Psychology, Statistical Section, 3*(2), 77–85. https://doi.org/10.1111/j.2044-8317.1950.tb00285.x

Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin, 117*(3), 497–529. https://doi.org/10.1037/0033-2909.117.3.497

Beadle-Brown, J., Beecham, J., Leigh, J., Whelton, R., & Richardson, L. (2021). Outcomes and costs of skilled support for people with severe or profound intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities, 34*(1), 42–54. https://doi.org/10.1111/jar.12782

Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2015). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, *29*(5), 409–421. https://doi.org/10.1111/jar.12200

Behzadnia, B., Rezaei, F., & Salehi, M. (2022). A need-supportive teaching approach among students with intellectual disability in physical education. *Psychology of Sport and Exercise, 60*, 102156. https://doi.org/10.1016/j.psychsport.2022.102156

Beighton, C., & Wills, J. (2019). How parents describe the positive aspects of parenting their child who has intellectual disabilities: A systematic review and narrative synthesis. *Journal of Applied Research in Intellectual Disabilities, 32*(5), 1255–1279. https://doi.org/10.1111/jar.12617

Bigby C., Bowers B., & Webber R. (2011). Planning and decision making about the future care of older group home residents and transition to residential aged care. *Journal of Intellectual Disability Research 55*(8), 777–789. https://doi.org/10.1111/j.1365-2788.2010.01297.x

Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S.-N., & Wiesel, I. (2021). Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences. *Journal of Intellectual & Developmental Disability*, *47*(2), 165–176. https://doi.org/10.3109/13668250.2021.1954481

Boumans, J., Van Boekel, L. C., Baan, C. A., & Luijkx, K. G. (2019). How can autonomy be maintained and informal care improved for people with dementia living in residential care facilities: A systematic literature review. *The Gerontologist*, *59*(6), e709–e730. https://doi.org/10.1093/geront/gny096

Bowen, G. A. (2006). Grounded theory and sensitizing concepts. *International Journal of Qualitative Methods, 5*(3), 12–23. https://doi.org/10.1177/160940690600500304

Bradshaw, E. L., Duineveld, J., Conigrave, J. H., Steward, B. A., Ferber, K., Joussemet, M., Parker, P., & Ryan, R. M. (2024). Disentangling autonomy-supportive and psychologically controlling parenting: A meta-analysis of self-determination theory's dual process model across cultures. *American Psychologist*. https://doi.org/10.31234/osf.io/maf3e

Bredewold, F., & van der Weele, S. (2024). Navigating uncertainty: Taking methodological cues from relatives and care professionals for researching the perspectives of people with profound intellectual and multiple disabilities. *Journal Of Intellectual & Developmental Disability*, 1–12. https://doi.org/10.3109/13668250.2024.2408553

Bridges W. (2004). *Transitions: Making sense of life's changes*, 2nd ed., DaCapo Press: Cambridge, MA.

Bühler, K. (1924). *Die Geistige Entwicklung des Kindes [The spiritual development of the child]*, 4th ed. Gustav Fischer: Jena, Germany.

Buthelezi, S., & Mawila, D. (2024). There is always sorrow: Risk factors faced by parents of children presenting with severe intellectual disabilities. *Journal of Intellectual Disability - Diagnosis and Treatment*, *12*(1), 12–21. https://doi.org/10.6000/2292-2598.2024.12.01.2

Carey, E., Ryan, R., Sheikhi, A., & Dore, L. (2023). Exercising autonomy—The effectiveness and meaningfulness of autonomy support interventions engaged by adults with intellectual disability. A mixed-methods review. *British Journal of Learning Disabilities*, *51*(3), 307–323. https://doi.org/10.1111/bld.12464

Carter, E. W., Owens, L., Trainor, A. A., Sun, Y., & Swedeen, B. (2009). Self-determination skills and opportunities of adolescents with severe intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities, 114*(3), 179–192. https://doi.org/10.1352/1944-7558-114.3.179

Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research, 1*(2), 245–276. https://doi.org/10.1207/s15327906mbr0102_10

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage: London, UK.

Chirkov, V., Ryan, R. M., Kim, Y., & Kaplan, U. (2003). Differentiating autonomy from individualism and independence: A self-determination theory perspective on internalization of cultural orientations and well-being. *Journal of Personality and Social Psychology*, *84*(1), 97–110. https://doi.org/10.1037/0022-3514.84.1.97

Chu, S.-Y. (2018). Perspectives of Taiwanese families: A preliminary study on promoting self-determination skills of young children with disabilities. *Early Childhood Education Journal, 46*(6), 673–681. https://doi.org/10.1007/s10643-018-0909-7

Coiffait, F. M. M. (2012). *Cognitive factors and subjective wellbeing in parents who have children with profound and multiple intellectual disability* [Doctoral dissertation, University of Edinburgh]. Retrieved from Coiffait2013.pdf

Colmar, S., Maxwell, A., & Miller, L. (2006). Assessing intellectual disability in children: Are IQ measures sufficient, or even necessary? *Australian Journal of Guidance and Counselling*, *16*(2), 177–188. https://doi.org/10.1375/ajgc.16.2.177

Conners, F., Phillips, B., Rhodes, J., & Hamilton, J. (2014). Family experience in a regional participant contact registry for research on intellectual disability. *Intellectual and Developmental Disabilities, 52*, 112–123. https://doi.org/10.1352/1934-9556-52.2.112

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Sage: Thousand Oaks, CA, USA.

Coughlin, M. B., & Sethares, K. A. (2017). Chronic sorrow in parents of children with a chronic illness or disability: An integrative literature review. *Journal of Pediatric Nursing*, *37*, 108–116. https://doi.org/10.1016/j.pedn.2017.06.011

Cowan, P. A., & Cowan, C. P. (2003). Normative family transitions, normal family processes, and healthy child development. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (3rd ed., pp. 424–459). The Guilford Press.

Cudré-Mauroux, A., Piérart, G., & Vaucher, C. (2020). Partnership with social care professionals as a context for promoting self-determination among people with intellectual disabilities. *Research in Developmental Disabilities*, *99*, 103602. https://doi.org/10.1016/j.ridd.2020.103602

De Geeter K. I., Poppes P., & Vlaskamp C (2002). Parents as experts: the position of parents of children with profound multiple disabilities. *Child: Care, Health and Development 28*(6), 443–453. https://doi.org/10.1046/j.1365-2214.2002.00294.x

De Geus-Neelen K. C. J. M., van Oorsouw W. M. W. J., & Embregts, P. J. C. M. (2014). Individueel wonen. Een kans op meer keuzemogelijkheden en minder vrijheidsbeperking voor mensen met een ernstige verstandelijke beperking en gedragsproblemen? [Individual living. A chance of more choice opportunities and less restrictive interventions for people with severe intellectual disabilities and challenging behaviour?]. *Orthopedagogiek: Onderzoek en Praktijk 53*(12), 477–492.

De Geus-Neelen K. C. J. M., van Oorsouw W. M. W. J., Hendriks L. A. H. C., & Embregts P. J. C. M. (2019). Perceptions of staff and family of the quality of life of people with severe to profound intellectual disability. *Journal of Intellectual & Developmental Disability 44*(1), 42–50. https://doi.org/10.3109/13668250.2017.1310813

De Haas, C., Grace, J., Hope, J., & Nind, M. (2022). Doing research inclusively: Understanding what it means to do research with and alongside people with profound intellectual disabilities. *Social Sciences*, *11*(4), 159. https://doi.org/10.3390/socsci11040159

De Knegt, N. C., Lobbezoo, F., Schuengel, C., Evenhuis, H. M., & Scherder, E. J. (2017). Self-reported presence and experience of pain in adults with Down syndrome. *Pain Medicine*, *18*(7), 1247-1263. https://doi.org/10.1093/pm/pnw226

Dean, E. E., Kirby, A. V., Hagiwara, M., Shogren, K. A., Ersan, D. T., & Brown, S. (2021). Family role in the development of self-determination for youth with intellectual and developmental disabilities: A scoping review. *Intellectual and Developmental Disabilities, 59*(4), 315–334. https://doi.org/10.1352/1934-9556-59.4.315

Deci, E. L. (2004). Promoting intrinsic motivation and self-determination in people with mental retardation. In *International review of research in mental retardation* (Vol. 28, pp. 1–29). Academic Press. https://doi.org/10.1016/s0074-7750(04)28001-6

Deci, E. L., & Ryan, R. M. (2000). The "what" and "why" of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry, 11*(4), 227–268. https://doi.org/10.1207/S15327965PLI1104_01

Deci, E. L., & Ryan, R. M. (2002). Self-determination research: Reflections and future directions. In E. L. Deci & R. M. Ryan (Eds.), *Handbook of self-determination research* (pp. 431–441). University of Rochester Press: Rochester, NY, USA.

Deci, E. L., & Ryan, R. M. (2008). Facilitating optimal motivation and psychological well-being across life's domains. *Canadian Psychology/Psychologie Canadienne*, *49*(1), 14–23. https://doi.org/10.1037/0708-5591.49.1.14

Deci, E. L., & Ryan, R. M. (2012). Motivation, personality, and development within embedded social contexts: An overview of self-determination theory. In R. M. Ryan (Ed.), *Oxford Handbook of Human Motivation* (pp. 85–107). Oxford: Oxford University Press. https://doi.org/10.1093/oxfordhb/9780195399820.013.0006

Dhondt A., Van keer I., Ceulemans E., van der Putten A. A. J., & Maes B. (2023). Describing the communicative profiles of young children with a significant cognitive and motor developmental delay. *Augmentative and Alternative Communication 39*(2), 84–95. https://doi.org/10.1080/07434618.2022.2138780

Dhondt A., Van keer I., Nijs S., van der Putten A. A. J., & Maes B. (2021). In search of a novel way to analyze early communicative behavior. *Augmentative and Alternative Communication 37*(2), 87–101. https://doi.org/10.1080/07434618.2021.1928283

Dollar, C. A., Fredrick, L. D., Alberto, P. A., & Luke, J. K. (2012). Using simultaneous prompting to teach independent living and leisure skills to adults with severe intellectual disabilities. *Research in Developmental Disabilities, 33*(1), 189–195. https://doi.org/10.1016/j.ridd.2011.09.001

Doodeman, T. W. M., Schuengel, C., & Sterkenburg, P. S. (2022). Expressions of stress of people with severe intellectual disabilities and sensitive caregiving to regulate stress: A qualitative study. *Journal of Intellectual & Developmental Disability*, *47*(4), 308–317. https://doi.org/10.3109/13668250.2021.2011171

Doodeman, T. W. M., Schuengel, C., & Sterkenburg, P. S. (2023). Effects of the Attune & Stimulate-checklist for caregivers of people with severe and profound intellectual disabilities: A randomised controlled trial. *Journal of Applied Research in Intellectual Disabilities*, *36*(5), 1136–1149. https://doi.org/10.1111/jar.13135

Dorsman, N. I., Waninge, A., van der Schans, C. P., Luijkx, J., & van der Putten, A. A. J. (2023). The roles of adult siblings of individuals with a profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *36*(6), 1308–1318. https://doi.org/10.1111/jar.13149

Dos Santos, M. A., & Pereira-Martins, M. L. P. L. (2016). Coping strategies adopted by parents of children with intellectual disabilities. *Ciencia & Saude Coletiva*, *21*(10), 3233–3244. https://dx.doi.org/10.1590/1413-812320152110.14462016

Doyle, C. (2022a). Mothers' experiences of giving medicines to children with severe and profound intellectual disabilities—The impact on time. *Child: Care, Health and Development*, *48*(4), 558–568. https://doi.org/10.1111/cch.12960

