Understanding Triple-C

AND THE IMPORTANCE OF RELATIONSHIPS IN THE LIVES OF PEOPLE WITH INTELLECTUAL DISABILITIES WHO PRESENT CHALLENGING BEHAVIOUR

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Het onderzoek zoals beschreven in dit proefschrift is uitgevoerd aan het departement Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, Nederland.
Het onderzoek is financieel mogelijk gemaakt door zorgorganisatie ASVZ.

Het drukken van dit proefschrift is financieel mogelijk gemaakt door Tilburg University en ASVZ.

ISBN: 978-94-6423-420-6
Cover & Lay-out: Stefanie van den Herik || HerikMedia || herikmedia.nl
Printing: ProefschriftMaken || proefschriftmaken.nl

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Proefschrift ter verkrijging van de graad van doctor aan Tilburg University
op gezag van de rector magnificus, prof. dr. W.B.H.J. van de Donk,
in het openbaar te verdedigen ten overstaan van een
door het college voor promoties aangewezen commissie
in de Aula van de Universiteit op vrijdag 15 oktober 2021 om 13.30 uur

door

Tess Tournier
geboren op 11 oktober 1986 te Rotterdam

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“The question is not what you look at, but what you see”

Henry David Thoreau

Table of Contents

CHAPTER 1

1

General introduction

The Triple-C Approach

To improve the quality of life of people with intellectual disabilities and challenging behaviour, a variety of interventions have been developed (Banks & Bush, 2016). Despite these interventions, the needs of people with intellectual disabilities and challenging behaviour are often poorly met as the support from professionals and services is not sufficient enough (Griffith & Hastings, 2014; Griffith et al., 2013; Hastings, 2013). One of the causes might be that even though interventions are underpinned with scientific evidence, the feasibility of implementing the interventions in practice still needs attention (Bosco et al., 2019). In addition, the actions of practitioners are often based on intuition, which consists of tacit knowledge and knowledge from their education (Welsh & Lyons, 2001). When professionals use this tacit knowledge in practice, they may even develop their own interventions in a specific context. Such a development took place in the Netherlands in the early 1990s, when practitioners developed the values-driven Triple-C approach. Some serious scandals, concerning the support of people with intellectual disabilities and challenging behaviour, who were living in inhumane or inadequate services (e.g. long time use of physical restraints or physical abuse), were the starting point of the development of Triple-C (Van Wouwe & Van de Weerd, 2011, 2015). An approach which aimed to let people with intellectual disabilities and challenging behaviour experience an ordinary life as much as possible, and fulfil their human needs. The three C's represent Client, (i.e., the person with an intellectual disability), Coach (i.e., the support worker), Competence (i.e., the activity which the client and coach perform together).

To give more guidance to practitioners to provide sufficient support, Van Wouwe and Van de Weerd (2011, 2015) began developing their own value-driven approach. Stimulated by the normalization principle (Wolfensberger, 1983), and informed by attachment (Bowlby, 1988) and social learning theories (Bandura, 1978), the developers wanted to enable people with intellectual disabilities and challenging behaviour to experience a life as close as possible to the life of people without intellectual disabilities (i.e. an ordinary life; King's Fund Centre, 1980). The basis of this new approach was that human behaviour is determined by the interaction between an individual and his or her environment, and that challenging behaviour could be seen as a response to a challenging environment (Flynn et al., 2019; Hastings et al., 2018). Instead of trying to control the challenging behaviour, professionals who work with Triple-C should have an emphatic, understanding and compassionate response to challenging behaviour. Within the vision of Triple-C, it is assumed that by meeting the human needs (physical, emotional, mental and meaningful needs) of people with intellectual disabilities and challenging behaviour (Barrett, 2002; Maslow, 1943), an ordinary life can be experienced as much as possible.

Nowadays, the Triple-C approach is commonly used in the Netherlands to support people with intellectual disabilities and challenging behaviour. It is estimated that within the Netherlands, in 23 service providers, approximately 3,600 people, ranging from people with severe to borderline intellectual disabilities and challenging behaviour, are supported by Triple-C. The approach tries to promote a positive response towards people with intellectual disabilities and challenging behaviour; by achieving a meaningful lifestyle whereby people with intellectual disabilities and challenging behaviour receive unconditional support to improve their attachment to support staff. In the practical application of Triple-C by support staff, the development of an attachment relationship between an individual with an intellectual disability and challenging behaviour and a support worker is regarded as a significant pillar of the approach. The assumption is that this relationship could act as a buffer to challenging behaviour in stressful or complex situations. In these circumstances the support worker can act as a safe haven; the individual with an intellectual disability could turn to in times of distress. In quieter times, the support worker can act as a secure base; encouraging an individual with an intellectual disability to explore (new) situations and competences (Marvin et al., 2002). By working on meaningful activities together, an attachment relationship can be developed when support staff provide unconditional support.

In a first attempt to measure the effect of the Triple-C approach, a small, uncontrolled, double baseline study was completed with 53 individuals with severe challenging behaviour and different levels of intellectual disabilities (Van Wouwe et al., 2013). The changes on several measures were examined five times (within a time span of about one year), twice before they moved to a Triple-C environment and three times after they had moved. The initial results of this study seemed promising. After the use of Triple-C for one year, the communicative skills, daily living skills, and social skills increased (examined with the Vineland Adaptive Behavior Scales; De Bildt et al., 2005). No significant differences were found in the behavioural and emotional problems (measured by the Dutch version of Developmental Behavior Checklist; Dekker et al., 2002). The use of restrictive measures seemed to decrease when Triple-C was applied. This was based on numbers of daily reports of taking the participant down to the floor; separation in a designated room and the use of seclusion (e.g. bedroom, hallway).

Despite these positive findings and the widespread use of Triple-C in Dutch care for people with intellectual disabilities and challenging behaviour, the practice-based nature of the approach means that many of the professionals' actions or activities are often underpinned by their implicit knowledge about Triple-C. This implicit knowledge can become valuable, when analysed systematically with scientific procedures, add to a better understanding of practice-based interventions and underpin them with scientific knowledge (Drahota et al., 2016; Embregts, 2017). As Embregts (2017) stated, close collaboration between science and practice is therefore needed to achieve an optimal 'development of knowledge'. In the case of Triple-C, an explicit description of the elements and an understanding of the mechanisms of change are missing. Professionals can find it difficult to articulate how the approach is operationalized and positive changes are achieved. In addition, the application of Triple-C by support staff is not clear; how to provide unconditional support when performing meaningful activities together, in situations where challenging behaviour could occur? By systematically tapping into the implicit knowledge of experienced Triple-C support staff and psychologists, these insights might become more explicit, as they both have a significant role in applying the Triple-C approach in practice.

To have a better understanding of the context in which the Triple-C approach is applied, first a more detailed description of general constructs will be described; intellectual disability, challenging behaviour and its relation with the context, multicomponent approaches, and social relationships of people with intellectual disabilities and challenging behaviour.

People with Intellectual Disabilities and Challenging Behaviour

The term intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities as: *"Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18"* (Schalock et al., 2010). It is estimated that approximately 142.000 people in the Netherlands have an intellectual disability (Woittiez et al., 2014). In addition, people with a borderline level of intellectual functioning can apply for professional intellectual disabilities support as well (Woittiez et al., 2014). In total, this resulted in 166.000 people with intellectual disabilities or borderline level of functioning who received support from disability services in 2011; 72.000 of this population had a mild intellectual disability (IQ between 50 and 70), 57.000 had a moderate or severe intellectual disability (IQ below 50) and another 37.000 had a borderline level of intellectual functioning (IQ 70-85; Ras et al., 2013).

A part of this population of people with intellectual disabilities display 'behaviour that challenges'. Challenging behaviour is in this case not a diagnosis, the term is used to indicate that the behaviour is a challenge to family members, professionals and services. However, the behaviour may be functional for the individual with an intellectual disability themselves. For example, when someone is screaming or hitting themselves, this can be challenging for other people, but help the person with an intellectual disability to draw attention to their needs. Some challenging behaviour only appears in certain environments, and this behaviour might be considered challenging in some cultures or settings but not in others (Pilling et al., 2015). Emerson and Einfeld (2011) emphasised that challenging behaviour is defined socially at two levels. First, behaviour is defined as 'challenging' when it stands outside social norms, and it is culturally inappropriate. Second, when challenging behaviour occurs frequently, with a high level of severity and is long lasting, then social consequences might occur. These consequences are defined in terms of actual harm or the risk of harm to the person with an intellectual disability and other people, or exclusion from aspects of community life.

Prevalence of Challenging Behaviour

Three types of challenging behaviour are frequently reported in people with intellectual disabilities, that is aggressive behaviour, self-injurious behaviour and stereotyped behaviour. Considerable variation is reported in the prevalence of these challenging behaviours in total population studies of people with intellectual disabilities (Holden & Gitlesen, 2006; Jones et al., 2006; Lowe et al., 2007; Lunqvist, 2013). For example, Holden and Gitlesen (2006) reported challenging behaviour in 4-22% of the total population in Norway, whereas Lowe et al. (2007) reported 10% in the United Kingdom. Variability in prevalence rates might be due to the use of different definitions of challenging behaviour and differences in sampling methods (Emerson et al., 2001a). Studies looking at specific settings (e.g. institutional setting), subpopulations (e.g. people with profound intellectual and multiple disabilities) or different behaviours (e.g. self-injurious behaviour, stereotyped behaviour) have reported even higher frequencies; 50-80% (Bouras & Drummond, 1992; Poppes et al., 2010). Therefore, Bowring et al. (2017) completed a total population study in a defined area (Jersey, a Channel Island between England and France, which is a self-governing dependency of the United Kingdom), to provide a robust estimate of prevalence of challenging behaviour. They identified the entire administrative population of adults with intellectual disabilities and used a behaviour assessment tool with good psychometric properties (the Behaviour Problems Inventory – Short Form; Rojahn et al., 2012). The results of the study showed that 18.1 % of the participants with intellectual disabilities displayed challenging behaviour, which was similar to the other population studies (Jones et al., 2008: 18.7–22.5%; Lunqvist, 2013: 18.7%). In the study of Bowring et al. (2017), stereotyped behaviour was the most commonly reported form of challenging behaviour (10.9%), followed by aggressive and destructive behaviour (8.3%). Self-injurious behaviour was least reported (7.5%).

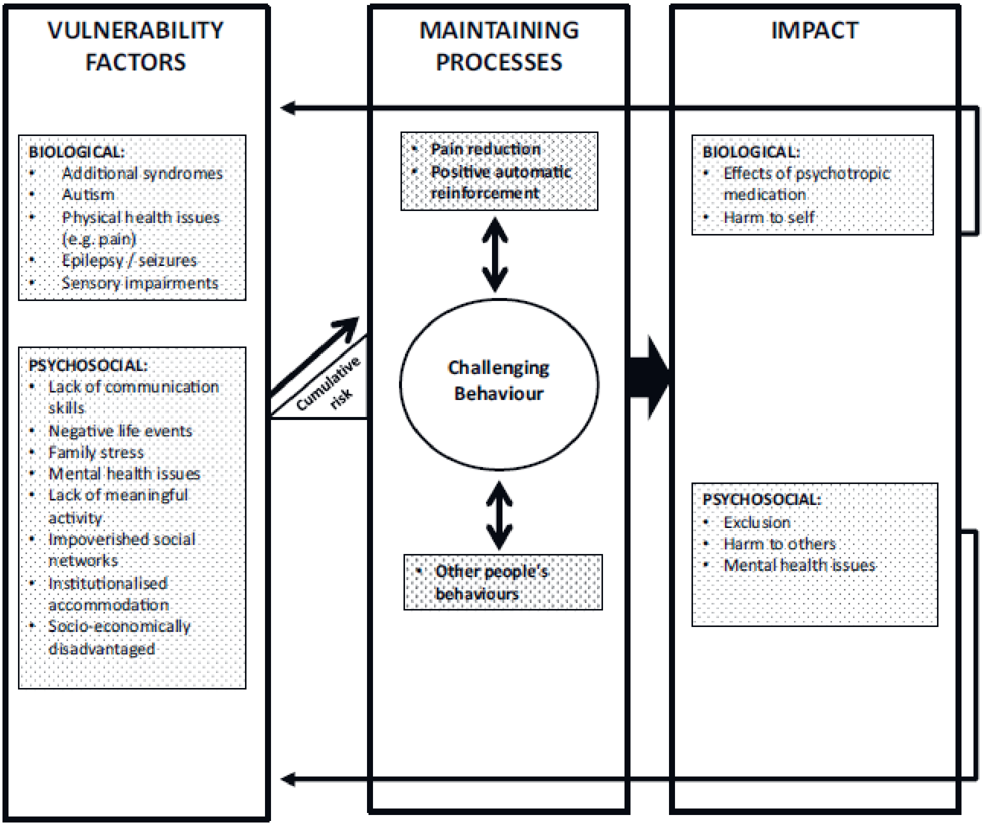
Challenging Behaviour and its Context

Challenging behaviour can be considered as a complex phenomenon, because there may be various causes that contribute to the development and/or reinforcement of it. To contribute to a more structured approach in the care for people with intellectual disabilities and challenging behaviour, a multidisciplinary guideline was developed in the Netherlands based on state of the art scientific and practice-based evidence. The guideline contains four main themes: the assessment of challenging behaviour, support and treatment of challenging behaviour, the use of psychotropic medication, and the organisation of care (Embregts et al., 2019).

In the international literature, Bowring et al. (2019) have summarised the scientific literature about challenging behaviour of people with intellectual disabilities into a framework, which illustrates the possible causes and maintaining factors contributing to challenging behaviour (figure 1).

Figure 1

The Revised (building on Hastings et al., 2013) Framework for Understanding Challenging Behaviour (Bowring et al., 2019)



This biopsychosocial framework displays multiple vulnerability factors which increase the likelihood of challenging behaviour to occur. Examples of such factors are having autism (Lunqvist, 2013; McClintock et al., 2003), experiencing a lack of communication skills (McClintock et al., 2003), having mental health issues (Painter et al., 2018), experience a lack of meaningful activities (Bowring et al., 2017; Lowe et al., 2007), and having impoverished social networks (Scott & Havercamp, 2014).

In the second column of figure 1, processes are described which could maintain the challenging behaviour. As challenging behaviours can be considered as 'useful' in some way for the individual with an intellectual disability, they serve an important function and therefore continue to occur. An understanding of the functions that challenging behaviours may serve is the core part of this framework and essential when it comes to intervention (Hastings et al., 2013; Embregts et al., 2019; Van den Bogaard et al., 2018). A first process that is described is pain reduction. For example, hitting an infected ear to release natural endorphins and dull the pain for a while can be an explanation for self-injurious behaviour (Hastings et al., 2013). The second process which can maintain challenging behaviour is 'positive automatic reinforcement'. In this case, challenging behaviour functions to get attention from others, to stimulate oneself, to get access to 'tangibles' (things that are tangible, such as food or preferred objects), and avoidance of demands from others (Hastings et al., 2013; Bowring et al., 2019). The last process mentioned in the second column is 'Other people's behaviour', such as family and support staff, which are a major part of the context of a person's day-to-day relationships. The process refers to environmental reinforcements by other people's responses. An example of how other people's behaviour can maintain the challenging behaviour is when support staff decide to ignore the 'attention seeking' behaviour of an individual with an intellectual disability, until this behaviour escalates and support staff can no longer ignore it and inadvertently reinforcing the challenging behaviour. In the longer term, the chances an individual with an intellectual disability will display this behaviour again, when attention is low or not available, increases. Another way other people's behaviour affects the maintaining process of challenging behaviour, are the beliefs and attitudes of support staff about why challenging behaviour occurs (Hastings & Remington, 1994; Hastings, 1997; Hastings et al., 2013; Van den Bogaard et al., 2020). Their understanding of likely causes of challenging behaviour may affect the behaviour of support staff. When support staff perceive the challenging behaviour as uncontrollable by the individual with an intellectual disability, they are more likely to respond with empathy and are more willing to help (Hill & Dagnan, 2002). The other way around; when people with intellectual disabilities and challenging behaviour themselves experience a lack of empathy for their situation from support staff, this may function as a reason for friction and increased likelihood of challenging behaviour (Griffith et al., 2013; Van den Bogaard et al., 2019).

The impact of challenging behaviour (column three of figure 1) on people with intellectual disabilities themselves and others can be substantial and negatively affect their quality of life (Heyvaert et al., 2015). People with intellectual disabilities may experience a deterioration in their quality of life due to restrictive practices (e.g. seclusion, manual and mechanical restraint, rapid tranquillisation and long-term sedation), physical abuse, placement breakdown and out-of-area placements (Embregts et al., 2019; Emerson & Einfeld, 2011). Moreover, the impact of their challenging behaviour might also have a reinforcing effect on the vulnerabilities presented in the first column (figure 1). Such as the prescription of more psychotropic medication (column three of figure 1) which in turn may have a cyclical impact on biological vulnerabilities for challenging behaviour (column one; Bowring et al., 2019).

Column three also describe the element ‘harm to others’. It was found that carers (family and support staff) experienced challenging behaviour as aversive, and they may become angry when people with intellectual disabilities display self-injurious behaviour (Mossman et al., 2002; Willems et al., 2016). To stop these aversive feelings, carers may respond in a way that paradoxically serves to maintain the challenging behaviour. For example, removing an activity someone dislikes, such as taking a shower, from a person who displays self-injurious behaviour. By removing this activity, it might make it more likely for the person to engage in self-injurious behaviours in the future to avoid that he or she must shower themselves. In addition, family and support staff have reported feelings of frustration, exhaustion, fatigue, burnout and stress, and feel unable to continue in their caring role (Hastings, 2002a; Lecavalier et al., 2006). Increased feelings of stress, which are associated with taking care for people with intellectual disabilities and challenging behaviour, are related to their ongoing exposure to challenging behaviour (Hastings, 2002a, 2002b). Family and support staff are likely to respond differently when they experience heightened stress, such as showing lowered patience in dealing with challenging behaviour, or they may begin to display greater vigilance for any adverse events (Hastings et al., 2013). A theory which explains the emotional responses of carers is the Attribution Theory of Weiner (1985, 1986). This theory asserts that carer’s attributions about the causes of a person’s behaviour influence the emotional responses to that behaviour, and the optimism as to whether or not the behaviour can change. On the other hand, the emotional responses and optimism also predicted to influence the helping behaviour of family and staff. When the challenging behaviour is considered to be less controllable for the individual with an intellectual disability and less stable (so more likely to be changeable), carers are more willing to help and respond with sympathy (Weiner, 1986; Van den Bogaard et al., 2020).

In sum, consideration of the wider life context of individuals with an intellectual disability is crucial to understand the elements of the framework presented in figure 1. That is, how challenging behaviour is defined, the vulnerabilities of the individual with an intellectual disability which can cause the challenging behaviour, and the maintaining effect of other people’s behaviour in the context of a person’s day-to-day relationships. The focus of this thesis is on the latter; the relational contextual background of challenging behaviour. The thesis focusses on two pathways concerning this context. First, research on systematically explicitating the Triple-C approach, which needs to be delivered in a relational context. Second, understanding in more detail the dimensions of the relationships, especially family relationships, as they are pervasive in individuals’ history and current care context. That is, how are family involved when their relative resides at a service facility, how people with intellectual disabilities perceive their family based social capital, and how challenging behaviour is associated with this capital.

The Context of the Triple-C Approach

As the context of an individual's life has significant impact on their vulnerability to developing challenging behaviour and its maintenance, the focus of support and interventions should be on fixing the challenging context rather than fixing the challenging behaviour (Carr et al., 2002). To be able to change facets of an individuals' living context, the support of people with intellectual disabilities and challenging behaviour calls for multicomponent approaches which aims to meet the individuals needs with respect to the multiple dimensions that define quality of life (Carr et al.,2002).

Multicomponent and Person-Centred Approaches

From the 1980's a broad-based movement emerged with respect to non-aversive behaviour management (Horner et al., 1990). More questions arose about the treatment of people with intellectual disabilities and challenging behaviour, as there were concerns that they were exposed to dehumanising interventions that were neither ethical nor beneficial (Durand, 1988; Guess et al., 1987). Positive procedures promoting the development of adaptive behaviour have built on the values that people with intellectual disabilities and challenging behaviour should be treated with the same respect and dignity as other people in society (LaVigna & Donnellan, 1986; McGee et al., 1987; Evans & Meyer, 1985). More encouragement and acknowledgement for lifestyle changes of people with intellectual disabilities and challenging behaviour appeared and it was desired that support should result in durable, generalised changes in behaviour, which eventually led to individuals' access to community settings, and social contact (Horner et al., 1990). Because in most cases these new approaches addressed a range of factors, multicomponent approaches were designed to increase the positive, and decrease the negative behaviour at the same time (Koegel & Koegel, 1988). Over time, it became more clear that a multicomponent approach should involve all relevant stakeholders who play a significant role in people's lives. Thus, not only professionals but for example family as well (Binnendyk et al., 2009).

Furthermore, the support plans of people with intellectual disabilities became more needs-driven rather than service-driven, as the hypothesis was that when an individual's needs were met, the quality of life would improve and challenging behaviour would decrease (Carr et al., 2002). As every individual has their own specific needs within the quality of life domains (that is physical, emotional and material well-being, interpersonal relations, personal development, self-determination, inclusion and rights; Schalock, 2004), person-centred approaches were used to personalise the needs, goals, and support. Characteristic of person-centred approaches is the open-ended perspective (no final goals are set), which fits well in the long term care for people with intellectual disabilities and challenging behaviour (Klatt et al., 2002; Sanderson, 2000).

Internationally, there are two person-centred, multicomponent approaches in the field of intellectual disability care with a strong theoretical base: Positive Behavioural

Support (Carr et al., 2002; Gore et al., 2013; McGill & Toogood, 1994) and Active Support (Flynn et al., 2018; Mansell & Beadle-Brown, 2012). Both approaches try to facilitate people's purposeful and meaningful interaction with the social and material environment (Totsika et al., 2008) and focus on positive social interactions because they assume that people are less likely to display challenging behaviour when they enjoy positive social interactions with those around them (Allen et al., 2013). Positive Behavioural Support has a comprehensive character and focuses in the long term on an improved quality of life. This value driven approach uses a combination of different elements to implement the intervention effectively. That is, the values of normalization, human rights, and self-determination (Carr et al., 2002; Gore et al., 2013). Active Support is a person-centred approach as well, and aims to enable people with intellectual disabilities to experience a rich and varied lifestyle in which their participation and independence is directly facilitated by the help and encouragement of support staff (Toogood, 2010). When delivered with fidelity, both approaches are likely to be effective in practice (Bigby et al., 2020; Bosco et al., 2019). Despite the existence of these evidence-based approaches, they are not commonly used in Dutch practice to support people with intellectual disabilities and challenging behaviour. A potential reason could be that the Dutch care context requires different characteristics, as care always takes place in a specific context, with specific professional capabilities and resources, and with its own history (Council for Public Health and Society, 2017). That is, aspects of evidence-based approaches may not always be transferable (Gabbay & Le May, 2004; Ioannidis, 2016) and the cultural and social context may have a significant influence on the development and use of care approaches. In case of the Dutch care for people with intellectual disabilities, there is a strong influence of the orthopedagogical perspective (Van Gennep, 1997), resulting in more emphasis on the contextual factors of support.

Preconditions of Multicomponent Approaches

Many people with intellectual disabilities and challenging behaviour reside in specialist services, which can be considered as a specific context (Iemmi et al., 2016). Because the context has significant impact on the behaviour people with intellectual disabilities display, multiple studies have examined factors that could affect the behaviour of people with intellectual disabilities who live in specialist services. One of the factors that seem to affect behaviour are organisational characteristics (Bosco et al., 2019; Dilworth et al., 2011; Olivier-Pijpers et al., 2020; Schalock et al., 2008; Sundblom et al., 2015). Research has shown that people with intellectual disabilities and challenging behaviour themselves (or their informant) point out several significant organisational characteristics that specifically affect their challenging behaviour. These include organisational values and having competent support staff (Olivier-Pijpers et al., 2020).

When focussing on the context and needs of people with intellectual disabilities, guidance of professionals by organisational values, and commitment to these common values, is required (Bigby & Beadle-Brown, 2018; Olivier-Pijpers et al., 2020; Pilling et al., 2015; Walker, 2012). It is assumed that organisational values exert a powerful influence over the quality of a service facility by influencing staff values and attitudes, thereby improving the support provided (Emerson et al., 1994). Values help an organisation engage the hearts and minds of professionals in the pursuit of common goals. By clarifying the values of individuals and organisations, professionals can gain meaning in their work and organisations can develop a dedicated workforce (Sullivan et al., 2001). In addition, a value-led approach avoids clinical decision-making based on personal opinion or circumstance and provides the most ethical means of operating (Gore et al., 2013). A precondition for the effect of organisational values is that they are made explicit, as the degree of fit between organisational and staff values is predictive of effective implementation (Henry et al., 2001). Bigby et al. (2009) stated that the organisational values in the care of people with intellectual disabilities should be based on experiencing an 'ordinary life' (King's Fund Centre, 1980) and the normalisation principle (Wolfensberger, 1972, 1983). Although this normalisation principle differs slightly from the Triple-C 'normalisation principle', as Wolfensberger (1972, 1980) interprets normalisation as specifying various standards of behaviour to which an individual with an intellectual disability should conform, and that normalisation measures can be offered in some circumstances and imposed in others (Perrin & Nirje, 1985). Whereas Triple-C implies normalisation as the opportunity for people with intellectual disabilities to live a life as similar in nature as possible to that of others.

Furthermore, competent support staff are essential to delivering multicomponent approaches (Bigby et al., 2009; McClean et al., 2005; Olivier-Pijpers et al., 2020; Embregts, 2011). Training competent support staff requires carefully prepared training goals, training format and training techniques (Willems et al., 2016; Zijlmans et al., 2011). However, training on itself is not enough to improve the competences of support staff. The combination of training and coaching on-the-job seems successful; where simple classroom knowledge and skills, and daily working practice and attitudes come together (Deveau & McGill, 2016; Van Oorsouw et al., 2009). When organising regular training and coaching within an organisation, it can become more than a transfer of strategic information from experts to practitioners, but rather a process of mutual education involving capacity building that ultimately results in systems change (Carr et al., 2002).

To organise the coaching on-the-job to support staff to become more competent, practice leadership by a team captain or first-line manager seems to be necessary (Beadle-Brown et al., 2014). Practice leadership is defined as the development and maintenance of good staff support for people with intellectual disabilities, through multiple elements (Mansell et al., 2004). Practice leaders can help to implement the multicomponent approach with better fidelity by modelling good practice, providing coaching on-the-job to support staff and offering regular one-to-one supervision. This would help to deliver more sensitive support in terms of when, and how people with intellectual disabilities and challenging behaviour need and want it (Beadle-Brown et al., 2014; Mansell et al., 2004).