Doyle, C. (2022b). The importance of supportive relationships with general practitioners, hospitals and pharmacists for mothers who 'give medicines' to children with severe and profound intellectual disabilities. *Journal of Intellectual Disabilities*, *26*(1), 29–49. https://doi.org/10.1177/1744629520951003

Droogmans, G., Nijs, S., & Maes, B. (2024). Capturing staff perspectives on quality interaction with clients with intellectual disability: A diary study. *Intellectual and Developmental Disabilities*, *62*(5), 376–391. https://doi.org/10.1352/1934-9556-62.5.376

Eekhout, I., Enders, C. K., Twisk, J. W., de Boer, M. R., de Vet, H. C., & Heymans, M. W. (2015). Including auxiliary item information in longitudinal data analyses improved handling missing questionnaire outcome data. *Journal of Clinical Epidemiology, 68*(6), 637–645. https://doi.org/10.1016/j.jclinepi.2015.01.012

Embregts P. J. C. M., Heerkens L., Frielink N., Giesbers S., Vromans L., & Jahoda A. (2021). Experiences of mothers caring for a child with an intellectual disability during the COVID-19 pandemic in the Netherlands. *Journal of Intellectual Disability Research 65*(8), 760–771. https://doi.org/10.1111/jir.12859

Embregts, P. J. C. M., Negenman, A., Habraken, J. M., de Boer, M. E., Frederiks, B. J. M., & Hertogh, C. M. P. M. (2019). Restraint interventions in people with moderate to profound intellectual disabilities: Perspectives of support staff and family members. *Journal of Applied Research in Intellectual Disabilities, 32*(1), 172–183. https://doi.org/10.1111/jar.12519

Emerson, E., Felce, D., & Stancliffe, R. J. (2013). Issues concerning self-report data and population-based data sets involving people with intellectual disabilities. *Intellectual and Developmental Disabilities*, *51*(5), 333–348. https://doi.org/10.1352/1934-9556-51.5.333

Emond Pelletier, J., & Joussemet, M. (2017). The benefits of supporting the autonomy of individuals with mild intellectual disabilities: An experimental study. *Journal of Applied Research in Intellectual Disabilities*, *30*(5), 830–846. https://doi.org/10.1111/jar.12274

Erickson, A. S. G., Noonan, P. M., Zheng, C., & Brussow, J. A. (2015). The relationship between self-determination and academic achievement for adolescents with intellectual disabilities. *Research in Developmental Disabilities*, *36*, 45-54. https://doi.org/10.1016/j.ridd.2014.09.008

Estreder, Y., Martínez-Tur, V., Moliner, C., Gracia, E., & Lira, E. (2024). The voice of persons with intellectual disability: Why does autonomy support make them feel better? *Applied Psychology*, *73*(3), 1055–1070. https://doi.org/10.1111/apps.12487

Evans C., Margison F., & Barkham M. (1998). The contribution of reliable and clinically significant change methods to evidence-based mental health. *British Medical Journal Mental Health 1*(3), 70–72. http://dx.doi.org/10.1136/ebmh.1.3.70

Faber J., Fonseca L. M. (2014). How sample size influences research outcomes. *Dental Press Journal of Orthodontics 19*, 27–29. https://doi.org/10.1590/2176-9451.19.4.027-029.ebo

Fava, L., & Strauss, K. (2009). Multi-sensory rooms: Comparing effects of the Snoezelen and the Stimulus Preference environment on the behavior of adults with profound mental retardation. *Research in Developmental Disabilities*, *31*(1), 160–171. https://doi.org/10.1016/j.ridd.2009.08.006

Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, *16*(1), 51–74. https://doi.org/10.1016/0891-4222(94)00028-8

Flanagan, J. C. (1978). A research approach to improving our quality of life. *American Psychologist, 33*(2), 138–147. https://doi.org/10.1037/0003-066X.33.2.138

Flynn, S., Vereenooghe, L., Hastings, R. P., Adams, D., Cooper, S.-A., Gore, N., Hatton, C., Hood, K., Jahoda, A., Langdon, P. E., McNamara, R., Oliver, C., Roy, A., Totsika, V., & Waite, J. (2017). Measurement tools for mental health problems and mental well-being in people with severe or profound intellectual disabilities: A systematic review. *Clinical Psychology Review*, *57*, 32–44. https://doi.org/10.1016/j.cpr.2017.08.006

Fokkema, M., & Greiff, S. (2017). How performing PCA and CFA on the same data equals trouble: Overfitting in the assessment of internal structure and some editorial thoughts on it [Editorial]. *European Journal of Psychological Assessment, 33*(6), 399–402. https://doi.org/10.1027/1015-5759/a000460

Foley, K.-R., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability and Rehabilitation*, *34*(20), 1747–1764. https://doi.org/10.3109/09638288.2012.660603

Forster, S., Gray, K. M., Taffe, J., Einfeld, S. L., & Tonge, B. J. (2011). Behavioural and emotional problems in people with severe and profound intellectual disability. *Journal of Intellectual Disability Research*, *55*(2), 190–198. https://doi.org/10.1111/j.1365-2788.2010.01373.x

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

Frankena, T. K. (2019). *Optimising inclusive health research: where expectations and realities meet. Meaningful collaboration with people with intellectual disabilities* [Doctoral dissertation, Radboud Universiteit Nijmegen]. Retrieved from 199055.pdf

Frankena, T. K., Naaldenberg, J., Cardol, M., Garcia Iriarte, E., Buchner, T., Brooker, K., Embregts, P. J. C. M., Joosa, E., Crowther, F., Schormans, A. F., Schippers, A., Walmsley, J., O'Brien, P., Linehan, C., Northway, R., van Schrojenstein Landman-de Valk, H., & Leusink, G. (2018). A consensus statement on how to conduct inclusive health research. *Journal Of Intellectual Disability Research*, *63*(1), 1–11. https://doi.org/10.1111/jir.12486

Frielink, N., Schuengel, C., & Embregts, P. J. C. M. (2018). Autonomy support, need satisfaction, and motivation for support among adults with intellectual disability: Testing a self-determination theory model. *American Journal on Intellectual and Developmental Disabilities, 123*(1), 33–49. https://doi.org/10.1352/1944-7558-123.1.33

Frielink, N., Schuengel, C., & Embregts, P. J. C. M. (2019). Psychometric properties of the Basic Psychological Need Satisfaction and Frustration Scale – Intellectual Disability (BPNSFS-ID). *European Journal of Psychological Assessment, 35*(1), 37–45. https://doi.org/10.1027/1015-5759/a000366

Frielink, N., Schuengel, C., & Embregts, P. J. C. M. (2021). Evaluating the self-determination continuum towards seeking support among people with mild to borderline intellectual disabilities. *Journal of Intellectual Disability Research*, *65*(4), 348–360. https://doi.org/10.1111/jir.12819

Frielink, N., Schuengel, C., van der Ven, S. H. G., & Embregts, P. J. C. M. (2024). The prospective associations between autonomy support, basic psychological needs, motivation and well-being among people with a mild to borderline intellectual disability: A two-wave study. *Journal of Intellectual Disability Research, 68*(10), 1192–1207. https://doi.org/10.1111/jir.13163

Fusinska-Korpik, A., & Gacek, M. (2022). Decision-making in people with mild intellectual disability: Relations with intelligence and a measure of executive functioning. *Journal of Intellectual & Developmental Disability, 47*(1), 87–95. https://doi.org/10.3109/13668250.2021.1945416

Gauthier-Boudreault, C., Couture, M., & Gallagher, F. (2018). How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability. *Journal* *of Applied Research in Intellectual Disabilities*, *31*(S2), 215–223. https://doi.org/10.1111/jar.12394

Gauthier-Boudreault, C., Couture, M., & Gallagher, F. (2021). Obstacles to the transition to adulthood of people with severe to profound intellectual disability and potential solutions: Perspectives of professionals in one region of Quebec. *Journal of Intellectual & Developmental Disability*, *46*(3), 239–249. https://doi.org/10.3109/13668250.2021.1873753

Gauthier-Boudreault, C., Gallagher, F., & Couture, M. (2017). Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing? *Research in Developmental Disabilities*, *66*, 16–26. https://doi.org/10.1016/j.ridd.2017.05.001

Geuze, L., & Goossensen, A. (2019). Parents caring for children with normal life span threatening disabilities: A narrative review of literature. *Scandinavian Journal of Caring Sciences*, *33*(2), 279–297. https://doi.org/10.1111/scs.12643

Geuze, L., & Goossensen, A. (2021). Exploring the experiences of Dutch parents caring for children with profound intellectual and multiple disabilities: A thematic analysis of their blogs. *Global Qualitative Nursing Research*, *8*, 23333936211028170. https://doi.org/10.1177/23333936211028170

Geuze, L., & Goossensen, A. (2023). Caring for children with profound intellectual and multiple disabilities: images and metaphors expressed by Dutch parents. *Disability & Society*, *39*(7), 1840–1858. https://doi.org/10.1080/09687599.2023.2164846

Geuze, L., Goossensen, A., & Schrevel, S. (2023). “Continuously struggling for balance”: The lived experiences of Dutch parents caring for children with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, *48*(2), 161–171. https://doi.org/10.3109/13668250.2022.2073707

Gillison, F., Standage, M., & Skevington, S. (2008). Changes in quality of life and psychological need satisfaction following the transition to secondary school. *British Journal of Educational Psychology, 78*(1), 149–162. https://doi.org/10.1348/000709907X209863

Gjermestad, A., Skarsaune, S. N., & Bartlett, R. L. (2022). Advancing inclusive research with people with profound and multiple learning disabilities through a sensory-dialogical approach. *Journal of Intellectual Disabilities*, *27*(1), 40–53. https://doi.org/10.1177/17446295211062390

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine: New York, NY, USA.

Glasser, W. (1998). *Choice Theory: A New Psychology of Personal Freedom*. HarperCollinsPublishers.

Goldbart, J. (2023). Communication as a human right for children with profound intellectual disabilities. *Developmental Medicine & Child Neurology*, *65*(6). https://doi.org/10.1111/dmcn.15564

Goldbart, J., & Caton, S. (2010). *Communication and people with the most complex needs: What works and why this is essential*. Research Institute for Health and Social Change Manchester Metropolitan University (MMU). Retrieved from Mencap Comms_guide_dec_10.pdf

Goodall, M., Irving, K., & Nevin, M. (2023). The recognition, assessment and perceptions of total pain in people with profound intellectual disabilities: A mixed methods systematic review. *Journal of Applied Research in Intellectual Disabilities*, *36*(5), 940–950. https://doi.org/10.1111/jar.13132

Gordon, J. (2009). An evidence-based approach for supporting parents experiencing chronic sorrow. *Pediatric Nursing, 35*(2), 115–119. https://pubmed.ncbi.nlm.nih.gov/19472675

Grace, J., Nind, M., de Haas, C., & Hope, J. (2024). Expanding possibilities for inclusive research: Learning from people with profound intellectual and multiple disabilities and decolonising research. *Social Sciences*, *13*(1), 37. https://doi.org/10.3390/socsci13010037

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

Griffiths, C., & Smith, M. (2017). You and me: The structural basis for the interaction of people with severe and profound intellectual disability and others. *Journal of Intellectual Disabilities*, *21*(2), 103–117. https://doi.org/10.1177/1744629516644380

Grolnick, W. S. (2009). The role of parents in facilitating autonomous self-regulation for education. *Theory and Research in Education, 7*(2), 164–173. https://doi.org/10.1177/1477878509104321

Grolnick, W. S., Gurland, S. T., DeCourcey, W., & Jacob, K. (2002). Antecedents and consequences of mothers' autonomy support: An experimental investigation. *Developmental Psychology*, *38*(1), 143–155. https://doi.org/10.1037/0012-1649.38.1.143

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

Gruber-Baldini, A. L., Shardell, M., Lloyd, K. D., & Magaziner, J. (2012). Use of Proxies and Informants. In A. B. Newman & J. A. Cauley (Eds.), *The epidemiology of aging* (pp. 81–90). https://doi.org/10.1007/978-94-007-5061-6_6

Guay, F., Ratelle, C. F., & Chanal, J. (2008). Optimal learning in optimal contexts: The role of self-determination in education. *Canadian Psychology/Psychologie Canadienne*, *49*(3), 233–240. https://doi.org/10.1037/a0012758

Gucciardi, E., Di Liao, C., & Cameron, J. I. (2010). determining the factors associated with health research participation. *Journal of Ambulatory Care Management*, *33*(3), 272–284. https://doi.org/10.1097/jac.0b013e3181e62d3c

Haishi, K., Okuzumi, H., & Kokubun, M. (2011). Effects of age, intelligence and executive control function on saccadic reaction time in persons with intellectual disabilities. *Research in Developmental Disabilities*, *32*(6), 2644–2650. https://doi.org/10.1016/j.ridd.2011.06.009

Hall, S. A., & Rossetti, Z. (2018). The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*(3), 423–434. https://doi.org/10.1111/jar.12421

Hammann, T., Valič, J., Slapničar, G., & Luštrek, M. (2022). The missing piece: Physiological data as a factor for identifying emotions of people with profound intellectual and multiple disabilities. *International Journal of Developmental Disabilities, 70*(5), 887–903. https://doi.org/10.1080/20473869.2022.2154928

Hardré, P. L., & Reeve, J. (2009). Training corporate managers to adopt a more autonomy-supportive motivating style toward employees: An intervention study. *International Journal of Training and Development*, *13*(3), 165–184. https://doi.org/10.1111/j.1468-2419.2009.00325.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

Helwig, C. C. (2006). The development of personal autonomy throughout cultures. *Cognitive Development*, *21*(4), 458–473. https://doi.org/10.1016/j.cogdev.2006.06.009

Hewitt, O., Langdon, P. E., Tapp, K., & Larkin, M. (2023). A systematic review and narrative synthesis of inclusive health and social care research with people with intellectual disabilities: How are co-researchers involved and what are their experiences? *Journal of Applied Research in Intellectual Disabilities*, *36*(4), 681–701. https://doi.org/10.1111/jar.13100

Hogg, J., Juhlberg, K., & Lambe, L. (2007). Policy, service pathways and mortality: a 10-year longitudinal study of people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, *51*(5), 366–376. https://doi.org/10.1111/j.1365-2788.2006.00884.x

Hoogsteyns, M., Zaal-Schuller, I., Huisman, S., Nieuwenhuijse, A. M., van Etten-Jamaludi, F., Willems, D., & Kruithof, K. (2023). Tacit knowledge in dyads of persons with profound intellectual and multiple disabilities and their caregivers: An interpretative literature study. *Journal of Applied Research in Intellectual Disabilities*, *36*(5), 966–977. https://doi.org/10.1111/jar.13134

Hornstra, L., Stroet, K., van Eijden, E., Goudsblom, J., & Roskamp, C. (2018). Teacher expectation effects on need-supportive teaching, student motivation, and engagement: A self-determination perspective. *Educational Research and Evaluation, 24*(3-5), 324–345. https://doi.org/10.1080/13803611.2018.1550841

Hostyn, I., Daelman, M., Janssen, M. J., & Maes, B. (2010). Describing dialogue between persons with profound intellectual and multiple disabilities and direct support staff using the scale for dialogical meaning making. *Journal of Intellectual Disability Research, 54*(8), 679–690. https://doi.org/10.1111/j.1365-2788.2010.01292.x

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

Hubach, A. G. (2020). *Exploring the lived experiences and coping strategies of parents of children with profound intellectual and multiple disabilities* [Doctoral dissertation, Liberty University]. Retrieved from viewcontent.cgi

Iacono, T., West, D., Bloomberg, K., & Johnson, H. (2009). Reliability and validity of the revised Triple C: C hecklist of C ommunicative C ompetencies for adults with severe and multiple disabilities. *Journal of Intellectual Disability Research*, *53*(1), 44–53. https://doi.org/10.1111/j.1365-2788.2008.01121.x

IBM Corp. (2020). *IBM SPSS Statistics for Windows* (Version 27.0) [Computer software]. IBM Corp: Armonk, NY.

Jacobs, P., MacMahon, K., & Quayle, E. (2018). Transition from school to adult services for young people with severe or profound intellectual disability: A systematic review utilizing framework synthesis. *Journal of Applied Research in Intellectual Disabilities, 31*(6), 962–982. https://doi.org/10.1111/jar.12466

Janssen, C. G. C., Voorman, J. M., Becher, J. G., Dallmeijer, A. J., & Schuengel, C. (2010). Course of health-related quality of life in 9–16-year-old children with cerebral palsy: Associations with gross motor abilities and mental health. *Disability and Rehabilitation, 32*(4), 344–351. https://doi.org/10.3109/09638280903166345

Jansen, S. L. G., van der Putten, A. A. J., Post, W. J., & Vlaskamp, C. (2017). Do they agree? How parents and professionals perceive the support provided to persons with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, *43*(4), 441–452. https://doi.org/10.3109/13668250.2017.1287885

Jansen, S. L. G., van der Putten, A. A. J., & Vlaskamp, C. (2013). What parents find important in the support of a child with profound intellectual and multiple disabilities. *Child: Care Health and Development*, *39*(3), 432–441. https://doi.org/10.1111/j.1365-2214.2012.01381.x

Jansen, S. L. G., van der Putten, A. A. J., & Vlaskamp, C. (2017). Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: A multiple case study. *Journal of Intellectual Disabilities*, *21*(1), 53–67. https://doi.org/10.1177/174462951664184

Jenaro, C., Flores, N., Gutiérrez-Bermejo, B., Vega, V., Pérez, C., & Cruz, M. (2020). Parental stress and family quality of life: Surveying family members of persons with intellectual disabilities. *International Journal of Environmental Research and Public Health, 17*(23), 9007. https://doi.org/10.3390/ijerph17239007

Kaiser, H. F. A. (1970). A second generation little jiffy. *Psychometrika, 35*(4), 401–416. https://doi.org/10.1007/BF02291817

Keirse, M. (2017). Een levend verlies. In *M. Keirse (Red.), Helpen bij verlies en verdriet. Een gids voor het gezin ende hulpverlener*, 207–221. Lannoo Meulenhoff-Belgium.

Kim, J. P., Mondal, S., Tsungmey, T., Ryan, K., Dunn, L. B., & Roberts, L. W. (2022). Influence of dispositional optimism on ethically salient research perspectives: A pilot study. *Ethics & Human Research*, *44*(3), 12–23. https://doi.org/10.1002/eahr.500126

Kins, E., Beyers, W., Soenens, B., & Vansteenkiste, M. (2009). Patterns of home leaving and subjective well-being in emerging adulthood: The role of motivational processes and parental autonomy support. *Developmental Psychology, 45*(5), 1416–1429. https://doi.org/10.1037/a0015580

Kosiedowski, M., Gluszak, B., Engelhardt, M., Krämer, T., & Urbanski, J. (2019). Global atlas of people with profound intellectual and multiple disabilities. *The Journal on Technology and Persons with Disabilities*, 106. Retrieved from https://www.researchgate.net/profile/Meike-Engelhardt/publication/334393137_Global_Atlas_of_People_with_Profound_Intellectual_and_Multiple_Disabilities/links/5d2727aca6fdcc2462d51fa1/Global-Atlas-of-People-with-Profound-Intellectual-and-Multiple-Disabilities.pdf

Kralik, D., Visentin, K., & van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing, 55*(3), 320–329. https://doi.org/10.1111/j.1365-2648.2006.03899.x

Kruithof, K., Hoogesteyns, M., Zaal-Schuller, I., Huisman, S., Willems, D., & Nieuwenhuijse, A. (2024). Parents' tacit knowledge of their child with profound intellectual and multiple disabilities: A qualitative study. *Journal of Intellectual & Developmental Disability*, 1-10. https://doi.org/10.3109/13668250.2024.2336084

Kruithof, K., IJzerman, L., Nieuwenhuijse, A., Huisman, S., Schippers, A., Willems, D., & Olsman, E. (2021). Siblings' and parents' perspectives on the future care for their family member with profound intellectual and multiple disabilities: A qualitative study. *Journal of Intellectual & Developmental Disability*, *46*(4), 351–361. https://doi.org/10.3109/13668250.2021.1892261

Kruithof, K., Willems, D., Nieuwenhuijse, A., & Olsman, E. (2022). Care and support for persons with profound intellectual and multiple disabilities without parents: A qualitative exploration. *Research in Developmental Disabilities*, *130*, 104334. https://doi.org/10.1016/j.ridd.2022.104334

Kruithof, K., Willems, D., van Etten-Jamaludin, F., & Olsman, E. (2020). Parents' knowledge of their child with profound intellectual and multiple disabilities: An interpretative synthesis. *Journal of Applied Research in Intellectual Disabilities, 33*(6), 1141–1150. https://doi.org/10.1111/jar.12740

Kúld, P. B., Frielink, N., Schuengel, C., & Embregts, P. J. C. M. (2024). Supporting self-determination of individuals with severe or profound intellectual and multiple disabilities according to relatives and healthcare professionals: A concept mapping study. *Journal of Applied Research in Intellectual Disabilities*, *37*(4), e13267. https://doi.org/10.1111/jar.13267

Kuld, P. B., Frielink, N., Zijlmans, M., Schuengel, C., & Embregts, P. J. C. M. (2023). Promoting self-determination of persons with severe or profound intellectual disabilities: A systematic review and meta-analysis. *Journal of Intellectual Disability Research, 67*(7), 589–629. https://doi.org/10.1111/jir.13036

Kuijken, N. M. J., Vlot-van Anrooij, K., van Schrojenstein Lantman-de Valk, H. M. J., Leusink, G., Naaldenberg, J., & Nijhuis-van der Sanden, M. W. (2019). Stakeholder expectations, roles and responsibilities in Dutch health promotion for people with intellectual disabilities. *Health Promotion International*, *34*(5), e59-e70. https://doi.org/10.1093/heapro/day059

Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M.-C., Courbois, Y., Keith, K. D., Schalock, R., Verdugo, M. A., & Walsh, P. N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research, 49*(10), 740–744. https://doi.org/10.1111/j.1365-2788.2005.00743.x

Lahaije, S. T., Luijkx, J., Waninge, A., & van der Putten, A. A. J. (2023a). Support needs of families with a child with profound intellectual and multiple disabilities. *International Journal of Developmental Disabilities*, 1–14. https://doi.org/10.1080/20473869.2023.2168718

Lahaije, S. T., Luijkx, J., Waninge, A., & van der Putten, A. A. J. (2023b). Well-Being of families with a child with profound intellectual and multiple disabilities. *Research and Practice for Persons with Severe Disabilities*, *48*(2), 63–78. https://doi.org/10.1177/15407969231173916

Lee, C. E., & Burke, M. M. (2018). Caregiving roles of siblings of adults with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(3), 237–246. https://doi.org/10.1111/jppi.12246

Lifshitz, H., Klein, P. S., & Cohen, S. F. (2010). Effects of MISC intervention on cognition, autonomy, and behavioral functioning of adult consumers with severe intellectual disability. *Research in Developmental Disabilities, 31*(4), 881–894. https://doi.org/10.1016/j.ridd.2010.02.012