Last, a group of professionals that have a significant share in the training and coaching of support staff beside practice leaders are psychologists. Psychologists support staff to implement and apply multicomponent approaches with fidelity (Stenfert Kroese & Smith, 2018). Developing effective collaborative relationships between the psychologist and members of the staff team can help to promote positive practices. Moreover, by creating opportunities for support staff to share their experiences and acknowledge the difficulties of working with people with intellectual disabilities and challenging behaviour, a learning climate can be established (Stenfert Kroese & Smith, 2018). When support staff experience a safer climate in their team, they will show higher support-seeking behaviour when they are not sure about how to support an individual with an intellectual disability and challenging behaviour properly (Knotter et al., 2013; Willems et al., 2016).

Social Relationships

The main focus of this thesis is on the relational contextual background of challenging behaviour. That is, the maintaining effect of other people's behaviour in the context of a person's day-to-day relationships. The first part of this introduction elaborated on the Triple-C approach and its care context (first pathway). The second pathway of this thesis focusses on understanding in more detail the dimensions of relationships, especially family relationships, as they are pervasive in individuals' history and current care context. Research shows that positive, close social relationships have a beneficial effect on health and wellbeing (Antonucci, 2001; Scott & Havercamp, 2018). That is, when people are more socially connected to family, friends and community, they are happier and physically healthier than people who are less well connected (Cohen & Wills, 1985; Frielink et al., 2018). People with intellectual disabilities rate their social relationships as the most significant domain of all the quality of life domains; having social relationships provides a sense of satisfaction with life and improves their self-esteem (Cummins & Lau 2005; Forrester-Jones & Barnes, 2008; Liang et al., 2001). Although there is strong evidence about the importance of social relationships, people with intellectual disabilities have relatively small social networks compared to those without intellectual disabilities; on average they consist of ten to eleven people (Van Asselt-Goverts et al., 2013). The people in these social networks can be divided in two groups: the informal network (e.g. family, friends, acquaintances) and the formal network (e.g. support staff, psychologist, social worker; Chappell & Blandford, 1991).

Formal Networks

Professionals often have a significant role in the formal networks of people with intellectual disabilities. This applies to people who live independently in supported group homes, as well as for people who live in a residential facility (Forrester-Jones et al., 2006; Van Asselt-Goverts et al., 2013, 2015; Verdonschot et al., 2009). These are semi-enclosed sites with various facilities where they stay permanently (Robertson et al., 2001). Support staff and other professionals are highly appreciated by people with intellectual disabilities, because of the instrumental support (e.g. running a household, assistance with finances), and the emotional support they provide (e.g. listen to their problems; Giesbers et al., 2019b; Roeleveld et al., 2011; Van Asselt-Goverts et al., 2013). The degree of affection (i.e. feeling safe and secure), and preference (i.e. preference for a person, liking the contact) was assessed by people with intellectual disabilities to be comparable to feelings they have about their family (Van Asselt-Goverts et al., 2013). Some people with mild intellectual disabilities even see professionals as part of their family (Widmer et al., 2008). In the case of people with intellectual disabilities and challenging behaviour, positive staff relationships can support people's emotional regulation and serve as a source of guidance and advice (Clarke et al., 2019). These relationships can also have effect on quality of life domains, such as interpersonal relationships, personal development, self-determination, and emotional wellbeing (Schalock, 2004), and good relationships offer a sense of security to people with intellectual disabilities (Moses, 2000; Schuengel et al., 2010). Therefore, fostering meaningful relationships between support staff and people with intellectual disabilities and challenging behaviour is important (Embregts, 2011; Hastings, 2010; Hastings & Remington, 1994).

People with intellectual disabilities and challenging behaviour themselves value support staff that are patient, genuinely interested, helpful, share a sense of fun, have mutual respect, have a calm and consistent approach, and explain information clearly (Griffith et al., 2013; Roeleveld et al., 2011; Van den Bogaard et al., 2019). Experiencing a positive, warm relationship can provide confidence to make progress toward valued goals (Harker-Longton & Fish, 2002; Pert et al., 2013; Ruef & Turnbull, 2002). When a good relationship is established between an individual with an intellectual disability and a support worker, it can have a positive impact on both their emotional well-being and challenging behaviour (Clarkson et al., 2009; Fish & Culshaw, 2005). Moreover, people with intellectual disabilities and challenging behaviour noticed that having a rapport with a support worker that consists for a longer time, an attachment relationship could develop (Clarkson et al., 2009; Adshead, 1998; De Schipper et al., 2006). This could be a valuable development for people with intellectual disabilities and challenging behaviour, as they appear to have insecure attachment relationships more often than people without intellectual disabilities (Schuengel & Janssen, 2006). Eventually, this can result in problems with regulation of anxiety and the development of future, secure attachment relationships. The disordered attachment can display themselves in challenging behaviour towards support staff and/or the environment (De Schipper & Schuengel, 2010; Janssen et al., 2002). Therefore, the quality of the response from a support worker to the proximity- and contact-seeking behaviour of the individual with an intellectual disability is of great importance to manifest itself in high quality relationships (and in some cases attachment relationships) between them (Giesbers et al., 2019b).

Informal Networks

The informal social networks of people with intellectual disabilities mainly consist of family members (Giesbers et al., 2020; Sanderson et al., 2017). Family has their own significant role in the lives of people with intellectual disabilities, as they contribute to aspects of people's needs (Binnendyk et al., 2009). That is, the relationships with family members are usually characterised by unconditional love, emotional closeness and a long-term perspective (Bigby & Fyffe, 2012). These relationships are a potent source of meaning in life and contribute to a sense of belonging, due to their non-transitory, ubiquitous nature (Krause, 2007; Lambert et al., 2010).

Despite the significance of family, earlier research showed that people with mild intellectual disabilities without challenging behaviour perceive their family networks often smaller than people without intellectual disabilities (Giesbers et al., 2020). Although there is a diversity within the family relationships, such as stepfamily, uncles and aunts, in-laws and friends, the nuclear family (parents and siblings), and in particular the parents, play the most important role in people's networks (Giesbers et al., 2020). People with mild intellectual disabilities without challenging behaviour have on average fewer relationships with family members (both receiving and giving support), their relationships with family members are less reciprocal and they appear to have a less central position in the network than people without intellectual disabilities (Widmer et al., 2008). However, it is not clear yet if these family network characteristics also apply to the family networks of people with intellectual disabilities and challenging behaviour.

Family Networks of People with Intellectual Disabilities and Challenging Behaviour

People with intellectual disabilities and challenging behaviour themselves indicated that positive family relationships provided a sense of belonging and the opportunity to participate in valued, equal relationships with family members (Clarke et al., 2019). However, people with intellectual disabilities who display challenging behaviour seem to experience a higher level of social exclusion, resulting in smaller and/or less supportive social networks (Myrbakk & Von Tetzchner, 2008; Robertson et al., 2001). The smaller social networks and limited amount of support this group receive can be seen as both the cause and the result of the challenging behaviour. People may become more distant from individuals who are presenting challenging behaviour which, in turn, may cause more challenging behaviour (Greenberg et al., 2006; Orsmond et al., 2003).

Nouwens et al. (2017) identified a subgroup of people with mild intellectual disabilities in which personal problems often co-occurred with family problems. More specifically, the children's and parents' problems had a continuous and negative influence on each other, thereby reinforcing each other. In addition, the living situation of people with intellectual disabilities and their challenging behaviour might also be related to smaller social networks, as they are more likely to live in residential facilities (Bigby, 2012). Due to the more remote and secure nature of these residential facilities, people with intellectual disabilities and challenging behaviour could have fewer opportunities to make new contacts, which may lead to fewer social relationships and inclusion in society (Bigby, 2012). Smaller social networks can be critical as people with intellectual disabilities and challenging behaviour often experience more stress, but have fewer social resources available to cope with that stress (Lunsky & Benson, 2001).

However, the results presented above describe the possible effects of challenging behaviour on social networks in general. Little is known about the specific characteristics of family networks, such as whom do people with challenging behaviour consider as significant family? By whom are they supported and, in turn, who do they support? Are these supportive relationships reciprocal? Therefore, the second pathway of this thesis is to get a better understanding of the dimensions of family relationships of people with intellectual disabilities and challenging behaviour. Because the answers to these questions might be valuable for person-centred approaches such as Triple-C. That is, it is known that sustainable, reciprocal relationships have a positive effect on the self-esteem of people with intellectual disabilities (Baumeister & Leary, 1995; Forrester-Jones & Barnes, 2008; Liang et al., 2001), and having a more central place within the family network can provide a sense of belonging. Last, relationships can provide an outlet for fears and frustrations and give encouragement and assistance in times of difficulty, in this way, the relationships can act as a buffer between the impact of stress and the mental health consequences (Scott & Havercamp, 2014).

Collaboration between Formal and Informal Networks

Another argument why it is necessary to learn more about the family network characteristics of people with intellectual disabilities and challenging behaviour is for professionals to be able to involve these significant family members in the application of person-centred approaches. People with intellectual disabilities and challenging behaviour have a higher chance to move away from their family home due to their challenging behaviour (Llewellyn et al., 1999; Mirfin-Veitch et al., 2003). Despite this replacement, family usually remains the most continuous factor in the life of an individual with an intellectual disability (Giesbers et al., 2020; Kamstra et al., 2015). Regardless the significant role of family in the lives of people with intellectual disabilities, it may not always be self-evident that families are involved in the application or development of person-centred, multicomponent approaches. This can be considered as a drawback, as the lifelong bond that parents have with their child with an intellectual disability and challenging behaviour is beneficial for a better understanding of a person's needs (Bigby & Fyffe, 2012; Ryan & Quinlan, 2018). In addition, person-centred approaches seem to be more effective when family is more strongly involved (Dunlap & Fox, 2007). Even though family can have a valuable role and add to the support of people with intellectual disabilities and challenging behaviour, the collaboration between professionals and family can be difficult for a number of different reasons, such as poor communication, inadequate support and a lack of coordination (Redmond & Richardson, 2003; Ryan & Quinlan, 2018). Although professionals are highly aware of the needs and challenges faced by families, yet, they struggle to collaborate effectively with families. Professionals indicate that they sometimes struggle with families who can be demanding and others who seem uninvolved or hard to reach. Therefore, professionals can find it sometimes hard to attune to the different styles and priorities of collaboration and care (John, 2020; Mooney & Lashewicz, 2014). However, both parties play a significant part in the lives of people with intellectual disabilities, and are core relationships in their lives. Therefore, the collaboration between the two parties should be characterised by partnership (Keen, 2007; Morrow & Malin, 2004). Which means that family is considered as an equal partner (Knox, 2000) and the collaboration is about common goals, mutual respect, shared decision making, honesty and trust (Keen, 2007). As the involvement of family in multicomponent, person-centred approach may be difficult and/or not self-evident, it is an issue that needs to be considered.

Aims and Outline of the Thesis

Aims

The first pathway of the thesis focuses on the operationalisation of the practice-based Triple-C approach. The second pathway of the thesis examines the involvement of family in person-centred approaches and the perceived relationships within the family networks of people with mild intellectual disabilities and challenging behaviour.

Although Triple-C is widely used in the care for people with intellectual disabilities and challenging behaviour in the Netherlands, the practice-based nature of the approach means that many of the professionals' actions or activities are often underpinned by their implicit knowledge about Triple-C. Professionals can find it difficult to articulate how the approach is operationalized and positive changes are achieved. Therefore, the first aim of this thesis was to establish a logic model of Triple-C; a model which represents the elements of the approach. That is, the underpinning assumptions, aim, organisational preconditions, competencies of professionals, how Triple-C should be applied in practice, and which outcomes are expected. In addition, due to practice-based nature of Triple-C, the application of the intervention in practice is mostly underpinned with professionals' implicit knowledge. For that reason, the second aim was to operationalize the implicit knowledge and skills of experienced Triple-C professionals (support staff and psychologists) regarding the relationship building between an individual with an intellectual disability and a support worker. These insights can be used to improve training and the support by support staff in the application of Triple-C.

In addition to the relationships with support staff, family relationships are also of great value to people with intellectual disabilities and challenging behaviour (Clarke et al., 2019). However, little is known about how families are involved in the planning and delivery of person-centred approaches in general, and more specifically in Triple-C. Along with whom people with mild intellectual disabilities and challenging behaviour consider as (significant) family. Therefore, the aim of the second pathway is first, to get insight in the involvement of family in person-centred approaches in general, and second, to investigate the family networks in terms of emotional support of people with mild intellectual disabilities and challenging behaviour.

Thesis Outline

The thesis consists of nine chapters, of which this general introduction is the first. The first pathway of this thesis, research on systematically operationalising the Triple-C approach, will be elaborated in Chapter 2 and 3. The study in **Chapter 2** describes the process of building a Triple-C logic model. Qualitative methods were used to collect the data; interviews with the founders of Triple-C, focus groups with experienced Triple-C professionals and the analysis of published accounts of the Triple-C approach. Data gathered from these sources were analysed using content analysis. The results of the analyses were used to shape the Triple-C logic model. In **Chapter 3**, an element of the Triple-C approach was investigated, that is, when is a real connection between a support worker and an individual with an intellectual disability considered, and what does this connection looks like? This focus was chosen as this can be considered to be a precondition for developing a relationship between a support worker and an individual with an intellectual disability. A qualitative method was used to try to capture the tacit knowledge of experienced Triple-C support staff and psychologists regarding the relatedness between an individual with an intellectual disability and a support worker. The second pathway of this thesis is explicated in Chapter 4, 5, 6, 7 and 8. **Chapter 4** contains a scoping review of the frequency and type of family involvement in the application of person-centred approaches in the care for people with intellectual disabilities and challenging behaviour. In **Chapter 5**, the process of adapting the Family Network Method into an intellectual disability version is described. The Family Network Method – Intellectual Disability (FNM-ID) can be used to obtain detailed information about the perceived given and received emotional support within a family network of an individual with mild intellectual disability. The method maps the broader network structure of interdependencies among all members of the family network in which support relationships with network members are embedded. In **Chapter 6**, the differences in perceived emotional support in family networks of people with mild intellectual disabilities and their key support staff are examined, by interviewing 138 pairs of an individual with a mild intellectual disability (aged 18-40 years) and their key support worker, using the FNM-ID. The divergence in perspectives are examined as well. **Chapter 7** contains an exploratory study; the family networks of people with mild intellectual disabilities with and without challenging behaviour were compared on seven social network measures, obtained with the FNM-ID. In **Chapter 8**, the results of a latent class analysis are displayed. Based on the emotionally supportive relationships of 137 participants with mild intellectual disabilities (aged 18-40 years), obtained with the FNM-ID, different typologies of family networks were examined. Moreover, this study examined if wellbeing and behavioural and emotional problems were associated with certain family network typologies. Finally, in the general discussion of **Chapter 9**, the findings, strengths and limitations of the thesis are summarised. In addition, implications for future research, policy, and practice are discussed.