Lloyd, T., & Hastings, R. P. (2009). Parental locus of control and psychological well-being in mothers of children with intellectual disability. *Journal of Intellectual and Developmental Disability*, *34*(2), 104–115. https://doi.org/10.1080/13668250902862074

Ludwig, N. N., Wojnaroski, M., Suskauer, S. J., Slomine, B. S., Kaiser, A., Paltell, K., Evans, L., Tucker, K., Chapman, C. A. T., Conecker, G., Hecker, J., Schust Myers, L., Downs, J., & Berg, A. T. (2024). Novel approaches to measuring cognition in individuals with severe to profound functional impairment: A pilot study in SCN2A-related disorder. *Epilepsy & Behavior*, *160*, 109975. https://doi.org/10.1016/j.yebeh.2024.109975

Luijkx, J., van der Putten, A. A. J., & Vlaskamp, C. (2017). Time use of parents raising children with severe or profound intellectual and multiple disabilities. *Child: Care, Health and Development, 43*(4), 518–526. https://doi.org/10.1111/cch.12446

Luijkx, J., van der Putten, A. A. J., & Vlaskamp, C. (2019). A valuable burden? The impact of children with profound intellectual and multiple disabilities on family life. *Journal of Intellectual & Developmental Disability*, *44*(2), 184–189. https://doi.org/10.3109/13668250.2017.1326588

Luitwieler, N., Luijkx, J., Salavati, M., van der Schans, C. P., van der Putten, A. A. J., & Waninge, A. (2021). Variables related to the quality of life of families that have a child with severe to profound intellectual disabilities: A systematic review. *Heliyon*, *7*(7). https://doi.org/10.1016/j.heliyon.2021.e07372

Lynn Snow, A., Cook, K. F., Lin, P.-S., Morgan, R. O., & Magaziner, J. (2005). Proxies and other external raters: methodological considerations. *Health Services Research, 40*(5p2), 1676–1693. https://doi.org/10.1111/j.1475-6773.2005.00447.x

Maes, B., Lambrechts, G., Hostyn, I., & Petry, K. (2007). Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature. *Journal of Intellectual and Developmental Disability*, *32*(3), 163–178. https://doi.org/10.1080/13668250701549427

Maes, B., Nijs, S., Vandesande, S., Van keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J., Petitpierre, G., van der Putten, A. A. J. (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

Maes, B., Penne, A., Petry, K., & Vos, P. (2016). *Vragenlijst over stemming, interesse en plezier: Nederlandse vertaling en handleiding van de Mood, Interest & Pleasure Questionnaire (MIPQ)* [Mood, interest and pleasure questionnaire: Dutch translation and manual of the Mood, Interest & Pleasure Questionnaire (MIPQ)]. Publisher: KU Leuven, Onderzoekseenheid gezins- en orthopedagogiek & Multiplus.

Mammadov, S., & Schroeder, K. (2023). A meta-analytic review of the relationships between autonomy support and positive learning outcomes. *Contemporary Educational Psychology, 70*, 102235. https://doi.org/10.1016/j.cedpsych.2023.102

Martin, A. M., Andrews, T., Goldbart, J., & Landers, M. (2022). Reconciling communication repertoires: Navigating interactions involving persons with severe/profound intellectual disability, a classic grounded theory study. *Journal of Intellectual Disability Research*, *66*(4), 332–352. https://doi.org/10.1111/jir.12921

Martínez-Tur, V., Moliner, C., Peñarroja, V., Gracia, E., & Peiró, J. M. (2015). From service quality in organisations to self-determination at home. *Journal of Intellectual Disability Research, 59*(10), 882–890. https://doi.org/10.1111/jir.12190

Matérne, M., & Holmefur, M. (2022). Residential care staff are the key to quality of health care for adults with profound intellectual and multiple disabilities in Sweden. *BMC Health Services Research*, *22*(1), 228. https://doi.org/10.1186/s12913-022-07641-y

Matson, J. L., Dixon, D. R., & Matson, M. L. (2005). Assessing and treating aggression in children and adolescents with developmental disabilities: A 20-year overview. *Educational Psychology, 25*(2–3), 151–181. https://doi.org/10.1080/0144341042000301148

Matson, J. L., & Mahan, S. (2010). Antipsychotic drug side effects for persons with intellectual disability. *Research in Developmental Disabilities, 31*(6), 1570–1576. https://doi.org/10.1016/j.ridd.2010.05.005

McConnell, A., Sanford, C., Martin, J., Cameto, R., & Hodge, L. (2021). Skills, behaviors, expectations, and experiences associated with improved postsecondary outcomes for students with significant cognitive disabilities. *Research and Practice for Persons with Severe Disabilities*, *46*(4), 240–258. https://doi.org/10.1177/15407969211053810

Meleis, A. I., Sawyer, L. M., Im, E. O., Messias, D. K. H., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science, 23*(1), 12–28. https://doi.org/10.1097/00012272-200009000-00006

Mill, A., Mayes, R., & McConnell, D. (2009). Negotiating autonomy within the family: The experiences of young adults with intellectual disabilities. *British Journal of Learning Disabilities*, *38*(3), 194–200. https://doi.org/10.1111/j.1468-3156.2009.00575.x

Milyavskaya, M., & Koestner, R. (2011). Psychological needs, motivation, and well-being: A test of self-determination theory across multiple domains. *Personality and Individual Differences*, *50*(3), 387–391. https://doi.org/10.1016/j.paid.2010.10.029

Mol-Bakker, A., van der Putten, A. A. J., Krijnen, W. P., & Waninge, A. (2024, August). The course of physical health conditions in young children with profound intellectual and multiple disabilities [Conference abstract]. *Journal of Intellectual Disability Research 68*(7), 854. https://doi.org/10.1111/jir.13166

Moreno, J., & Saldaña, D. (2005). Use of a computer-assisted program to improve metacognition in persons with severe intellectual disabilities. *Research in Developmental Disabilities, 26*(4), 341–357. https://doi.org/10.1016/j.ridd.2004.07.005

Mumbardó-Adam, C., Vicente, E., & Balboni, G. (2023). Self-determination and quality of life of people with intellectual and developmental disabilities: Past, present, and future of close research paths. *Journal of Policy and Practice in Intellectual Disabilities, 21,* e124601. https://doi.org/10.1111/jppi.12460

Murphy, B. A., Watts, A. L., Baker, Z. G., Don, B. P., Jolink, T. A., & Algoe, S. B. (2023). The Basic Psychological Need Satisfaction and Frustration Scales probably do not validly measure need frustration. *Psychological Assessment, 35*(2), 127–139. https://doi.org/10.1037/pas0001193

Nadig, A., Flanagan, T., White, K., & Bhatnagar, S. (2018). Results of a RCT on a transition support program for adults with ASD: Effects on self-determination and quality of life. *Autism Research, 11*(12), 1712–1728. https://doi.org/10.1002/aur.2027

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

Namazi, K. H., & Johnson, B. D. (1992). Pertinent autonomy for residents with dementias: Modification of the physical environment to enhance independence. *The American Journal of Alzheimer's Disease and Related Disorders & Research*, *7*(1), 16–21. https://doi.org/10.1177/153331759200700105

Neece, C. L., Kraemer, B. R., & Blacher, J. (2009). Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities, 47*(1), 31–43. https://doi.org/10.1352/2009.47:31-43

Nguyen, L., Jack, S. M., Davis, H., Bellefeuille, S., Arafeh, D., Di Rezze, B., Ketelaar, M., & Gorter, J. W. (2024). Being a sibling of a youth with a neurodisability: A qualitative study about the roles and responsibilities during the transition to adulthood. *Child Care Health and Development*, *50*(2). https://doi.org/10.1111/cch.13241

Nicholson, C., Finlay, W. M. L., & Stagg, S. (2021). Forms of resistance in people with severe and profound intellectual disabilities. *Sociology of Health & Illness*, *43*(3), 642–659. https://doi.org/10.1111/1467-9566.13246

Nieuwenhuijse, A. M., Willems, D. L., & Kruithof, K. (2024). Understanding quality of life of persons with profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 21*(1), e12473. https://doi.org/10.1111/jppi.12473

Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., & Olsman, E. (2022). 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

Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., & Olsman, E. (2023). Parent perspectives on the assessment of quality of life of their children with profound intellectual and multiple disabilities in the Netherlands. *Research in Developmental Disabilities*, *139*, 104536. https://doi.org/10.1016/j.ridd.2023.104536

Nind, M., & Grace, J. (2024). The emotional wellbeing of students with profound intellectual disabilities and those who work with them: A relational reading. *Disability & Society*, 1–22. https://doi.org/10.1080/09687599.2024.2407819

Núñez, J. L., & León, J. (2015). Autonomy support in the classroom. *European Psychologist*. *20*(4), 275–283. https://doi.org/10.1027/1016-9040/a000234

O'Brien, P., Iriarte, E. G., Conkey, R. M., Butler, S., & O'Brien, B. (2022). Inclusive research and intellectual disabilities: Moving forward on a road less well-travelled. *Social Sciences*, *11*(10), 483. https://doi.org/10.3390/socsci11100483

Oliveira, J. E., Mendonça, M., Coimbra, S., & Fontaine, A. M. (2014). Family support in the transition to adulthood in Portugal–Its effects on identity capital development, uncertainty management and psychological well-being. *Journal of Adolescence, 37*(8), 1449–1462. https://doi.org/10.1016/j.adolescence.2014.07.004

Olsman, E., Nieuwenhuijse, A. M., & Willems, D. L. (2021). Witnessing quality of life of persons with profound intellectual and multiple disabilities: A practical-philosophical approach. *Health Care Analysis, 29*(2), 144–153. https://doi.org/10.1007/s10728-021-00428-y

Overwijk, A., Hilgenkamp, T. I., van der Schans, C. P., van der Putten, A. A. J., & Waninge, A. (2021). Needs of direct support professionals to support people with intellectual disabilities in leading a healthy lifestyle. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 263–272. https://doi.org/10.1111/jppi.12383

Patty, N. J. S., van Meeteren, K. M., Willemen, A. M., Verdonk, M., Mol, M. A. E., Ketelaar, M., & Schuengel, C. (2024). Understanding burnout among parents of children with complex care needs: A scoping review followed by a stakeholder consultation. *Journal of Child and Family Studies 33,* 1378–1392. https://doi-org.vu-nl.idm.oclc.org/10.1007/s10826-024-02825-y

Paulhus, D. L. (2002). Socially desirable responding: The evolution of a construct. In H. I. Braun, D. N. Jackson, & D. E. Wiley (Eds.), *The Role of Constructs in Psychological and Educational Measurement* (pp. 49–69). Mahwah NJ: Erlbaum.

Paulhus, D. L. (2017). Socially desirable responding on self-reports. In V. Zeigler-Hill & T. K. Shackelford (Eds.), *Encyclopedia of Personality and Individual Differences* (pp. 1–5). Springer, Cham. https://doi.org/10.1007/978-3-319-28099-8_1349-1

Pelleboer-Gunnink, H. A., van Oorsouw, W. M. W. J., van Weeghel, J., & Embregts, P. J. C. M. (2021a). Stigma research in the field of intellectual disabilities: A scoping review on the perspective of care providers. *International Journal of Developmental Disabilities, 67*(3), 168–187. https://doi.org/10.1080/20473869.2019.1616990

Pelleboer-Gunnink, H. A., van Weeghel, J., & Embregts, P. J. C. M. (2021b). Public stigmatisation of people with intellectual disabilities: a mixed-method population survey into stereotypes and their relationship with familiarity and discrimination. *Disability and Rehabilitation*, *43*(4), 489–497. https://doi.org/10.1080/09638288.2019.16306

Penninga, W., Hendriks, A. H., van Bakel, H. J., & Embregts, P. J. C. M. (2024a). A behavioural description of meaningful moments of interaction between people with profound intellectual disabilities and support staff. *Journal of Applied Research in Intellectual Disabilities*, *37*(4), e13245. https://doi.org/10.1111/jar.13245

Penninga, W., Hendriks, A. H., van Bakel, H. J., & Embregts, P. J. C. M. (2024b). Predecessors of behavioural initiatives by people with profound intellectual disabilities during their interactions with support staff: An exploratory microanalytical analysis. *British Journal of Learning Disabilities*, 1–11. https://doi.org/10.1111/bld.12622

Petry, K., Kuppens, S., Vos, P., & Maes, B. (2010). Psychometric evaluation of the Dutch version of the Mood, Interest and Pleasure Questionnaire (MIPQ). *Research in Developmental Disabilities, 31*(6), 1652–1658. https://doi.org/10.1016/j.ridd.2010.04.011

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

Petry, K., Maes, B., & Vlaskamp, C. (2007). Support characteristics associated with the quality of life of people with profound intellectual and multiple disabilities: The perspective of parents and direct support staff. *Journal of Policy and Practice in Intellectual Disabilities*, *4*(2), 104–110. https://doi.org/10.1111/j.1741-1130.2007.00107.x

Petry, K., Maes, B., & Vlaskamp, C. (2008). *QOL-PMD: Vragenlijst over de kwaliteit van leven van personen met ernstig meervoudige beperkingen. Opbouw en handleiding*. KU Leuven, Centrum voor gezins- en orthopedagogiek.

Petry, K., Maes, B., & Vlaskamp, C. (2009a). Measuring the quality of life of people with profound multiple disabilities using the QOL-PMD: First results. *Research in Developmental Disabilities, 30*(6), 1394–1405. https://doi.org/10.1016/j.ridd.2009.06.007

Petry, K., Maes, B., & Vlaskamp, C. (2009b). Psychometric evaluation of a questionnaire to measure the quality of life of people with profound multiple disabilities (QOL-PMD). *Research in Developmental Disabilities, 30*(6), 1326–1336. https://doi.org/10.1016/j.ridd.2009.05.009

Polanyi, M. (2009). Tacit Knowing. In *The tacit dimension* (pp. 1-26). University of Chicago press.

Ponterotto, J. G., & Ruckdeschel, D. E. (2007). An overview of coefficient alpha and a reliability matrix for estimating adequacy of internal consistency coefficients with psychological research measures. *Perceptual and Motor Skills, 105*(3), 997–1014. https://doi.org/10.2466/pms.105.3.997-1014

Porter, J., Ouvry, C., Morgan, M., & Downs, C. (2001). Interpreting the communication of people with profound and multiple learning difficulties. *British Journal of Learning Disabilities*, *29*(1), 12–16. https://doi.org/10.1046/j.1468-3156.2001.00083.x

QSR International (2018). *NVivo Qualitative Data Analysis Software* (Version 12) [Computer software]. QSR International Pty Ltd.: Melbourne, Australia.

Raghavan, R., Pawson, N., & Small, N. (2013). Family carers' perspectives on post-school transition of young people with intellectual disabilities with special reference to ethnicity. *Journal of Intellectual Disability Research*, *57*(10), 936–946. https://doi.org/10.1111/j.1365-2788.2012.01588.x

Ras, R., Embregts, P. J. C. M., Mergler, S., & Schuengel, C. (2020). *Minimale Dataset voor mensen met verstandelijke beperkingen: Evaluatie*. Vrije Universiteit. Retrieved from https://research.vu.nl/files/118763302/Rapport_Evaluatie_Basis_MDS_VB.pdf

Reeve, J. (2002). Self-determination theory applied to educational settings. In E. L. Deci & R. M. Ryan (Eds.), *Handbook of self-determination research* (pp. 183–204). University of Rochester Press: Rochester.

Reeve, J., Jang, H., Carrell, D., Jeon, S., & Barch, J. (2004). Enhancing students' engagement by increasing teachers' autonomy support. *Motivation and Emotion*, *28*(2), 147–169. https://doi.org/10.1023/b:moem.0000032312.95499.6f

Robbins, R. J. (1994). An assessment of perceptions of parental autonomy support and control: Child and parent correlates [Unpublished doctoral dissertation]. Department of Psychology, University of Rochester.

Roche, L., Sigafoos, J., Lancioni, G. E., O'Reilly, M. F., & Green, V. A. (2015). Microswitch technology for enabling self-determined responding in children with profound and multiple disabilities: A systematic review. *Augmentative and Alternative Communication, 31*(3), 246–258. https://doi.org/10.3109/07434618.2015.1024888

Roos, E., & Søndenaa, E. (2020). Improving the transition process to independent living for adolescents with profound intellectual disabilities. Experiences of parents and employees. *BMC Health Services Research*, *20*(1), 1–12. https://doi.org/10.1186/s12913-020-05976-y

Roos, J., Koppen, G., Vollmer, T. C., Van Schijndel-Speet, M., & Dijkxhoorn, Y. (2022). Unlimited surrounding: A scoping review on the impact of the built environment on health, behavior, and quality of life of individuals with intellectual disabilities in long-term care. *HERD Health Environments Research & Design Journal*, *15*(3), 295–314. https://doi.org/10.1177/19375867221085040

Ross, E., & Oliver, C. (2003). Preliminary analysis of the psychometric properties of the Mood, Interest & Pleasure Questionnaire (MIPQ) for adults with severe and profound learning disabilities. *British Journal of Clinical Psychology, 42*(1), 81–93. https://doi.org/10.1348/014466503762842039

Rousseau, M.-C., Baumstarck, K., Khaldi-Cherif, S., Brisse, C., Felce, A., Moheng, B., Loundou, A., de Villemeur, T. B., Auquier, P., & the French Polyhandicap Group. (2019). Impact of severe polyhandicap on parents' quality of life: A large French cross-sectional study. *PloS One*, *14*(2), e0211640. https://doi.org/10.1371/journal.pone.0211640

Rousseau, M.-C., Baumstarck, K., Leroy, T., Khaldi-Cherif, C., Brisse, C., Boyer, L., Resseguier, N., Morando, C., de Villemeur, T. B., & Auquier, P. (2017). Impact of caring for patients with severe and complex disabilities on health care workers' quality of life: Determinants and specificities. *Developmental Medicine & Child Neurology*, *59*(7), 732–737. https://doi.org/10.1111/dmcn.13428

Rudy, D., Sheldon, K. M., Awong, T., & Tan, H. H. (2007). Autonomy, culture, and well-being: The benefits of inclusive autonomy. *Journal of Research in Personality*, *41*(5), 983–1007. https://doi.org/10.1016/j.jrp.2006.11.004

Ryan, R. M., & Deci, E. L. (2000a). Intrinsic and extrinsic motivations: Classic definitions and new directions. *Contemporary Educational Psychology, 25*(1), 54–67. https://doi.org/10.1006/ceps.1999.1020

Ryan, R. M., & Deci, E. L. (2000b). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68–78. https://doi.org/10.1037/0003-066X.55.1.68

Ryan, R. M., & Deci, E. L. (2002). An overview of self-determination theory: An organismic dialectical perspective. In E. L. Deci & R. Ryan, (Eds.), *Handbook of self-determination research* (pp. 3–33). University of Rochester Press: Rochester, NY.

Ryan, R. M., & Deci, E. L. (2006). Self-regulation and the problem of human autonomy: Does psychology need choice, self-determination, and will? *Journal of Personality, 74*(6), 1557–1586. https://doi.org/10.1111/j.1467-6494.2006.00420.x

Ryan, R. M., Deci, E. L., Grolnick, W. S., & La Guardia, J. G. (2015). The significance of autonomy and autonomy support in psychological development and psychopathology. In D. Cicchetti & J. D. Cohen (Eds.), *Developmental psychopathology, Vol. 1: Theory and method* (2nd ed., pp. 795–849). Wiley: Hoboken.

Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on self-determination theory. *European Health Psychologist, 10*(1), 2–5. Retrieved from https://selfdeterminationtheory.org/wp-content/uploads/2014/04/2008_RyanPatrickDeciWilliams_EHP.pdf

Sato, N., & Araki, A. (2022). Fathers' involvement in rearing children with profound intellectual and multiple disabilities. *Journal of Family Nursing*, *28*(1), 57–68. https://doi.org/10.1177/10748407211037345

Schalock, R. L., & Felce, D. (2004). Quality of life and subjective well-being: Conceptual and measurement issues. In E. Emerson, C. Hatton, T. Thomson, & T. R. Parmenter (Eds.), *International handbook of applied research in intellectual disabilities* (pp. 261–279). Wiley eBooks. https://doi.org/10.1002/9780470713198

Schalock, R. L., Luckasson, R., & Shogren, K. A. (2020). Going beyond environment to context: Leveraging the power of context to produce change. *International Journal of Environmental Research and Public Health*, *17*(6), 1885. https://doi.org/10.3390/ijerph17061885

Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners* (pp. 11–30). American Association on Mental Retardation: Washington, DC. USA.

Schoenmakers, H., & de Vos, N. (2016). Pubers laten van zich horen over jongeren met ernstige meervoudige beperkingen. Retrieved from amerpoort-werkt-pubers-laten-van-zich-horen-emb-digitaal.pdf

Schuengel, C., & Oosterman, M. (2019). Parenting self-efficacy. In M. H. Bornstein (Ed.), *Handbook of parenting, Vol. 3: Being and becoming a parent* (3th ed., pp. 642–668). Routledge.

Scott, H. M., & Havercamp, S. M. (2018). Comparisons of self and proxy report on health-related factors in people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 31*(5), 927–936. https://doi.org/10.1111/jar.12452

Seong, Y., Wehmeyer, M. L., Palmer, S. B., & Little, T. D. (2015). Effects of the self-directed individualized education program on self-determination and transition of adolescents with disabilities. *Career Development and Transition for Exceptional Individuals, 38*(3), 132–141. https://doi.org/10.1177/2165143414544359

Shogren, K. A., & Broussard, R. (2011). Exploring the perceptions of self-determination of individuals with intellectual disability. *Intellectual and Developmental Disabilities, 49*(2), 86–102. https://doi.org/10.1352/1934-9556-49.2.86

Shogren, K. A., Garnier Villarreal, M., Lang, K., & Seo, H. (2017a). Mediating role of self-determination constructs in explaining the relationship between school factors and postschool outcomes. *Exceptional Children*, *83*(2), 165–180. https://doi.org/10.1177/0014402916660089

Shogren, K. A., Little, T. D., & Wehmeyer, M. L. (2017b). Human agentic theories and the development of self-determination. In M. L. Wehmeyer, K. A. Shogren, T. D. Little, & S. J. Lopez, (Eds.), *Development of self-determination through the life-course* (pp. 17–26). Springer. https://doi.org/10.1007/978-94-024-1042-6_2

Shogren, K. A., Wehmeyer, M. L., & Palmer, S. B. (2017c). Causal agency theory. In M. L. Wehmeyer, K. A. Shogren, T. D. Little, & S. J. Lopez (Eds.), *Development of self-determination through the life-course* (pp. 55–67). Springer: Dordrecht, The Netherlands. https://doi.org/10.1007/978-94-024-1042-6_5

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A. J., Little, T. J., & Lopez, S. (2015). Causal agency theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities*, *50*(3), 251–263. https://dialnet.unirioja.es/servlet/articulo?codigo=5182103