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CHAPTER 2

2

Developing a logic model for the Triple-C intervention: A practice-derived intervention to support people with intellectual disability and challenging behaviour

This chapter has been published as:
Tournier, T., Hendriks, A. H. C., Jahoda, A., Hastings, R. P., & Embregts, P. J. C. M. (2020). Developing a logic model for the Triple-C intervention: A practice-derived intervention to support people with intellectual disability and challenging behaviour. *Journal of Policy and Practice in Intellectual Disabilities, 17*(4), 297-307. https://doi.org/10.1111/jppi.12333

Abstract

Partly due to a lack of evidence-based methods to support people with intellectual disability and challenging behaviour, their needs are often poorly met. One way to generate rapid evidence is to systematically describe and monitor interventions that are considered to be "good practice"—to develop evidence based on practical knowledge. This study describes the Dutch practice-based intervention Triple-C (Client, Coach, Competence). The intervention was developed in practice to support people with severe intellectual disability to borderline functioning and challenging behaviour. The practice-based nature of Triple-C means that many of the professionals' actions or activities are often underpinned by their implicit knowledge about the intervention they are delivering. Consequently, as the emphasis is on practice, the professionals can find it difficult to articulate how the intervention is operationalized and positive change achieved. This study aimed to assess the practical knowledge of Triple-C professionals and to develop an understanding of the mechanisms of change for Triple-C to improve understanding and to inform future research about the intervention. Through an iterative process, a logic model was developed to describe the intervention and its underlying assumptions. The development of the logic model was shaped using interviews with the founders, focus groups with support staff, psychologists, managers and members of the board of a service provider, and the analysis of published accounts of the Triple-C intervention. Data gathered from these sources were analysed using content analysis. The logic model of the Triple-C intervention provides insight into the key elements of the approach, such as the need for unconditional supportive relationship and carrying out meaningful activities. Moreover, the potential relationship with existing evidence-based interventions such as Positive Behavioural Support and Active Support are described. Defining the underlying logic of a practice-based intervention like Triple-C is an important first step toward producing an evidence base for interventions developed from clinical practice.

The needs of people with intellectual disability and challenging behaviour are often poorly met due to a lack of appropriate support from services and professionals (Griffith & Hastings, 2014; Griffith et al., 2013; Hastings, 2013). One reason for this problem might be a lack of evidence-based practice, established through the application of randomized-controlled trial designs or other robust research methods (Pilling et al., 2015). Even if there is scientific evidence, the feasibility and applicability of interventions in practice still needs attention. For example, Hassiotis et al. (2018) carried out a randomized controlled trial of Positive Behaviour Support training for staff working with people with intellectual disability and challenging behaviour. The results showed that there were no differences in the level of challenging behaviour of individuals whose clinicians received Positive Behaviour Support training and those who received care as usual. A process evaluation of this study identified poor delivery of Positive Behavioural Support as one possible key factor contributing to the outcome (Bosco et al., 2019). The use of evidence-based knowledge in practice might increase if knowledge from community stakeholders such as support staff or psychologists and service users were to be used to inform the development of a new intervention or in analysing practice-based interventions (Drahota et al., 2016; Embregts, 2017; Embregts et al., 2018; Garretsen et al., 2007). Different forms of knowledge may offer complementary ways of understanding good practice. For example, Schön (1983) proposed that competent practitioners usually know more than they are able to explain. According to his theory, becoming a reflective practitioner can help professionals to make their thought processes more explicit. As such, a first step toward generating evidence in collaboration with community stakeholders could be defining the underpinning theory and proposed mechanisms of change for practice-based interventions (Hastings, 2013; Hastings et al., 2013).

Practice-based evidence can be generated by systematically monitoring interventions that are considered to be "good practice". In general, data are collected prospectively and/or retrospectively and focus on service user variables, processes of care, and outcomes important to other stakeholders (Bergstrom, 2008). The findings of this data collection may help to indicate the potential effectiveness of interventions developed in practice by professionals in a briefer time frame than developing completely new interventions. The coordination of information generated through such activity can go some way to building a much needed body of evidence on effectiveness (Bergstrom, 2008; Emerson & Einfeld, 2011). One of the difficulties of collecting data about practice-based interventions is that the underpinning theory and processes may not be clearly articulated by professionals or service users which developed the practice-based evidence, nor how they relate to established approaches or evidence based interventions. In this article, we describe a process to collect and analyse data to elucidate the key elements of an intervention for challenging behaviour that has been developed in practice.

A variety of interventions have been developed to improve the quality of life of people with intellectual disability and challenging behaviour (Banks & Bush, 2016). These interventions aim to enable people with intellectual disability and challenging behaviour to increase their confidence and self-esteem through an environment which supports people with intellectual disability effectively and providing the optimal setting to support positive interactions and opportunities. Providing good-quality care and opportunities for developing interests and skills ultimately helps people with intellectual disabilities to master their environment and reduces the likelihood of challenging behaviour might occurring (NICE Guideline, No. 11, May 2015). Examples of comprehensive evidence-based approaches with a strong theoretical base to enhance quality of life are Positive Behavioural Support (Carr et al., 2002; Gore et al., 2013; McGill & Toogood, 1994) and Active Support (Flynn et al., 2018; Mansell & Beadle-Brown, 2012). Both interventions have a growing and robust evidence base (Bigby et al., 2019; Bosco et al., 2019) and are likely to be effective in practice if they are translated into practice as intended (i.e., delivered with fidelity). Despite the existence of these evidence-based interventions, practitioners' actions are still often based on intuition, which consists of both tacit knowledge and knowledge from their education (Welsh & Lyons, 2001). Turning this knowledge into practice, local practitioners (e.g., support staff or psychologists) may even develop their own interventions in a specific context. An example is a values-driven intervention, called Triple-C (Client, Coach, Competence) (Van Wouwe & Van de Weerd, 2011, 2015), developed in the early 1990s by local practitioners in the Netherlands. The development of this approach was stimulated by several serious scandals concerning the support of people with intellectual disability and severe challenging behaviour, who were living in inadequate or inhumane services. Dutch practitioners were lacking sufficient support and needed guidance which led to the development of Triple-C. The three C's represent Client (i.e., the person with intellectual disability), Coach (i.e., the support worker), Competence (i.e., the activity which the client and coach perform together). Van Wouwe and Van de Weerd wanted to enable their service users to experience "an ordinary life"; a life as close as possible to the life of people without intellectual disability (King's Fund, 1980). Informed by attachment and social learning theories (Bandura, 1978; Bowlby, 1988), and by the normalization principle (Wolfensberger, 1983), they developed Triple-C in Dutch practice. One of the founders' central ideas is that human behaviour is determined by the interaction between an individual and his or her environment, as challenging behaviour can be seen as a response to a challenging environment (Flynn et al., 2019; Hastings et al., 2018). Therefore, an empathic, understanding and compassionate response to challenging behaviour is needed. For that reason, meeting individuals' human needs is emphasized in the intervention (Barrett, 2002; Maslow, 1943) of people with intellectual disability, ranging from people with severe to borderline intellectual disabilities and challenging behaviour instead of support staff trying to control the challenging behaviour. By achieving a meaningful lifestyle whereby people with intellectual disability and challenging behaviour receive unconditional support to improve their attachment to support staff, a positive response was tried to reach.

In the Netherlands, Triple-C is applied in 23 different service providers, which together support approximately 3,600 people with intellectual disability and challenging behaviour. In 2013, an uncontrolled study was carried out to measure the effect of Triple-C by Van Wouwe et al. (2013). A longitudinal design was used to examine changes in 53 individuals with severe challenging behaviour, who moved to live in a Triple-C setting. There were two data collection points before the participants moved to a Triple-C setting and three further data collection points after they moved to a Triple-C setting. Their level of functioning varied from severe intellectual disability to below average functioning. Pearson correlation tests were computed to assess the relationship between Triple-C, adaptive skills (Vineland Adaptive Behavior Scales; De Bildt et al., 2005), emotional and behavioural problems (measured by the Dutch version of Developmental Behavior Checklist; Dekker et al., 2002), and numbers of the use of restrictive measures from daily reports. The study found a positive correlation between the use of Triple-C and communicative skills ($r = .503$, $n = 46$, $p = .01$), daily living skills ($r = .463$, $n = 46$, $p = .01$), and social skills ($r = .574$, $n = 46$, $p = .01$). There was no significant correlation found between the use of Triple-C and emotional and behavioural problems ($r = .021$, $n = 46$). Negative correlations were found between the use of Triple-C and the use of restrictive measures: taking the participant down to the floor ($r = -.251$, $n = 46$, $p = <.01$), separation in designated room ($r = -.551$, $n = 46$, $p = <.01$) and seclude person to different room (e.g. bedroom, hallway) ($r = -.642$, $n = 46$, $p = <.01$). However, the practice-based nature of Triple-C means that many of the professionals' actions or activities are often underpinned by their implicit knowledge about the intervention they are delivering. Consequently, as the emphasis is on practice, the professionals can find it difficult to articulate how the intervention is operationalized and positive change achieved. This study aims to assess the practical knowledge of Triple-C professionals and to develop an understanding of the mechanisms of change for the intervention to improve understanding and to inform future research.

Logic Models

Building an evidence base that informs policy and practice, along with a clear understanding of the assumptions which underpin an intervention and an explanation of how an intervention works, are needed. Depicting an intervention in a logic model can help to clarify underpinning assumptions (Moore et al., 2015). A logic model presents a plausible description of how an intervention will work under certain conditions to solve identified problems (Bickman, 1987). Logic models are related to program theory, which presents a theory of action or change that drives the intervention and are useful for describing the assumptions about resources and activities (particularly in relation to key stakeholders), as well as how these are expected to lead to intended outcomes (McLaughlin & Jordan, 2010; Shakman & Rodriguez, 2015). Scott et al. (2018) suggested that logic models can also be used to evaluate the effectiveness of interventions for intellectual disability practice, which is an important step toward evidence-based practice.

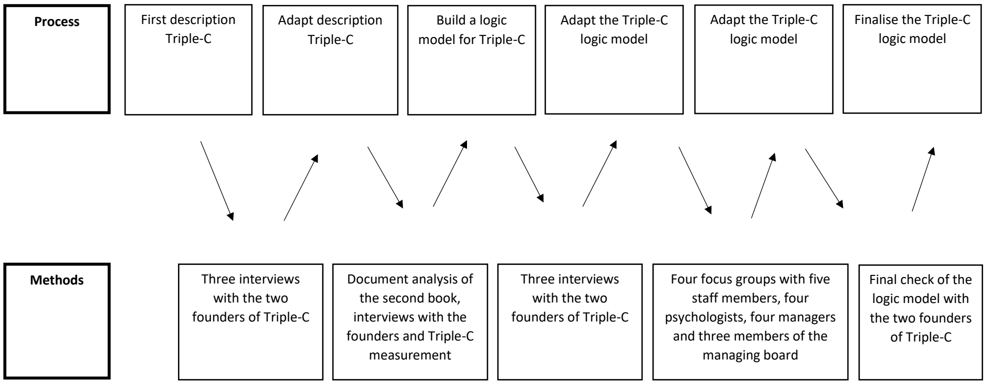
Elements for a logic model include intervention components (inputs that are required to support the intervention), processes (the essential action steps necessary to produce intervention outputs and outcomes), output (the direct products of program activities), outcomes (e.g., changes, benefits, or problem reduction), and assumptions (the underlying theory of how the intervention should lead to the intended outcomes; McLaughlin & Jordan, 2010; W.K. Kellogg Foundation, 2004). There are several ways to present a logic model, although typically this is as a diagram (Savaya & Waysman, 2005). A logic model can be developed through five stages: (1) collecting relevant information from multiple sources, (2) clearly defining the problem the intervention will solve and its context, (3) defining the elements of the model, (4) drawing the model, and (5) verifying the model with stakeholders (McLaughlin & Jordan, 2010). In this article, we focus on constructing a logic model for the practice-based Triple-C intervention by carrying out these five stages.

Developing the Triple-C Logic Model

Figure 1 describes the process as well as the methods used to develop a logic model for the Triple-C intervention. Ethical approval for this process was obtained from Tilburg University (EC-2015.29).

Figure 1

Process used to Construct a Logic Model of the Triple-C Intervention



The development process began with an initial description of Triple-C, which featured the significant elements of the intervention and gave an insight into knowledge gaps of the researchers. The description was based on the available official documents about the intervention, including the first book about the Triple-C intervention (Van Wouwe & Van de Weerd, 2011) and Triple-C training and teaching materials (developed by the founders). Subsequently, three semi-structured interviews with the founders of the intervention were carried out by the first author. The aims of these interviews were (1) to become more familiar with the Triple-C intervention, (2) to test whether the interpretations of the official documents were accurate, and (3) to fill gaps (unclear, incomplete, or missing information) in the description with the founders' implicit knowledge. The interviews provided additional details, but there was still missing information. For example, the descriptions of how different professionals (support staff, psychologists, and managers) should apply Triple-C in practice remained unclear, the mechanisms of change were also unclear, and the proposed outcomes of the intervention for different stakeholders were not specified clearly.

To provide more information, three types of official documents about the Triple-C intervention were selected for analysis: the second book about the intervention written by the founders of Triple-C (Van Wouwe & Van de Weerd, 2015), a questionnaire that is used to measure whether Triple-C is delivered with fidelity (Van Wouwe, Simons, & Janssen, 2011), and the first three interviews with the founders. These documents were selected because they contained the most exhaustive and contemporary information about Triple-C. A qualitative content analysis (Thomas, 2006; Wildemuth, 2016) was used to condense data obtained from the documents into categories or themes based on valid inference and interpretation. The software program Atlas.ti (Friese, 2019) was used to help carry out these analyses.

Following the content analysis procedure, the information about Triple-C was summarized in a draft logic model. All the categories identified were allocated to the different elements of a logic model. The founders of Triple-C were then interviewed a further three times about the content of this draft logic model (version 1). These interviews focused on the founders' perspectives on the themes, how the logic model was built (different columns and categories) and aimed to clarify codes from the content analyses which remained unclear. Feedback from the interviews was processed and this resulted in an adapted logic model (version 2).

Without a formal manual of the Triple-C intervention, it could not be assumed that the intervention was being delivered according to the developers' logic. Therefore, version 2 of the logic model was tested in focus groups with support staff, managers, psychologists, and a group of other professionals who were involved with the implementation of Triple-C. Professionals were selected by the Triple-C founders, based on their extensive expertise with the intervention. In total four psychologists, four managers, five support staff members, and three other professionals (a member of the board of directors, head of human resources, and treatment manager), all from the same service provider, participated in separate focus groups. Homogeneous groups were explicitly chosen because different professionals are likely to bring different perspectives to the intervention, depending on their training and different roles in services.

Each focus group lasted 2 hr and the meetings were audiotaped and transcribed verbatim afterward. A framework analysis (Krueger, 1994; Ritchie & Spencer, 1994) was used to analyse the information from the focus groups with professionals. The logic model functioned as the framework and an a priori question was set: Do the data from the focus groups confirm, complement, or contradict the data in the logic model? Confirming and complementary codes were generated through this process of analysis and small adaptations were made to the logic model (version 3).

The penultimate version of the logic model was discussed with the two founders of Triple-C. Based on their comments, a final version of the logic model was produced.

The Triple-C Logic Model

Figure 2 shows the final version of the Triple-C logic model. The purpose of the model is to set out the required elements of the intervention to achieve the intended outcomes. All participants, especially the founders, emphasized that for the effective implementation of Triple-C, a combination of skilled professionals and a service which is steeped in the vision and Triple-C values are needed.

Main Goal

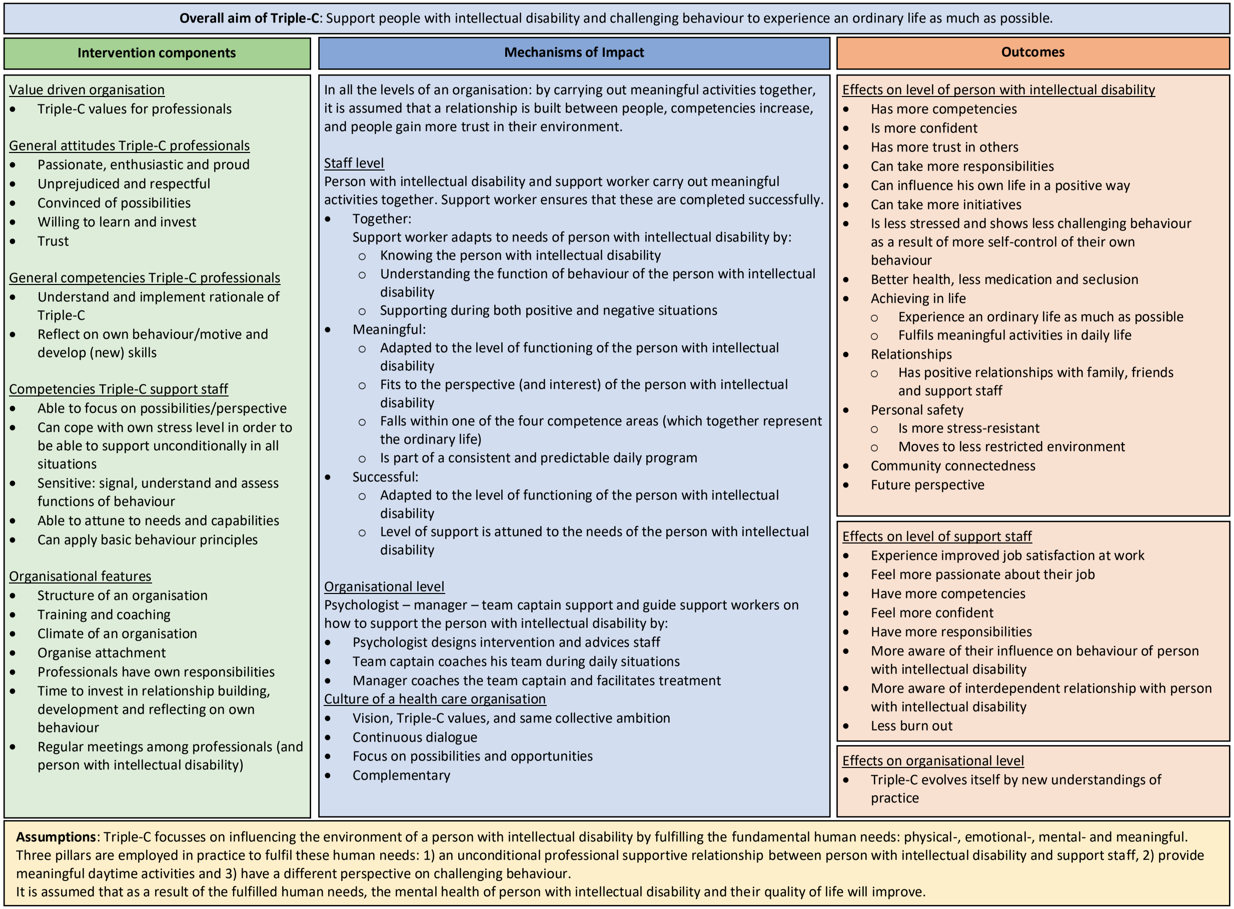
The text box for the overall aim of the intervention describes the main goal of Triple-C: people with intellectual disability experience an ordinary life as much as possible (note that "ordinary" is considered to be a relative concept here, given the nature of the challenging behaviour, adjustments to the environment have to be made, but only as much as needed).

Assumptions

The bottom box represents the assumptions that underpin the intervention and is regarded as the vision of Triple-C. Individuals at all organizational levels are expected to think, watch, and act from the same vision. Triple-C's core assumption is that people's environments play a key role in determining their behaviour. The intervention focuses on influencing the environment of a person with intellectual disability to meet their fundamental human needs as described by Maslow (1943) and Barrett (2002): physical, emotional, mental, and meaningful needs. It is hypothesized that these needs have to be met to allow the person with intellectual disability to have a good quality of life and eventually reduce the challenging behaviour (Triple-C proponents actively describe this reduction as a "side effect").

To meet human needs in practice, the vision of Triple-C employs three "pillars": (1) an unconditional professional supportive relationship between the person with intellectual disability and support staff, (2) the provision of meaningful daytime activities, and (3) a

Figure 2
Logic Model Triple-C Intervention



Overall aim of Triple-C: Support people with intellectual disability and challenging behaviour to experience an ordinary life as much as possible.

Intervention components

Value driven organisation
- Triple-C values for professionals

General attitudes Triple-C professionals
- Passionate, enthusiastic and proud
- Unprejudiced and respectful
- Convinced of possibilities
- Willing to learn and invest
- Trust

General competencies Triple-C professionals
- Understand and implement rationale of Triple-C
- Reflect on own behaviour/motive and develop (new) skills

Competencies Triple-C support staff
- Able to focus on possibilities/perspective
- Can cope with own stress level in order to be able to support unconditionally in all situations
- Sensitive: signal, understand and assess functions of behaviour
- Able to attune to needs and capabilities
- Can apply basic behaviour principles

Organisational features
- Structure of an organisation
- Training and coaching
- Climate of an organisation
- Organise attachment
- Professionals have own responsibilities
- Time to invest in relationship building, development and reflecting on own behaviour
- Regular meetings among professionals (and person with intellectual disability)

Mechanisms of Impact

In all the levels of an organisation: by carrying out meaningful activities together, it is assumed that a relationship is built between people, competencies increase, and people gain more trust in their environment.

Staff level
Person with intellectual disability and support worker carry out meaningful activities together. Support worker ensures that these are completed successfully.
- Together:
  Support worker adapts to needs of person with intellectual disability by:
  - Knowing the person with intellectual disability
  - Understanding the function of behaviour of the person with intellectual disability
  - Supporting during both positive and negative situations
- Meaningful:
  - Adapted to the level of functioning of the person with intellectual disability
  - Fits to the perspective (and interest) of the person with intellectual disability
  - Falls within one of the four competence areas (which together represent the ordinary life)
  - Is part of a consistent and predictable daily program
- Successful:
  - Adapted to the level of functioning of the person with intellectual disability
  - Level of support is attuned to the needs of the person with intellectual disability

Organisational level
Psychologist – manager – team captain support and guide support workers on how to support the person with intellectual disability by:
- Psychologist designs intervention and advices staff
- Team captain coaches his team during daily situations
- Manager coaches the team captain and facilitates treatment

Culture of a health care organisation
- Vision, Triple-C values, and same collective ambition
- Continuous dialogue
- Focus on possibilities and opportunities
- Complementary

Outcomes

Effects on level of person with intellectual disability
- Has more competencies
- Is more confident
- Has more trust in others
- Can take more responsibilities
- Can influence his own life in a positive way
- Can take more initiatives
- Is less stressed and shows less challenging behaviour as a result of more self-control of their own behaviour
- Better health, less medication and seclusion
- Achieving in life
  - Experience an ordinary life as much as possible
  - Fulfils meaningful activities in daily life
- Relationships
  - Has positive relationships with family, friends and support staff
- Personal safety
  - Is more stress-resistant
  - Moves to less restricted environment
- Community connectedness
- Future perspective

Effects on level of support staff
- Experience improved job satisfaction at work
- Feel more passionate about their job
- Have more competencies
- Feel more confident
- Have more responsibilities
- More aware of their influence on behaviour of person with intellectual disability
- More aware of interdependent relationship with person with intellectual disability
- Less burn out

Effects on organisational level
- Triple-C evolves itself by new understandings of practice

Assumptions: Triple-C focusses on influencing the environment of a person with intellectual disability by fulfilling the fundamental human needs: physical-, emotional-, mental- and meaningful. Three pillars are employed in practice to fulfil these human needs: 1) an unconditional professional supportive relationship between person with intellectual disability and support staff, 2) provide meaningful daytime activities and 3) have a different perspective on challenging behaviour.
It is assumed that as a result of the fulfilled human needs, the mental health of person with intellectual disability and their quality of life will improve.

"different perspective" on challenging behaviour (i.e., trying to understand why these behaviours occur; asking which human needs are not met). It is hypothesized that by engaging in an unconditional professional supportive relationship with the person with intellectual disability, support staff need be able to create a safe and secure (social) environment in which they can truly connect with the person with intellectual disability (physical and emotional needs). This relationship is built by doing meaningful daily activities together (in the competence areas of personal care, leisure, work/education, and living) in a safe, consistent, and predictable environment (physical, mental, and meaningful needs). Furthermore, support staff need to be able take a "different perspective" on challenging behaviour; they can interpret challenging behaviour as a signal that they are not fulfilling the human needs of a person with intellectual disability effectively, instead of seeing challenging behaviour as a symptom which need to be eliminated by medicine or restrictions. Although the main focus of the intervention is on the person with intellectual disability, the assumptions also apply to the collaboration with and support of staff. As a consequence, adopting Triple-C as a healthcare organization and working as a professional in line with these Triple-C assumptions, there are hypothesized to be effects on the collaboration, culture, and outcomes for professionals.

Intervention Components

According to the documents and the participants, the Triple-C intervention consists of a vision (Assumption box) and a method (Intervention components and Mechanisms of Change box) which are considered inseparable. To implement the vision and method effectively, the model requires active and positive involvement at all levels in an organization. This vision expresses itself in Triple-C values which correspond with the human needs. According to Triple-C, all professionals in an organization need to be able to operate from these Triple-C values toward people with intellectual disability and their colleagues:

- People need other people to become, and stay, a human being.
- Life-enhancing environments elicit positive human behaviour.
- Experiencing unconditional support leads to feelings of recognition and being appreciated.
- Living together in a social group requires mutual respect and interdependence.
- Every person has the right to control and influence their own life.
- Quality of life is a co-creation of an interaction between individuals and their (social) environment.
- In interaction with their environment, people want to give meaning to life.

General attitudes and competencies (second and third component in the intervention column) are thought to be required for all Triple-C professionals. A general attitude is to be willing to learn and to invest in each other and oneself. Reflecting on one's own behaviour is considered to play a significant role in developing (new) skills, as well as in having the courage to put oneself in a vulnerable position and having trust in one's own potential and the person with intellectual disability. In line with the general vision in care for people with intellectual disability, Triple-C professionals need to be able to involve relatives of people with intellectual disability in their lives but also to be able to collaborate with relatives, in complex situations.