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education*, *48*(4), 256–267. https://doi.org/10.1177/0022466913489733

Skarsaune, S. N. (2023). Self-determination of people with profound intellectual and multiple disabilities. *Developmental Medicine & Child Neurology*, *65*, 16–23. https://doi.org/10.1111/dmcn.15363

Skarsaune, S. K. N. (2023). Self-determination of people with profound intellectual and multiple disabilities. *Developmental Medicine & Child Neurology, 65*(1), 16–23. https://doi.org/10.1111/dmcn.15363

Skarsaune, S. K. N. (2024). Persons with profound and multiple learning disabilities as subjects of knowledge: Exploring the possibilities of empathy. *British Journal of Learning Disabilities, 52*(1), 101–109. https://doi.org/10.1111/bld.12550

Skarsaune, S. K. N., Hanisch, H. M., & Gjermestad, A. (2021). Self-determination: What can we learn from persons with profound intellectual and multiple disabilities? *Scandinavian Journal of Disability Research, 23*(1), 317–327. http://doi.org/10.16993/sjdr.830

Slemp, G. R., Kern, M. L., Patrick, K. J., & Ryan, R. M. (2018). Leader autonomy support in the workplace: A meta-analytic review. *Motivation and Emotion*, *42*, 706–724. https://doi.org/10.1007/s11031-018-9698-y

Soenens, B., Vansteenkiste, M., Lens, W., Luyckx, K., Goossens, L., Beyers, W., & Ryan, R. M. (2007). Conceptualizing parental autonomy support: Adolescent perceptions of promotion of independence versus promotion of volitional functioning. *Developmental Psychology, 43*(3), 633–646. https://doi.org/10.1037/0012-1649.43.3.633

Spaniol, M., & Danielsson, H. (2022). A meta-analysis of the executive function components inhibition, shifting, and attention in intellectual disabilities. *Journal of Intellectual Disability Research, 66*(1-2), 9–31. https://doi.org/10.1111/jir.12878

Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and selfdetermination. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 91–98. https://doi.org/10.1002/mrdd.1013

Stancliffe, R. J., Abery, B. H., & Smith, J. (2000a). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation, 105*(6), 431–454. https://doi.org/10.1352/0895-8017(2000)105

Stancliffe, R., Abery, B. H., Springborg, H., & Elkin, S. (2000b). Substitute decision making and personal control: Implications for self-determination. *Mental Retardation 38,*(5), 407–421. https://doi.org/10.1352/0047-6765(2000)038

Stancliffe, R., & Wehmeyer, M. L. (1995). Variability in the availability of choice to adults with mental retardation. *Journal of Vocational Rehabilitation*, *5*(4), 319–328. https://eric.ed.gov/?id=EJ514785

Sterne, J. A. C., White, I. R., Carlin, J. B., Spratt, M., Royston, P., Kenward, M. G., Wood, A. M., & Carpenter, J. R. (2009). Multiple imputation for missing data in epidemiological and clinical research: Potential and pitfalls. *British Medical Journal, 338*, b2393. https://doi.org/10.1136/bmj.b2393

Swank, J. M., & Mullen, P. R. (2017). Evaluating evidence for conceptually related constructs using bivariate correlations. *Measurement and Evaluation in Counseling and Development, 50*(4), 270–274. https://doi.org/10.1080/07481756.2017.1339562

Tadema, A. C., & Vlaskamp, C. (2010). The time and effort in taking care of children with profound intellectual and multiple disabilities: A study on care load and support. *British Journal of Learning Disabilities, 38*(1), 41–48. https://doi.org/10.1111/j.1468-3156.2009.00561.x

Tang, M., Wang, D., & Guerrien, A. (2020). A systematic review and meta-analysis on basic psychological need satisfaction, motivation, and well-being in later life: Contributions of self-determination theory. *PsyCh Journal*, *9*(1), 5–33. https://doi.org/10.1002/pchj.293

Taylor, W. D., Cobigo, V., & Ouellette-Kuntz, H. (2019). A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 32*(5), 1116–1128. https://doi.org/10.1111/jar.12601

Thurm, A., Kelleher, B., & Wheeler, A. (2020). Outcome measures for core symptoms of intellectual disability: State of the field. *American Journal on Intellectual and Developmental Disabilities*, *125*(6), 418–433. https://doi.org/10.1352/1944-7558-125.6.418

TOP 10 EMB onderzoeksagenda: De belangrijkste vragen van ouders aan onderzoekers. (2021). Retrieved from https://aw-emb.nl/media/EMB_TOP_10_Onderzoeksagenda.pdf

Tyrer, F., McGrother, C. W., Thorp, C. F., Taub, N. A., Bhaumik, S., & Cicchetti, D. V. (2008). The Leicestershire Intellectual Disability Tool: A simple measure to identify moderate to profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *21*(3), 268–276. https://doi.org/10.1111/j.1468-3148.2007.00409.x

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. United Nations Headquarters: New York, NY, USA. Retrieved from https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

Valdovinos, M. G., Caruso, M., Roberts, C., Kim, G., & Kennedy, C. H. (2005). Medical and behavioral symptoms as potential medication side effects in adults with developmental disabilities. *American Journal on Mental Retardation*, *110*(3), 164–170. https://doi.org/10.1352/0895-8017(2005)110

Van den Bosch, K. A., Andringa, T. C., Peterson, W., Ruijssenaars, W. A. J. J. M., & Vlaskamp, C. (2016). A comparison of natural and non-natural soundscapes on people with severe or profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, *42*(3), 301–307. https://doi.org/10.3109/13668250.2016.1250251

Van der Putten, A. A. J., Vlaskamp, C., Luijkx, J., Poppes, P., & Groningen, R. (2017). *Kinderen en volwassenen met zeer ernstige verstandelijke en meervoudige beperkingen: Tijd voor een nieuw perspectief* [Position paper]. Research Centre EMB, Rijksuniversiteit Groningen. Retrieved from https://www.qolcentre.eu/wp-content/uploads/2018/09/mensen-meerv-bep-pos-pap-van-derputten-2017.pdf

Van keer, I., & Maes, B. (2018). Contextual factors influencing the developmental characteristics of young children with severe to profound intellectual disability: A critical review. *Journal of Intellectual & Developmental Disability, 43*(2), 183–201. https://doi.org/10.3109/13668250.2016.1252458

Van Timmeren, E. A., van der Schans, C. P., van der Putten, A. A. J., Krijnen, W. P., Steenbergen, H. A., van Schrojenstein Lantman-de Valk, H. M. J., & Waninge, A. (2017). Physical health issues in adults with severe or profound intellectual and motor disabilities: A systematic review of cross-sectional studies. *Journal of Intellectual Disability Research, 61*(1), 30–49. https://doi.org/10.1111/jir.12296

Van Tuyll van Serooskerken, J. M., Willemen, A. M., de La Croix, A., Embregts, P. J. C. M., & Schuengel, C. (2022). Satisfying basic psychological needs among people with complex support needs: A self-determination theory-guided analysis of primary relatives' perspectives. *Disabilities, 2*, 330–347. https://doi.org/10.3390/disabilities2020024

Van Tuyll van Serooskerken, J. M., Willemen, A. M., Embregts, P. J. C. M., & Schuengel, C. (2024). Parent-perceived autonomy-supportive experiences and basic psychological needs of people with complex support needs: Development and preliminary psychometric evaluation of two questionnaires. *Journal of Intellectual Disabilities*. https://doi.org/10.1177/17446295241237553

Vandesande, S., Bosmans, G., & Maes, B. (2019). Can I be your safe haven and secure base? A parental perspective on parent-child attachment in young children with a severe or profound intellectual disability. *Research in Developmental Disabilities, 93*, 103452. https://doi.org/10.1016/j.ridd.2019.103452

Vandesande, S., Bosmans, G., Sterkenburg, P., Schuengel, C., & Maes, B. (2021). The Attachment Strengths and Needs Interview for parents of children with severe or profound intellectual disabilities: An acceptability and feasibility study. *Journal of Intellectual and Developmental Disabilities, 47*(2), 118–130. https://doi.org/10.3109/13668250.2021.1925528

Vandesande, S., Bosmans, G., Sterkenburg, P., Schuengel, C., van den Noortgate, W., & Maes, B. (2019). Comfort provided by parents versus strangers after eliciting stress in children with severe or profound intellectual disabilities: Does it make a difference? *Attachment & Human Development*, *22*(4), 425–447. https://doi.org/10.1080/14616734.2019.1659835

Vansteenkiste, M., Niemiec, C. P., & Soenens, B. (2010). The development of the five mini-theories of self-determination theory: An historical overview, emerging trends, and future directions. In T. C. Urdan & S. A. Karabenick (Eds.) *The Decade Ahead: Theoretical Perspectives on Motivation and Achievement* (Vol. 16 Part A, pp. 105–165). Leeds: Emerald Group Publishing Limited. https://doi.org/10.1108/S0749-7423(2010)000016A007

Vansteenkiste, M., & Ryan, R. M. (2013). On psychological growth and vulnerability: Basic psychological need satisfaction and need frustration as a unifying principle. *Journal of Psychotherapy Integration*, *23*(3), 263–280. https://doi.org/10.1037/a0032359

Vansteenkiste, M., Ryan, R. M., & Soenens, B. (2020). Basic psychological need theory: Advancements, critical themes, and future directions [Editorial]. *Motivation and Emotion, 44*(1), 1–31. https://doi.org/10.1007/s11031-019-09818-1

Vansteenkiste, M., Simons, J., Lens, W., Sheldon, K. M., & Deci, E. L. (2004). Motivating learning, performance, and persistence: The synergistic effects of intrinsic goal contents and autonomy-supportive contexts. *Journal of Personality and Social Psychology*, *87*(2), 246–260. https://doi.org/10.1037/0022-3514.87.2.246

Vasquez, A. C., Patall, E. A., Fong, C. J., Corrigan, A. S., & Pine, L. (2016). Parent autonomy support, academic achievement, and psychosocial functioning: A meta-analysis of research. *Educational Psychology Review*, *28*(3), 605–644. https://doi.org/10.1007/s10648-015-9329-z

Vaucher, C., Cudré-Mauroux, A., & Piérart, G. (2020). Environmental, personal, and relational barriers and facilitators to self-determination among adults with intellectual disabilities. *Scandinavian Journal of Disability Research, 22*(1), 97–107. https://doi.org/10.16993/sjdr.624

Vereijken, F. R., Giesbers, S. A., Jahoda, A., & Embregts, P. J. C. M. (2024). The experiences of parents arranging the move of their young adult offspring with intellectual disabilities to 24-hour residential settings: A continuing puzzle. *Journal of Intellectual & Developmental Disability, 49*(3), 298–310. https://doi.org/10.3109/13668250.2023.2254942

Verhage, M. L., Oosterman, M., & Schuengel, C. (2013). Parenting self-efficacy is associated with cry perception, not autonomic responses, during a cry response task. *Parenting, 13*(4), 253–265. https://doi.org/10.1080/15295192.2013.832570

Vicente, E., Mumbardó-Adam, C., Guillén, V. M., Coma-Roselló, T., Bravo-Álvarez, M. Á., & Sánchez, S. (2020). Self-determination in people with intellectual disability: The mediating role of opportunities. *International Journal of Environmental Research and Public Health*, *17*(17), 6201. https://doi.org/10.3390/ijerph17176201

Vicente, E., Pérez-Curiel, P., Mumbardó-Adam, C., Guillén, V. M., & Bravo-Álvarez, M. Á. (2023). Personal factors, living environments, and specialized supports: Their role in the self-determination of people with intellectual disability. *Behavioral Sciences*, *13*(7), 530. https://doi.org/10.3390/bs13070530

Vicente, E. V., Verdugo, M. A., Gómez-Vela, M., Fernández-Pulido, R., Wehmeyer, M. L., & Guillén, V. M. (2019). Personal characteristics and school contextual variables associated with student self-determination in the Spanish context. *Journal of Intellectual and Developmental Disabilities, 44*(1), 23–34. https://doi.org/10.3109/13668250.2017.1310828

Vicente, E., Verdugo, M. A., Guillen, V. M., Martínez-Molina, A., Gómez, L. E., & Ibañez, A. (2020). Advances in the assessment of self-determination: Internal structure of a scale for people with intellectual disabilities aged 11 to 40. *Journal of Intellectual Disability Research, 64*(9), 700–712. https://doi.org/10.1111/jir.12762

Vlaskamp, C. (2005). Interdisciplinary assessment of people with profound intellectual and multiple disabilities. In J. Hogg & A. Langa (Eds.) *Assessing adults with intellectual disabilities: A service providers' guide* (pp. 39–51). The British Psychological Society and Blackwell Publishing Ltd.