It is hypothesized that support staff working with people with intellectual disability on a daily basis need *specific competencies* to support in line with the vision and to apply the method sufficiently. A competence which is regarded as significant is having the capacity to focus on the potential of a person with intellectual disability, even in the most complex situations instead of focusing on their challenging behaviour. Within Triple-C, support staff are expected to be stimulated to support the person with intellectual disability unconditionally without conducting exclusion or punishment interventions. It is assumed that this requires support workers who can cope with their own stress level in complex situations, who are able to support the person with intellectual disability in emotionally charged circumstances, who are sensitive, and have the competence to see/feel the needs of the person with intellectual disability. Lastly, support staff need to be able to understand and to apply basic behaviour principles like shaping (e.g., the process of reinforcing successively closer and closer approximations to a desired terminal behaviour like having dinner with fork and knife), fading (e.g., decreasing the level of support needed to cook a meal), chaining (e.g., breaking down the activity in smaller steps and supporting the individual to carry out steps in the right sequence), prompting strategies (taking the individual's hand and guiding them through an activity) and also modelling (e.g., support worker brushes his teeth, the person with intellectual disability imitates this activity).

The first *organizational feature* in the model is the structure of a Triple-C organization. Based on the interviews and focus groups, team work is viewed as a very significant element of the intervention, as using Triple-C with people with challenging behaviour is challenging for support workers themselves. The lines of communication between the different members of the team are direct, so that professionals can respond quickly to the needs of the person. In the structure of an organization, a team of support workers is supported by a psychologist, manager and team captain (in Triple-C terms known as the "support-triangle") on a structural basis. The members of the support-triangle have their own roles and complementary tasks as described in the process section. However, these individual roles should be underpinned by a sense of shared responsibility to ensure optimal care is provided by the team of support workers, in order to promote the well-being of the person with an intellectual disability. Additionally, the support-triangle has the so-called "line crossing authorities" which implies that—if needed—the members are allowed to take over the tasks of a colleague. For example, a psychologist can take over a management task (temporarily). This might be valuable in case one professional of the support-triangle is less experienced in working according to Triple-C.

The second organizational feature is to get a better understanding of the vision, Triple-C values and the method. All (new) Triple-C professionals are requested to attend 1 or 2 days of training annually, to keep their understanding, knowledge and skills of the intervention up to date. The training is provided by the founders of the intervention or other trainers (trained by the founders; mainly psychologists and team captains). In addition, professionals need to be coached on the job by the team captain and more experienced colleagues. It is considered that constant reflection is needed on their own functioning and how they apply the vision and Triple-C values in practice. This reflection is supposed to contribute to a better understanding of their own actions, motivation and values, and the vision.

The healthcare organization is expected to create a supportive atmosphere, the third organizational feature, for individuals with intellectual disability and professionals. It is assumed this requires an open, transparent climate and policy to create a learning climate in which professionals can develop their skills and practice. Eventually, it is hypothesized that professionals should feel more connected with each other by all working from the same vision and values.

The fourth feature is to organize attachment: the feeling of relatedness/connection among professionals as well as attachment between professionals and people with intellectual disability. This attachment is assumed to be promoted by creating a warm and supportive work environment, where people feel secure and committed. A secure base might contribute to exploration and development by all participants. A practical implication of promoting attachment is working with small teams (eight staff members, a team captain, psychologist and manager) and trying to avoid too many personnel changes.

It is assumed that professionals can better attune to the needs of people with intellectual disability in different settings and situations when they are allowed to make their own decisions on which support would be sufficient (fifth organizational feature). They are not rigorously pinned to a fixed response, which describes how to respond to the behaviour of the person with intellectual disability regardless the situation.

Mechanisms of Impact

Staff level

The second column of figure 2 describes the mechanisms of change of the intervention according to the documents and participants. As Triple-C is used to support very different groups of people with intellectual disability, the intervention is supposed to offer a broad framework that can be adapted to address the different needs. The core of the Triple-C intervention is that the person with intellectual disability and support workers carry out meaningful activities together with the aim of building a relationship between people and to increase their competencies. The support worker needs to try to ensure that meaningful activities are completed successfully as a positive reinforcer.

Together

The activities are carried out together by the person with intellectual disability and the staff member. Staff support unconditionally, especially in stressful situations, is thought to contribute to the development of a relationship of trust (e.g., the person with an intellectual disability needs to be able to rely on their support staff, no matter what type of behaviour they are showing). During the first (introductory) phase, staff develop an understanding of the function of the challenging behaviour by reflecting about the behaviour with their colleagues and a psychologist (during or after their shift and during their regular team meetings). Function is described in relation to the human needs being expressed. Staff discuss how they can adapt their support to meet the needs of the person with intellectual disability. When the person gets more familiar with his or her new environment, the daily program becomes more personalized and goals for the treatment are set (never focused on reducing challenging behaviour, always on how the person can be helped to experience "an ordinary life" by carrying out daily activities). These goals are established in collaboration with the person with an intellectual disability and the psychologist. So support staff need to know the person with intellectual disability (history, family/social context, interest or dislike, general skills and abilities, communication styles, and disorders; information is obtained from relatives, other involved professionals) to help them understand which human needs are not met and respond appropriately. To build up this knowledge and a shared understanding about the person with intellectual disability, support staff and the psychologist discuss the needs of a person in regular joint meetings. In addition, the psychologist and team captain (or key worker) involve relatives to learn more about the history of a person with intellectual disability.

Meaningful

Living in a Triple-C home means from the start participating in a consistent and predictable daily activity program. This should include activities of the four Triple-C competence areas: leisure, work/education, personal care, and living. Furthermore, the activities fit to the interest of the person with intellectual disability and they are focused on their development (perspective). Meaningful activities need to be adapted to the level of functioning of the person with an intellectual disability by breaking down complex activities into steps and/or adapting the level of support (depending on the person's capabilities, on day-to-day opportunities, and competencies of the support worker) so the person with intellectual disability can carry out the activity as independently as possible.

Successful

Completing the activities successfully may contribute to the relationship of trust among the individual with intellectual disability and support staff.

Organizational level

The second element in the process column is the organizational features. Support staff need guidance and assistance from the support-triangle on how to support people with challenging behaviour, especially in stressful situations. Therefore, members of the support-triangle regularly visit the location of day-to-day care. It is hypothesized that providing clear guidance and support to a team requires: (1) a strong collaboration among all the members of the support-triangle, based on equality and trust, and (2) regular reflection on whether the support-triangle is acting according to Triple-C values to make sure everyone is working along the same lines. All members of the support-triangle have their own roles and tasks. The psychologist designs the Triple-C intervention for each person with intellectual disability and supports staff to create a pedagogical and congenial climate. The team captain supports the team to translate the advice of the psychologist into practice from an expert-companionship perspective and by giving coaching on the job. Collaboration between a psychologist and team captain is significant, since the team captain provides the psychologist with information about daily functioning of the people with intellectual disability and challenging behaviour as well as about support staff. With respect to the manager, two main tasks can be identified based on the interviews and focus groups: (1) facilitating the intervention (e.g. finances, hire staff), and (2) coaching the team captain on how to support his/her team to work according the Triple-C vision and values.

The final topic in the logic model process column is *the culture of a healthcare organization*. It is important that the whole system is steeped in the vision and Triple-C values; all forms of consultation are conducted from these two perspectives. Professionals are supposed to have the same collective ambition and have a continuous dialogue about how they apply the vision and values in practice. To support the person with intellectual disability to experience an ordinary life as much as possible, professionals need to be able to focus on opportunities in (collaborative) decision making.

Outcomes

The final column (outcomes) depicts the outcomes for the different stakeholders of the intervention; people with intellectual disability, professionals, and organization. The Triple-C intervention components and processes are proposed to have a positive effect on the personal competencies and quality of life of people with intellectual disability as well as professionals. It is assumed the person with intellectual disability will: (1) feel more confident because of the increased competencies, (2) be able to handle more responsibilities and control over their own life, (3) develop more trust in other people and themselves, and (4) as a result have less stress and less challenging behaviour. Their quality of life is also assumed to improve because: (a) their daily program is filled with meaningful activities, allowing them to experience a more ordinary life, and (b) they have more positive relationships with family, friends and staff, and feel more security. The use of psychotropic medication and seclusion should also diminish and some people should be able to move to a less restricted environment.

A potential outcome for support staff is to experience improved job satisfaction and passion for their job. As a result of the training, coaching on the job and regular reflection, it is hypothesized that they should develop more competencies, confidence, and will be able to cope with greater responsibility. It is assumed that these positive improvements will result in less support staff burnout.

Discussion

Triple-C is a Dutch practice-based intervention for supporting people with intellectual disability and challenging behaviour, which has now been applied in Dutch practice for more than 25 years. This study is an important first step toward further development of this practice-based intervention by making tacit knowledge of professionals more explicit. Through an iterative process, a logic model was developed to describe the intervention and its underlying assumptions. The development of the logic model was shaped by using interviews with the founders, focus groups with professionals, and the analysis of published accounts of Triple-C. The result, a conceptual description of the intervention, can be the first step to inform robust research to examine Triple-C's potential effectiveness.

The process of development of Triple-C is different compared to data-driven interventions such as Positive Behavioural Support and Active Support. These interventions are underpinned with scientific evidence (Flynn et al., 2018; Gore et al., 2013). Triple-C on the other hand is based on practice-based knowledge. Starting an intervention based on knowledge from professionals like psychologists and support staff gives scientists the opportunity to learn from a valuable source of professional knowledge, which can contribute, alongside scientific knowledge to the care of people with intellectual disability (Embregts, 2017; Garretsen et al., 2007). Practice-based knowledge is developed by professionals through learning and reflecting on their work, and the reactions of people with intellectual disability and support staff toward interventions.

A next significant step in developing a practice-based intervention like Triple-C is to examine whether Triple-C or elements of the intervention can be underpinned with already existing evidence of evidence-based interventions in intellectual disability. Triple-C shows similarities with Positive Behavioural Support and Active Support. Like Positive Behavioural Support, Triple-C focuses in the long term on an improved quality of life, has a values driven approach and a comprehensive character. Both interventions are multicomponent framework interventions whereby different elements should be used in combination to implement the intervention effectively. Both approaches are informed by the values of normalization, human rights, and self-determination to deliver effective person-centred support to people with challenging behaviour. However, Positive

Behavioural Support, in contrast to Triple-C, is a functionally informed intervention which also uses direct behaviour change technologies to reduce challenging behaviour. Unlike Triple-C, Positive Behavioural Support also includes a range of evidence-based and clearly specified behaviour change technologies to directly enhance skills and learning in those with intellectual disability. In Positive Behavioural Support, socially valid interventions are also included to enhance quality of life outcomes for both the person themselves and their paid or family carers (Carr et al., 2002; Gore et al., 2013). Triple-C does not explicitly include targeting outcomes for family members like Positive Behavioural Support does, but do try to enhance the quality of life outcomes for both the person themselves and their paid carers. Giving family members a more prominent place in the intervention would be a valuable addition. Also, Triple-C shows similarities with Active Support in terms of the focus on engagement in meaningful daily activities. Active Support is, like Triple-C, a person-centred approach which aims to enable people with intellectual disability to experience a rich and varied lifestyle in which their participation and independence is directly facilitated by the help and encouragement provided by staff. Active Support includes initial workshop training and one-to-one Interactive Training of staff in everyday support settings (Toogood, 2010). Triple-C professionals receive coaching on the job, but this is ongoing rather than being an initial clearly specified (and manualized) aspect of the intervention as in Active Support. Next, Active Support includes the completion and monitoring of plans and documents for each individual, to ensure continuing high levels of engagement (Flynn et al., 2018). Although each individual's record is annually reviewed, and documents to register the progress towards set goals are also available in the Triple-C intervention, they are not used on an everyday basis like the recording systems in Active Support. This might be a possible addition to the current Triple-C intervention to support a high level of engagement. Further research on the day-to-day delivery of Triple-C should reveal the amount of overlap with other interventions such as Positive Behavioural Support and Active Support.

In countries such as the United Kingdom and the Netherlands, Triple-C, Positive Behavioural Support and Active Support are developed in parallel for people with intellectual disability (and challenging behaviour). As such, there are general and comparable effective intervention components in, for example, Triple-C and Positive Behavioural Support (e.g., value driven and match support with each person's capabilities), that are likely to be effective in different countries. However, aspects of evidence-based interventions may not always be transferable (Gabbay & Le May, 2004; Ioannidis, 2016) and the social and cultural context may have a significant influence on the use and development of care interventions. For example, Dutch care for people with intellectual disability is strongly influenced by the orthopedagogical perspective (van Gennep, 1997) resulting in more emphasis on the contextual factors of support, whereas other interventions focus more on support of the individual without taking contextual factors into account.

A potential limitation of Triple-C is that a focus on the bigger picture (e.g., good relationships and an active life) may have been at the expense of a detailed description of how to deliver the intervention in practice. It is reflected in the final logic model, which emphasizes values and ideas and not the practicalities or details of the intervention. In addition, in the logic model, no elements are linked specifically because the researchers focused on gathering information about the essential Triple-C elements without focusing on specific relations. To be able to carry out research on Triple-C in future, additional steps are needed. First, expected coherence between elements in the logic model should be identified; to determine which elements might influence which processes and outcomes. Then it would be possible to formulate more specific hypotheses for future research. Second, a limitation of the logic model is that the differentiation between short and longer term outcomes is missing. Future work is needed to clarify these outcomes, which could be in another iteration of the logic model. Third, mechanisms of change need to be defined in more detail, to provide guidance about what people need to do, on a day-to-day basis to deliver Triple-C. Last, and related to the third point, is then a clearer tool for evaluating and reviewing when Triple-C is being delivered or the level of quality of the delivery of Triple-C (i.e., treatment fidelity). An observational study of what staff do in practice in Triple-C settings would be a useful next step to help define the intervention components.

Building the Triple-C logic model was a complex process including challenges that may apply to defining practice-derived interventions. First, the founders of the intervention had strong beliefs about what they do, rooted in long years of experience. The process involved having respect and sensitivity about the founders' views, whilst finding a way of making their tacit knowledge explicit. At the same time, the researcher also needed to examine in more detail than has been described to date how professionals interpret the intervention and think how it should be applied in practice. Second, after clarifying the aims of the project, appropriate methods and participants were selected to obtain the necessary information, through a series of iterative steps, such as reflecting with different stakeholders (scientists and practitioners), adopting mixed methods, involving a range of participants, and collecting different types of data so that different perspectives on the intervention were taken into account. This iterative approach was a way of trying to avoid overlooking significant elements. Moreover, the researchers noticed that not all the information could be gathered from one source. Multiple sources were needed to get a clear understanding of the intervention. For example, each group of professionals had their own experiences with and phraseology about the intervention due to their different daily tasks (e.g. psychologists talked more about setting treatment goals, staff members talked more about how they worked on building a relationship). The researchers had to check during the interviews and focus groups if all the participants meant the same with regard to the vision and method. In the end, there were no major inconsistencies. When inconsistencies were found, the researcher went back to the founders to check how the vision or method was intended to be implemented.

In the further development of Triple-C intervention, it would be valuable to take into account the views and experiences of people with intellectual disability and challenging behaviour. Furthermore, the logic model is focused on people with intellectual disability within settings where they are supported by staff. However, many people with intellectual disability live with the support of their family members or family members are a central part of their lives. Further consideration should be given to whether family members could use a Triple-C model as well as whether family members can be involved in Triple-C teams that are led by support staff. This addition could be explained by social systems theory, which deals with the complexity and interdependencies of social relations (Coleman, 1986).

The advantage of building the logic model of the Triple-C intervention is that it can identify dimensions that could be important for future implementation and research. This includes describing how staff and individuals can carry out meaningful activities together and how staff can provide unconditional support. Furthermore, the model could be used to measure the core outcomes, at the level of a person with intellectual disability and staff level, to examine effectiveness. This study is an example of how (practice-based) interventions in the field of intellectual disability could use logic models to guide evaluation of practice, policy and research interventions. Last, this study has shown how the cultural context can have a significant influence on the use and development of care interventions.

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CHAPTER 3

“Connectedness” between people with intellectual disabilities and challenging behaviour and support staff: Perceptions of psychologists and support staff

This chapter has been submitted for publication as:
Tournier, T., Hendriks, A. H. C., Jahoda, A., Hastings, R. P., & Embregts, P. J. C. M. (submitted). “Connectedness” between people with intellectual disabilities and challenging behaviour and support staff: Perceptions of psychologists and support staff. *Journal of Intellectual Disabilities.*

Abstract

Background

The tacit practical knowledge of psychologists and support staff to foster a real connection between support staff and people with intellectual disabilities and challenging behaviour was explored.

Method

Six dyads comprising individuals with intellectual disabilities and challenging behaviour and their support staff were video recorded during joint engagement in an activity. Ten psychologists and ten support staff pinpointed moments of real connection in a video compilation, and shared their interpretations about what they considered to be a real connection.

Results

Participants designated real connections as occurring when they noticed concrete interactions taking place. Based on thematic analysis of the data, four themes were identified that encapsulated what professionals deemed to be a real connection.

Discussion

Joint engagement in an activity appears to be a context that fosters opportunities for real connection. Furthermore, support staff should adopt a sensitive attitude and create a safe atmosphere, to establish real connections.

Social relations are essential to health and well-being (Helliwell & Putnam, 2004), and have been linked to both an increased quality of life and a decreased likelihood of experiencing depressive symptoms amongst people with intellectual disabilities (Lunsky & Benson, 2001). Conversely, feelings of loneliness and a lack of social ties have been associated with an increased risk of being diagnosed with a mental illness (Scott & Havercamp, 2014). Moreover, social relations provide people with intellectual disabilities with a sense of satisfaction and enhance their self-esteem (Liang et al., 2001). The significance of social relations is also apparent in the case of people with intellectual disabilities and challenging behaviour. For example, people with intellectual disabilities themselves have reported that positive relationships with peers and family can mitigate against challenging behaviour, insofar as these relationships induce a feeling of safety, belonging and being liked, which, in turn, can generate a sense of contentment, calmness, and security (Clarke et al., 2019).

When people with intellectual disabilities and challenging behaviour are living in service facilities, the social relationships that they have with support staff constitute a large part of their network (Van Asselt-Goverts et al., 2015). Indeed, relationships with support staff are highly valued by people with intellectual disabilities and challenging behaviour. Moreover, support staff have been found to play a significant and meaningful role in their social network, in terms of providing both instrumental support (e.g. supporting them to prepare meals) and emotional support (e.g. listening to their problems; Griffith et al., 2013). People with intellectual disabilities and challenging behaviour characterise such positive relationships with support staff as being trusting, and as having someone who can provide them with clear advice, guidance, support in solving problems, and have fun with them (Clarke et al., 2019). The attributes of support staff that are deemed to facilitate positive relationships by people with intellectual disabilities and challenging behaviour include: having time for them, being competent, being genuinely interested in their lives, and adopting a calm and consistent approach (e.g., Clarke et al., 2019; Van den Bogaard et al., 2019). Engaging in a positive relationship with support staff can increase their confidence, and, in turn, help them to achieve their goals (Ruef & Turnbull, 2002).

Person-centred approaches, such as Positive Behavioural Support (Carr et al., 2002; Gore et al., 2013;), Active Support (Mansell & Beadle-Brown, 2012) and Triple-C (Tournier et al., 2020), emphasise the importance of the relationship between people with intellectual disabilities (and challenging behaviour) and support staff. A 'real connection' is an integral part of such a positive relationship, in that it enables support staff to gain insight into, and respond to, the needs of people with intellectual disabilities (Hermsen et al., 2014; Reinders, 2010). To gain insight into the underlying process of how to establish a connection, some researchers have analysed the actions of support staff. For example, Antonsson et al. (2013) focused on successful interactions between support staff and 11 people with various levels of intellectual disabilities (some of whom also displayed challenging behaviour), all with communication difficulties. Their results showed that support staff tailored their language to the individual, ensured that their communication was directly relevant to the activity they were engaged in, as well as using signs and body language to facilitate their understanding. Other studies have also reported that support staff adjust their communication to suit the needs of people with intellectual disabilities, who have limited communication skills. For example, Johnson et al. (2012) adopted a grounded theory approach to analysing data generated via observations and interviews with six people who had severe intellectual disabilities and limited communication skills, and their staff and family members. Adjusting how one communicates was framed as being part of how someone connects with people with intellectual disabilities and limited communication skills.

One way through which to gain insight into what precisely constitutes a real connection between people with intellectual disabilities and challenging behaviour and support staff, is to examine the tacit knowledge of psychologists and support staff. This is knowledge that 'is acquired through experience and of which we are unaware' (Burford & Jahoda, 2011, p.180). In the current study, we utilised a video review method known as the Burford Review Process (BRP; Burford, 1993; Burford & Jahoda, 2012). This method aims to gain insight into individuals' intuitive judgements about human action that they witness in video material, that is, what they are drawn to in the observed action. Within this approach, the researcher's task is to allow participants to make these judgements, without constraining them via the use of pre-determined codes or categories. In the present study, the tacit knowledge of professionals concerning real connections between support staff and people with intellectual disabilities and challenging behaviour was explored, by examining 1) when psychologists and support staff considered moments of real connection as having occurred, and 2) what psychologists and support staff considered to be real connections.

Method

Participants

The first step of the research involved six dyads comprising people with various levels of intellectual disabilities and challenging behaviour and their support staff being video recorded in five different group homes based on a residential site of a Dutch service provider. All support staff were male, and their mean age was 34.8 years (range 28-42). Their average work experience in supporting people with intellectual disabilities was 9.2 years (range 8-11). Two support staff attended secondary vocational education, four completed higher professional education. All the people in the videos with intellectual disabilities and challenging behaviour were male, and had varying levels of intellectual disabilities based on the results of the Wechsler Adult Intelligence Scale (Wechsler, 2012; severe = 1, moderate = 2, mild = 1) and, in the case of one participant, the Vineland-3 Scale (Communication: 2;5 years, Daily Living Skills: 4;1 years, and Socialization: 1;5 years;

Sparrow et al., 2016). The person with a mild intellectual disabilities was video recorded twice with two different support staff. The individuals with intellectual disabilities had lived, on average, in the residential facility for 16.6 years (range 6-30), and within their current group home for 5.3 years (range 0.9-9). Four of these individuals were officially diagnosed with autism, one of them also had Attention Deficit Hyperactivity Disorder. Another individual had posttraumatic stress disorder, type I and II. To give a general picture of the challenging behaviour displayed by the participants with intellectual disabilities over the last two months, the Dutch Behaviour Problems Inventory-01 (BPI-01; Dumont et al., 2014; Rojahn, et al., 2012) was used. The BPI-01 contains three sub-scales and items are rated on a frequency scale (0 = never to 4 = hourly), and a severity scale (0 = no problem to 3 = severe problem). The participants' scores for each scale on the BPI-01 are presented in Table 1.

In the second step of the research, ten support staff and ten psychologists who work with people with intellectual disabilities and challenging behaviour were invited to individually review the video compilation. All these professionals use the Triple-C approach in their work, and, were trained in the Triple-C vision and method. This is a person-centred approach from the Netherlands that is used to support people with intellectual disabilities and challenging behaviour. The approach has a strong focus on relationships between people with intellectual disabilities and support staff (Tournier et al., 2020). Given their background, we expected these staff to have tacit knowledge about 'connections' in the interactions between staff and people with intellectual disabilities. The average age of the support staff was 32.5 years (range 28-44), and eight of them were male. The average duration of their work experience caring for people with intellectual disabilities was 11.5 years (range 3-20). Three participants completed high school, five participants attended secondary vocational education, and two of them attended higher professional education. Nine psychologists were female and had worked for an average of 21.2 years (range 7-33) with people with intellectual disabilities. All of them had higher professional education and training in a range of academic disciplines, five of them also had postgraduate degrees in healthcare psychology.

Procedures

Ethical approval was obtained for the study from the Ethics Committee of Tilburg University (EC-2015.29). The two founders of Triple-C, two skilled Triple-C psychologists and two Triple-C managers were consulted to select both the support staff to record and the support staff and psychologists who would review the video compilation. Support staff that were to be recorded were asked if one of the residents in their group home would like to be recorded together with them while carrying out an activity. The support staff then invited the resident and contacted the resident's legal guardian to ask for their consent. All individuals gave their informed consent to be video recorded.

Table 1

Mean Frequency and Severity Scores on the BPI-01 for Individuals with Intellectual Disabilities

		Participant 1 (M)	**Participant 2 (M)**	**Participant 3 (M)**	**Participant 4 (M)**	**Participant 5 (M)**
Self-injurious behaviour	Frequency	2.00	1.00	2.25	1.60	2.00
	Severity	2.00	1.00	2.25	2.20	2.00
Stereotyped behaviour	Frequency	2.62	3.67	2.57	1.69	2.00
	Severity	1.77	1.33	2.07	1.38	1.20
Aggressive/ Destructive Behaviour	Frequency	2.00	3.00	2.50	1.20	0.00
	Severity	2.00	2.00	2.88	1.20	0.00

Video recording

The founders of Triple-C and the recorded support staff were consulted when a connection between people with intellectual disabilities and support staff was likely to occur. Based on their advice, video recordings were made of them during joint engagement in an activity: shopping for groceries, setting the table for dinner, having breakfast, replacing the rubbish bag, and serving coffee to roommates.

The researcher recorded the six dyads on three separate occasions. The third video of each dyad was used to select approximately 2 minutes of film, to produce the compilation video. The moments that were chosen had to be of sufficient quality; both the support worker and the person with an intellectual disability had to be heard clearly and be continuously visible. A compilation of video extracts was selected in order to provide a possible variety of forms of connectedness. In total, the video compilation was 13.37 minutes long. To capture typical interactions between support staff and people with intellectual disabilities and challenging behaviour, support staff were asked to support people with intellectual disabilities in the same way that they normally would when carrying out an activity together.

Review procedure

The video review process was completed virtually, using Microsoft Teams. As the relationship between the researcher and the reviewer is considered to be one of the essential elements in the BRP (Burford & Jahoda, 2012), the researcher attempted to create a relaxed atmosphere so the participant could settle down, become familiar with the situation, and thus feel at ease to share their thoughts. Reviewers were assured that they were neither under evaluation nor being judged on how well they 'performed' or 'saw' things, and that they were considered to be expert informants.

The reviewing sessions lasted between 42 to 105 minutes (*M* = 61.2 min). First, the researcher explained the aim of the study and the procedure, and then the participant was given the opportunity to ask any questions. The review process began with the question: "Could you please say 'Yes' when you think the person with an intellectual disability and challenging behaviour and the support worker are 'connected'?" Prior to the actual data collection taking place, the procedure was tested by showing a small sample of video to the participant, to ensure that the procedure was clear. Then, the official video compilation was shown to the participant and the marked moments were recorded. Finally, the researcher went through the videotape with the participant a second time, looking at each of the pinpointed moments, and asking the participant to explain why they highlighted these moments. The researcher did not engage in any in-depth discussion during this section, but rather asked clarifying questions (Burford et al., 2003). In the end, the participant was given the opportunity to make general comments about the video. The participants' views were audio recorded and transcribed verbatim.

Analysis

The analysis was executed in three steps. First, the marked moments for each participant (i.e. selected seconds) were entered into Excel and transferred to SPSS. Then, the average number of identified moments for each participant were calculated.