Vlaskamp, C., & Nakken, H. (2008). Therapeutic interventions in the Netherlands and Belgium in support of people with profound intellectual and multiple disabilities. *Education and Training in Developmental Disabilities*, *43*(3), 334–341. Retrieved from https://www.jstor.org/stable/23879795

Vos, P., de Cock, P., Munde, V., Neerinckx, H., Petry, K., van den Noortgate, W., & Maes, B. (2013a). The role of attention in the affective life of people with severe or profound intellectual disabilities. *Research in Developmental Disabilities, 34*(3), 902–909. https://doi.org/10.1016/j.ridd.2012.11.013

Vos, P., de Cock, P., Petry, K., van den Noortgate, W., & Maes, B. (2013b). Investigating the relationship between observed mood and emotions in people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research, 57*(5), 440–451. https://doi.org/10.1111/jir.12021

Vrolijk, P., van Lissa, C. J., Branje, S., Meeus, W. H. J., & Keizer, R. (2022). Parent–child personality similarity and differential autonomy support toward siblings. *Journal of Family Psychology, 36*(6), 839–850. https://doi.org/10.1037/fam0000955

Watson, J. (2012). Supported decision making for people with severe to profound intellectual disability, 'we're all in this together, aren't we'. In C. Bigby & C. Fyffe (Eds.), *Services and families working together to support adults with intellectual disability. Proceedings of the Sixth Roundtable on Intellectual Disability Policy* (pp. 38–48). Bundoora: La Trobe University.

Webb, K., Cuskelly, M., & Owen, C. (2024). The use of proxy measurement of internal states in people with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual Disabilities, 37*(4), e13241. https://doi.org/10.1111/jar.13241

Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities, 30*(3), 113–120. https://doi.org/10.2511/rpsd.30.3.113

Wehmeyer, Michael. (2018). Self-Determination and creating a society for all. *Men – Disability – Society, 41*(3), 5–14. https://doi.org/10.5604/01.3001.0012.7816

Wehmeyer, M. L. (2020a). Self-determination in adolescents and adults with intellectual and developmental disabilities. *Current Opinion in Psychiatry, 33*(2), 81–85. https://doi.org/10.1097/yco.0000000000000576

Wehmeyer, M. L. (2020b). The importance of self-determination to the quality of life of people with intellectual disability: A perspective. *International Journal of Environmental Research and Public Health, 17*(19), 7121. https://doi.org/10.3390/ijerph17197121

Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities, 51*(5), 399–411. https://doi.org/10.1352/1934-9556-51.5.399

Wehmeyer, M. L., Abery, B. H., Zhang, D., Ward, K., Willis, D., Amin Hossain, W., Balcazar, F., Ball, A., Bacon, A., Calkins, C., Heller, T., Goode, T., Dias, R., Jesien, G. S., McVeigh, T., Nygren, M. A., Palmer, S. B., Walker, H. M. (2011a). Personal self-determination and moderating variables that impact efforts to promote self-determination. *Exceptionality, 19*(1), 19–30. https://doi.org/10.1080/09362835.2011.537225

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research*, *45*(5), 371–383. https://doi.org/10.1046/j.1365-2788.2001.00342.x

Wehmeyer, M. L., Palmer, S. B., Lee, Y., Williams-Diehm, K., & Shogren, K. (2011b). A randomized-trial evaluation of the effect of *Whose future is it anyway?* on self-determination. *Career Development for Exceptional Individuals, 34*(1), 45–56. https://doi.org/10.1177/0885728810383559

Wehmeyer, M. L., & Shogren, K. A. (2016). Self-determination and choice. In N. N. Singh (Ed.), *Handbook of evidence-based practices in intellectual and developmental disabilities* (pp. 561–584). Springer: New York.

Wehmeyer, M. L., & Shogren, K. A. (2017). Applications of the self-determination construct to disability. In M. L. Wehmeyer, K. A. Shogren, T. D. Little, & S. J. Lopez (Eds.), *Development of self-determination through the life-course* (pp. 111–123). Springer: Dordrecht, The Netherlands. https://doi.org/10.1007/978-94-024-1042-6_9

Wehmeyer, M. L., Shogren, K. A., Little, T. D., & Lopez, S. J. (2017). Introduction to the self-determination construct. In M. L. Wehmeyer, K. A. Shogren, T. D. Little, & S. J. Lopez (Eds.), *Development of self-determination through the life-course* (pp. 3–16). Springer: Dordrecht, The Netherlands. https://doi.org/10.1007/978-94-024-1042-6_1

Werner, S. (2015). Public stigma and the perception of rights: Differences between intellectual and physical disabilities. *Research in Developmental Disabilities*, *38*, 262–271. https://doi.org/10.1016/j.ridd.2014.12.030

Westera, J. J., van der Molen, M. J., & Schuengel, C. (2023). Basic psychological needs and mental health in adolescents with a mild to borderline intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities*, *17*(2), 138–157. https://doi.org/10.1080/19315864.2023.2240732

Whicker, J. J., Muñoz, K., & Nelson, L. H. (2019). Parent challenges, perspectives and experiences caring for children who are deaf or hard-of-hearing with other disabilities: A comprehensive review. *International Journal of Audiology*, *58*(1), 5–11. https://doi.org/10.1080/14992027.2018.1534011

White, I. R., Royston, P., & Wood, A. M. (2011). Multiple imputation using chained equations: Issues and guidance for practice. *Statistics in Medicine, 30*(4), 377–399. https://doi.org/10.1002/sim.4067

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17*(3), 181–190. https://doi.org/10.1111/j.1468-3148.2004.00197.x

White, R. W. (1959). Motivation reconsidered: The concept of competence. *Psychological Review, 66*(5), 297–333. https://doi.org/10.1037/h0040934

Wilder, J., Magnusson, L., & Hanson, E. (2015). Professionals' and parents' shared learning in blended learning networks related to communication and augmentative and alternative communication for people with severe disabilities. *European Journal of Special Needs Education*, *30*(3), 367–383. https://doi.org/10.1080/08856257.2015.1023002

Williams-Diehm, K., Wehmeyer, M. L., Palmer, S., Soukup, J. H., & Garner, N. (2008). Self-determination and student involvement in transition planning: A multivariate analysis. *Journal on Developmental Disabilities, 14*(1), 25–36. https://oadd.org/wp-content/uploads/2008/01/williamsdiehmEtAl.pdf

Williams, G. C., McGregor, H. A., Sharp, D., Levesque, C., Kouides, R. W., Ryan, R. M., & Deci, E. L. (2006). Testing a self-determination theory intervention for motivating tobacco cessation: Supporting autonomy and competence in a clinical trial. *Health Psychology*, *25*(1), 91–101. https://doi.org/10.1037/0278-6133.25.1.91

Willow, S. A., Strnadová, I., & Danker, J. (2024). Developing the self-determination of children and young people with intellectual disabilities in schools: A systematic review of the literature. *Journal of Applied Research in Intellectual Disabilities*, *37*(4), e13247. https://doi.org/10.1111/jar.13247

Windsor, C., Zhang, T., Wilson, N. J., Blyth, K., Ballentine, N., & Speyer, R. (2023). Psychosocial-behavioural interventions for school-aged children with intellectual disabilities: A systematic review of randomised control trials. *Journal of Applied Research in Intellectual Disabilities*, *36*(3), 458–485. https://doi.org/10.1111/jar.13086

Woodbridge, R., Sullivan, M., Harding, E., Crutch, S., Gilhooly, K., Gilhooly, M., McIntyre, A., & Wilson, L. (2018). Use of the physical environment to support everyday activities for people with dementia: A systematic review. *Dementia*, *17*(5), 533–572. https://doi.org/10.1177/1471301216648670

Zaal-Schuller, I. H., Kruithof, K., Hoogsteyns, M., Nieuwenhuijse, A., Willems, D., & Huisman, S. (2024). Tacit knowledge in medical consultations for patients with profound intellectual and multiple disabilities: An exploratory qualitative study. *Journal of Intellectual & Developmental Disability*, 1–10. https://doi.org/10.3109/13668250.2024.2402380

Zheng, C., Gaumer Erickson, A., Kingston, N. M., & Noonan, P. M. (2014). The relationship among self-determination, self-concept, and academic achievement for students with learning disabilities. *Journal of Learning Disabilities*, *47*(5), 462–474. https://doi.org/10.1177/0022219412469688

Zijlstra, H. P., & Vlaskamp, C. (2005). The impact of medical conditions on the support of children with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, *18*(2), 151–161. https://doi.org/10.1111/j.1468-3148.2005.00244.x

Appendices

A. Authorship statement

Chapter 1	**General introduction**	
	J.M. van Tuyll van Serooskerken	Writing–outline; writing–original draft preparation; writing–review & editing
	A.M. Willemen	Supervision; writing–review & editing
	P.J.C.M. Embregts	Supervision; writing–review & editing
	C. Schuengel	Supervision; writing–review & editing
Chapter 2	**Satisfying basic psychological needs among people with complex support needs: A self-determination theory-guided analysis of primary relatives' perspectives**	
	J.M. van Tuyll van Serooskerken	Conceptualization; methodology; project-coordination; formal analysis; investigation; resources; data curation; interpretation of results; writing–original draft preparation; writing–review & editing; visualization; project administration; correspondence
	A.M. Willemen	Conceptualization; methodology; formal analysis; interpretation of results; writing–review & editing; supervision
	A. de la Croix	Methodology; formal analysis; interpretation of results; writing–review & editing
	P.J.C.M. Embregts	Conceptualization; methodology; validation; interpretation of results; writing–review & editing; supervision; funding acquisition
	C. Schuengel	Conceptualization; methodology; validation; interpretation of results; writing–review & editing; supervision; project administration; funding acquisition
Chapter 3	**Parent-perceived autonomy-supportive experiences and basic psychological needs of people with complex support needs: Development and preliminary psychometric evaluation of two questionnaires**	
	J.M. van Tuyll van Serooskerken	Conceptualization; methodology; project-coordination; formal analysis; investigation; resources; data curation; interpretation of results; writing–original draft preparation; writing–review & editing; visualization; project administration
	A.M. Willemen	Conceptualization; methodology; formal analysis; interpretation of results; writing–review & editing; supervision; correspondence
	P.J.C.M. Embregts	Conceptualization; methodology; validation; writing–review & editing; supervision; funding acquisition
	C. Schuengel	Conceptualization; methodology; validation; interpretation of results; writing–review & editing; supervision; project administration; funding acquisition

Chapter 4	**Change in self-determination-related constructs in persons with severe or profound intellectual and multiple disabilities in the context of transitions**	
	J.M. van Tuyll van Serooskerken	Conceptualization; methodology; project-coordination; formal analysis; investigation; resources; data curation; interpretation of results; writing–original draft preparation; writing–review & editing; visualization; project administration; correspondence
	A.M. Willemen	Conceptualization; methodology; formal analysis; interpretation of results; writing–review & editing; supervision
	P.J.C.M. Embregts	Conceptualization; methodology; validation; writing–review & editing; supervision; funding acquisition
	C. Schuengel	Conceptualization; methodology; validation; interpretation of results; writing–review & editing; supervision; project administration; funding acquisition
Chapter 5	**General discussion**	
	J.M. van Tuyll van Serooskerken	Writing–outline; writing–original draft preparation; writing–review & editing
	A.M. Willemen	Supervision; writing–review & editing
	P.J.C.M. Embregts	Supervision; writing–review & editing
	C. Schuengel	Supervision; writing–review & editing

B. Dankwoord

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Ik wil graag afsluiten met mijn eigen gezin. **Nova**, mijn lieve kleine meisje. Zes jaar geleden maakte jij mij moeder, en wat ben ik trots op jou. Je bent wijs, zorgzaam, sensitief, empathisch en hebt oog voor elk detail. Je hebt een geweldig gevoel voor getallen, vormen en patronen en ziet verbanden en oplossingen die ik soms zelf nog niet zie. Op school heb je inmiddels een grote groep vriendjes en vriendinnetjes en je doet niets liever dan elke dag met hen afspreken. Lieve Nova, ik hou zielsveel van jou en wens je een wereld waarin je elke dag mag blijven ontdekken wie je bent en wat je kunt, en altijd durft te vertrouwen op je eigen intuïtie. **Phoenix**, mijn kleine, blije ei. Met je brede lach, twinkelende ogen en ondeugende karakter vrolijk je, met je nog maar anderhalf jarig bestaan, al moeiteloos een hele kamer op. Je hebt zoveel liefde te geven, zoekt écht verbinding en geniet zichtbaar van de mensen om je heen. Je bent avontuurlijk en nieuwsgierig, en stort je met volle overgave op alles wat je ontdekt. Lieve Phoenix, ik hou ook zielsveel van jou en ben zó benieuwd naar alles wat je ons nog gaat laten zien. Lieve **Peter**, dit jaar zijn we zestien jaar samen. We leerden elkaar kennen op een feestje van Terri, waar we maar niet uitgepraat raakten. Al snel groeide onze band uit tot een diepgewortelde liefde waarin we allebei volledig onszelf kunnen zijn. Je bent puur, sociaal, hebt een bewonderenswaardig doorzettingsvermogen, een enorme drang om te blijven leren, en bijt je vast in alles wat je wilt begrijpen. Maar bovenal ben je een liefdevolle, fantastische partner en vader én laat je ons elke dag voelen hoeveel je van ons houdt. Je steunt me onvoorwaardelijk en voelt vaak eerder dan ikzelf aan wat ik nodig heb. Lieve Peter, dankjewel voor alles wat je voor mij bent. I love you… en ik win ;-)!

C. Curriculum Vitae

Jacqueline Marije van Tuyll van Serooskerken was born on 5 December 1987 in Heemstede, the Netherlands. After graduating from secondary education in 2005 (Dutch: havo-diploma) and 2007 (Dutch: vwo-diploma) at Mendel College in Haarlem, she started studying Industrial Design at Delft University of Technology that same year. This study soon turned out not to align with her interests, and in 2008 she switched to studying Psychology at Vrije Universiteit Amsterdam. While writing her bachelor's thesis in 2012, she discovered her interest in scientific research. This fascination was strengthened during her master's program in Developmental Psychology, during which she wrote her thesis on 'Result-Oriented Treatment' for adolescents with a mild intellectual disability within 's Heeren Loo Zorggroep in 2014, and subsequently published this as a scientific article. To further develop her research skills, she enrolled in the research master's program Clinical and Developmental Psychopathology, which she completed in 2016 at Vrije Universiteit Amsterdam. Alongside her studies between 2011 and 2013, she worked as a client buddy and care administration employee at the department of Emotional Disorders at the Bascule in Amsterdam. She also completed her clinical internship at the same department during that period. Throughout her research master, she held various research-related positions: as research assistant at the University of Amsterdam on a project concerning home-based Early Childhood Education for toddlers (Dutch: VVE thuis voor peuters, 2014–2015); as regional staff member at 's Heeren Loo Zorggroep where she conducted client-treatment data analysis and file research (2015–2016); and as research project coordinator at the former IWAL Amsterdam, Institute for Dyslexia (now part of RID Taal Rekenen), where she coordinated a randomized trial on a serious game aimed at the early detection of dyslexia and support for children with dyslexia. In December 2016, she started her PhD at the Academic Collaborative Center of Vrije Universiteit Amsterdam and 's Heeren Loo (since 2021: Viveon). As part of the project 'Choosing together: Network for self-determination of people with disabilities and intensive care needs,' she studied self-determination and life transitions in individuals with severe or profound intellectual and multiple disabilities. Her PhD was supervised by Prof. Dr. C. Scheungel (Viveon, Vrije Universiteit Amsterdam), Prof. Dr. P. J. C. M. Embregts (Tranzo, Tilburg University), and Dr. A. M. Willemen (Viveon, Vrije Universiteit Amsterdam). The results of this research are presented in this dissertation. She is currently working as a postdoctoral researcher at Viveon, Vrije Universiteit Amsterdam.

Jacqueline Marije van Tuyll van Serooskerken werd geboren op 5 december 1987 te Heemstede. Na het behalen van haar havo-diploma in 2005 en haar vwo-diploma in 2007 aan het Mendelcollege in Haarlem, begon zij in datzelfde jaar aan de studie Industrieel Ontwerpen aan de Technische Universiteit Delft. Al snel bleek deze studie niet goed aan te sluiten bij haar interesses, waarna zij in 2008 overstapte naar de studie Psychologie aan de Vrije Universiteit Amsterdam. Tijdens het schrijven van haar bachelorthese in 2012 ontdekte zij haar interesse in wetenschappelijk onderzoek. Deze belangstelling werd versterkt tijdens haar masteropleiding Ontwikkelingspsychologie, waarin zij in 2014 haar scriptie schreef over ‘Resultaatgericht Behandelen’ bij jongeren met een lichte verstandelijke beperking binnen ’s Heeren Loo Zorggroep en deze vervolgens publiceerde als wetenschappelijk artikel. Om haar onderzoeksvaardigheden verder te verdiepen, volgde zij aansluitend de research master Clinical and Developmental Psychopathology, die zij in 2016 afrondde aan de Vrije Universiteit Amsterdam. Naast haar studie was zij tussen 2011 en 2013 werkzaam als cliëntbuddy en medewerker zorgadministratie bij de afdeling Emotionele Stoornissen van de Bascule in Amsterdam. In deze periode liep zij daar ook haar klinische stage. Tijdens haar research master vervulde zij diverse onderzoeksfuncties: als onderzoeksassistent bij de Universiteit van Amsterdam voor een project over Voor- en Vroegschoolse Educatie (VVE) thuis voor peuters (2014–2015); als regionaal stafmedewerker bij ’s Heeren Loo Zorggroep waar zij cliënt-behandeldata en dossieronderzoek uitvoerde (2015–2016); en als onderzoeksprojectcoördinator bij het voormalig IWAL Amsterdam, Instituut voor Dyslexie (nu onderdeel van RID Taal Rekenen), waar zij een gerandomiseerde trial coördineerde rondom een serious game gericht op het vroegtijdig signaleren van dyslexie en het ondersteunen van kinderen met dyslexie. In december 2016 startte zij als promovenda bij de Academische Werkplaats van de Vrije Universiteit Amsterdam en ’s Heeren Loo (sinds 2021: Viveon). Binnen het project ‘Samen kunnen kiezen: Netwerk voor zelfbepaling van mensen met een beperking en een intensieve zorgvraag,’ deed zij onderzoek naar zelfbepaling en transities van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen. Haar promotietraject stond onder begeleiding van prof. dr. C. Scheungel (Viveon, Vrije Universiteit Amsterdam), prof. dr. P. J. C. M. Embregts (Tranzo, Tilburg University) en dr. A. M. Willemen (Viveon, Vrije Universiteit Amsterdam). De resultaten van dit onderzoek zijn beschreven in dit proefschrift. Momenteel is zij werkzaam als postdoctoraal onderzoeker bij Viveon, Vrije Universiteit Amsterdam.

D. Publications

van Tuyll van Serooskerken, J. M., van der Molen, M. J., & Bijl, B. (2016). Bouwstenen voor practice-based-evidence: Resultaat gericht behandelen van jongeren met een lichte verstandelijke beperking. *Tijdschrift voor Orthopedagogiek*, *55*(2), 51–62.

van Tuyll van Serooskerken, J. M., Willemen, A. M., de la Croix, A., Embregts, P. J. C. M., & Schuengel, C. (2022). Satisfying basic psychological needs among people with complex support needs: A self-determination theory-guided analysis of primary relatives' perspectives. *Disabilities, 2*(2), 330–347. DOI: 10.3390/disabilities2020024

van Tuyll van Serooskerken, J. M., Willemen, A. M., Embregts, P. J. C. M., & Schuengel, C. (in press). Parent-perceived autonomy-supportive experiences and basic psychological needs of people with complex support needs: Development and preliminary psychometric evaluation of two questionnaires. *Journal of Intellectual Disabilities*. DOI: 10.1177/17446295241237553

van Tuyll van Serooskerken, J. M., Willemen, A. M., Embregts, P. J. C. M., & Schuengel, C. (in press). Change in self-determination-related constructs in persons with severe or profound intellectual and multiple disabilities in the context of transitions. *Journal of Intellectual Disabilities*. DOI: 10.1177/17446295251317759

Op de cover van dit proefschrift is een zorgvuldig opgebouwde stapel stenen te zien, balancerend op een ruwe ondergrond. Deze stapel symboliseert de gelaagdheid en kwetsbare balans in het leven van mensen met (zeer) ernstige verstandelijke en meervoudige beperkingen, en in de zorgstructuren die hen omringen. Elke steen staat voor een essentieel element: de behoefte aan autonomie, competentie of verbondenheid; momenten van verandering; ondersteuning vanuit de omgeving; en de levenslange zoektocht van ouders naar betekenisvolle en passende keuzes om een zo waardig mogelijk bestaan voor hun kind te creëren. De stapel is niet vanzelfsprekend stevig. Elke keer wanneer er een steen verandert of een nieuwe bijkomt kan het geheel uit balans raken of onder (extra) druk komen te staan. Het in evenwicht houden vraagt om voortdurende aandacht, afstemming en een gezamenlijke inzet van families, professionals en andere betrokkenen. De manier waarop ouders en verwanten deze metaforische stenen dragen, begrijpen en vormgeven, staat centraal in dit proefschrift.

The cover of this dissertation shows a carefully constructed stack of stones, balancing on a rough surface. This stack symbolizes the layered and delicate balance in the lives of people with severe or profound intellectual and multiple disabilities, as well as in the care systems that surround them. Each stone represents an essential element: the need for autonomy, competence, or relatedness; moments of transition; support from the environment; and the lifelong pursuit by parents of meaningful and appropriate choices to create the most dignified life possible for their child. The stack is not inherently stable. Whenever a stone shifts or a new one is added, the entire structure may become unbalanced or come under (additional) strain. Maintaining balance requires continuous attention, coordination, and shared efforts of families, professionals, and others involved. This dissertation explores how primary relatives carry, interpret, and give shape to these metaphorical stones.

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's Heeren Loo