Second, moments of strong agreement were selected based on the results in step 1. Next, a detailed description was provided of several of these selected situations. No interpretations were made at this stage as to why participants considered these selected moments to be indicative of real connection.

Third, participants' comments about the selected moments were subjected to thematic analysis (Braun & Clarke, 2006), in order to identify, analyse and report patterns in the data. The data from the psychologists and support staff were individually analysed by two researchers, using an inductive approach. Atlas.ti software (Friese, 2019) was used to help conduct this analysis. Then, themes and categories were extracted for each subgroup from the codes by the two researchers, based on valid inference and interpretation. The results were then discussed with the whole research team.

Results

The first research question sought to examine *when* professionals considered a real connection between support staff and people with intellectual disabilities and challenging behaviour to have taken place, by tapping into their implicit knowledge on connectedness. The whole video contained 817 segments that were each a second long. The results showed that, on average, the 20 participants each marked 41 (rang 12 – 93) moments (i.e. seconds) of real connection between people with intellectual disabilities and support staff. For each second of video, on average, one participant marked a moment ($SD = 1.34$). A one second interval marked by two participants was deemed to be statistically significantly different to the expected frequency based on an even distribution of selected moments, $t(816) = -21.25$, $p < .001$. In Table 2, the number of participants that marked the same second as a moment of real connection upward of two participants for each second are displayed. These moments were considered as indicating agreement between participants.

To answer the second research question, *what* do professionals consider to be a real connection between support staff and people with intellectual disabilities and challenging behaviour, two analyses were carried out. The first was done to gain additional insight into the context in which participants had considered a connection to have taken place. The second analysis was conducted on the interpretations that participants gave about what they considered to be a real connection. With respect to the first part of this analysis, detailed descriptions were made of several examples of moments that were selected by five or more participants (Table 3). This selection was made due to the fact that a considerable number of the participants had marked these particular moments as being indicative of real connection.

Table 2

Frequency of the Moments of Agreement by the Participants

Number of participants marking the same second	Frequency of the occurrence
2	123
3	53
4	18
5	9
6	8
7	2
8	2
9	1

Table 3

Examples of Agreed Moments of Connection

Number of participants who marked the same second	General context	Examples of specific description of the context
5	Pouring coffee for roommates	The support worker sits on the couch while the person with an intellectual disability is pouring coffee in a cup. The support worker asks, "Shall I put some milk in it, or will you do that?"
	Picking a piece of fruit to take to work	The support worker and the person with an intellectual disability are both standing by the fruit bowl, while the person with an intellectual disability is grabbing a banana. Both look at what the person with an intellectual disability is doing. Then, the person with an intellectual disability looks at the support worker and says, "Is this healthy too?", while pointing at an orange. The support worker replies with "Vitamins are your friends boy, aren't they?" The person with an intellectual disability says "Yes".
6	Sitting at the breakfast table	The support worker holds the jar of peanut butter and the tub of cream cheese in front of the person with an intellectual disability. Both men are looking at the products. The person with an intellectual disability looks at the support worker and points to the cream cheese. The support worker says "Cream cheese… take your knife"

	Changing the rubbish bag	The support worker walks up to the person with an intellectual disability (who is opening a new rubbish bag), clenches his fist and asks, “Would you like to try out your new tools?” He stands next to the person with an intellectual disability who is looking at him and says, “Yes, I would like to try out my new tools that I bought on Saturday.”
7	Sitting at the breakfast table	The person with an intellectual disability slides their arm across the table towards the hand of the support worker. The support worker puts his hand on the person with an intellectual disability while they make eye contact. Then, the support worker releases the person with an intellectual disability’s hand, looks towards his coffee cup while asking, “What have you done yesterday?”
8	Doing groceries together	The support worker points towards a shelf while saying “That one?” The person with an intellectual disability looks where the support worker is pointing and picks a particular product.
9	Setting the table	The support worker stands at the counter and hands two glasses to the person with an intellectual disability while saying “Look, you can put these by the plates”. While saying this, he holds the glasses a bit longer, and the person with an intellectual disability, who is holding the glasses as well, looks him in the eyes.

The results in Table 3 depict concrete interactions between people with intellectual disabilities and challenging behaviour and support staff, including having brief conversations, making eye contact, and engaging in other forms of physical contact. Another notable result is that in all these situations support staff play an active and prominent role, for example, by giving instructions, making gestures or handing over tableware to set the table. In these scenarios, the people with intellectual disabilities often appear to be highly responsive towards the actions of support staff.

The second part of the analysis, which sought to understand *what* professionals consider to be real connections between support staff and people with intellectual disabilities and challenging behaviour, involved conducting a thematic analysis. The thematic analysis encapsulated four themes in participants’ explanations of what constituted a real connection: 1) the way in which connections between support staff and people with intellectual disabilities become visible; 2) support staff creating a safe atmosphere; 3) support staff attuning to the needs of people with intellectual disabilities in a sensitive way; and 4) people with intellectual disabilities attempting to connect with their support staff. In the description of these themes, the explanations of the reviewing psychologists and support staff were drawn upon.

Theme 1: The way in which connections between support staff and people with intellectual disabilities become visible

The first theme describes participants' explanations of what they deem to be real connections between support staff and people with intellectual disabilities and challenging behaviour. The theme was built upon two subthemes: *joint engagement in a meaningful activity* and *visible connection.*

Joint engagement in a meaningful activity. Both psychologists and support staff routinely talked about joint engagement in meaningful activity being an indicator of a real connection. They considered the joint share in an activity as the sign of a connection.

Now you see the connection. I actually think it is because they are now working on something together again with that sandwich. I can see immediately that the client calms down. [Psychologist 6]

Support staff often referred to a real connection as an 'invisible line' between support staff and people with intellectual disabilities and challenging behaviour. That is, even in the absence of explicit forms of contact, both people on the video knew exactly what had to be done in the activity, while the person with an intellectual disability was capable of executing the activity without the need for too much support.

Now you can see that the support worker is not focused on the client but knows exactly what the client is doing. I think that may actually be the most special connection; that you are not involved with each other, that you do not see each other, but that you know exactly what you can expect from each other at that moment. So, even though there is no real contact, there is a connection. [Support worker 1]

Participants sensed that people with intellectual disabilities and challenging behaviour and support staff paid attention to each other during the joint activity; they observed that the people in the video were following each other's actions when they worked together. During joint engagement in meaningful activities, the participants also believed that a connection took place when both people with intellectual disabilities and support staff acted in the 'here and now'. That is to say, they were not distracted in any way; rather, their focus was explicitly on the other while carrying out the activity together.

Visible connection. Participants frequently acknowledged explicit forms of connection while support staff and people with intellectual disabilities engaged in joint activities. Eye contact and both verbal and physical forms of contact were all indicators of a real connection. Different types of verbal contact were highlighted as indicating a connection. For example, when a support worker noticed that the person with an intellectual disability was tense, they tried to understand what was causing this tension by asking the person with an intellectual disability a question:

Yes, that piece is beautiful. "What are you looking at?" So, he [support worker] *noticed again, he sees the tension, "what are you looking at?" …, even when he sees [name person with intellectual disability] is actually with his thoughts somewhere else, then I* [support worker] *will try and put myself into his thoughts. So, that is what I think again, he is constantly looking for reciprocity. So, I like that very much*. [Psychologist 1]

Verbal contact was also used when support staff sensed that people with intellectual disabilities and challenging behaviour were more at ease, and sought to connect to them via engaging in brief conversations. The participants considered this to be a means through which to show genuine interest in people with intellectual disabilities, and to have an equal conversation.

In some instances, this verbal contact was combined with physical contact. For example, in one scenario a support worker put their hand on the shoulder of the person with an intellectual disability while giving him instructions. Participants indicated such forms of physical connection can have different effects on people with intellectual disabilities, such as providing comfort and reassurance.

Finally, eye contact between support staff and people with intellectual disabilities was also seen as a sign of connection by both groups of participants. Different attributions were given to this type of contact, such as the support worker checking if there was still a connection, reassuring the person with an intellectual disability during an activity, and letting them know that the support worker was still there for them.

Yes, that was exactly that moment of eye contact, where the support worker nods, "I understand you". I don't know exactly what [name person with an intellectual disability] *was talking about, but the support worker lets the person know "I hear you and I understand you".* [Support worker 5]

Theme 2: Support staff creating a safe atmosphere

In addition to the interpretations of moments of connectedness, the participants also noted that the recorded support staff created a safe atmosphere for people with intellectual disabilities and challenging behaviour. According to the comments of the participants, this atmosphere was considered significant for being able to connect with people with intellectual disabilities. This theme was built upon three subthemes: *support staff creating a familiar and reassuring feeling*; *support staff displaying an approachable attitude*; and *support staff being confirmative and complimentary*.

Support staff creating a familiar and reassuring feeling. The psychologists talked about support staff evoking feelings of familiarity and reassurance in order to connect with people with intellectual disabilities. By creating a familiar environment, people with intellectual disabilities were able to actively join in the mutual activity, which was considered to be indicative of a connection. In addition, psychologists reported that when support staff noticed that people with intellectual disabilities were unsure about what they were supposed to be doing in an activity, or were feeling stressed, they displayed a reassuring attitude that helped to maintain the connection.

He [support worker] *keeps calling his name, you know, and uh ... Also speaking in a very calm tone. He* [support worker] *is really doing it together.* [Name person with intellectual disability] *actually drops out from engaging in the activity 20 times in this video, but he brings him back in 20 times with the same tranquillity and I think that is very reassuring for the client.* [Psychologist 1]

Support staff displaying an approachable attitude. Psychologists and support staff also regarded the attitudes of the support staff as being significant for establishing connections with people with intellectual disabilities and challenging behaviour. When support staff adopted a respectful, kind, and calm attitude during the execution of a joint meaningful activity, the participants noticed a connection. Participants indicated that this is because people with intellectual disabilities are more willing to connect with support staff when they feel at ease with their carers' approachable attitude.

I think it is just above all his calmness and the sense of equality that he radiates ... I think that is his strength… [Psychologist 1]

Support staff being confirmative and complimentary. Both groups of participants mentioned that recorded support staff where confirmative and gave compliments while carrying out meaningful activities together. This behaviour of recorded support staff was considered to contribute to create a safe atmosphere in which a real connection could occur.

… [support worker] *considers it for a moment, and also approving of euh ... a nod with his head, like things are going well you know. A very small compliment that he* [support worker] *gives him very often, so that he* [person with intellectual disability] *really realises that it is going well. You are doing well, a kind of confirmation of it is going well.* [Support worker 6].

Theme 3: Support staff attuning to the needs of people with intellectual disabilities in a sensitive way

The third theme pertains to the sensitive attitude displayed by support staff. Both groups of participants considered that the sensitivity of staff played a significant role in terms of fostering a connection. This sensitive attitude was understood as showing genuine interest in people with intellectual disabilities, trying to place themselves in their mind and attempting to ascertain what they felt and needed. This theme was built upon two subthemes: *support staff adjusting their proximity and pace to establish a connection*; and *support staff adjusting their actions to foster a connection*.

Support staff adjusting their proximity and pace to establish a connection. Participants described the support staff as being sensitive when attuning their proximity to the needs of people with intellectual disabilities. That is, when support staff noticed that they had to be close to people with intellectual disabilities in order to be connected while executing a joint activity, or if they needed to give them more space. For example, one support worker noticed that the person with an intellectual disability was stressed and reached out to make a physical connection with them. In order to maintain this connection, the support worker made physical contact by placing their hand on the hand of the person with an intellectual disability:

Yes, what I like, is that he [support worker] *sees that hand coming towards his hand again, …, he* [support worker] *literally puts his hand on his hand for a moment, then lets it go again, you know, so he plays with the connection and really looks at him* [person with intellectual disability] *a little longer. Then he asks another question. So, he felt that tension well again.* [Psychologist 1]

Conversely, another support worker opted to take a step back when he sensed that the person with an intellectual disability could manage the activity independently.

There is a clear goal, but what I like most about this situation is that the client gets around 3 or 4 metres of space from the support worker at some point, and I think that might be the best connection there is. Like, okay, I see you, I am here for you, I'll help you, but go do it by yourself. I think that is the most beautiful kind of connection in this situation. [Support worker 1]

Participants also commented on how support staff slowed down their actions to develop a connection with people with intellectual disabilities. By taking their time and letting people with intellectual disabilities respond in their own time, support staff were able to truly connect to the person they were supporting.

Support staff adjusting their actions to foster a connection. Participants expressed that support staff used multiple actions to either become or maintain connected. Although the actions described in this part of the results section were mentioned independently, combinations of these actions were also mentioned. Examples of such actions were giving instructions, using gestures (pointing towards something), demonstrating (a part of) the activity themselves, or using objects (a glass or a plate) to clearly illustrate what needed to be done in the activity. Participants also observed that support staff used small sounds (making noises with cutlery) to maintain the attention of people with intellectual disabilities and thereby stay connected. To reduce the use of verbal language, in some cases support staff made their intentions clear by explicitly looking at something, so the person with an intellectual disability would also look at it and they would have a moment of shared attention:

Yes, I actually just think the moment he passes it to him, and you also see where you normally see people making eye contact, here you see [name support worker] *is now not looking on purpose,* [name person with an intellectual disability] *also does not look, in my opinion, and actually they both have the same position, so* [name support worker] *looks down and* [name person with an intellectual disability] *also looks down. While, yes,* [name support worker] *is not really busy with anything. He just looks at something, or down, to make* [name person with an intellectual disability] *also look down. So, I like it, how he does that trick.* [Support worker 11]

Other actions that were described as being used to either become connected or maintain connection were when support staff captioned their own actions (i.e., saying out loud what they were doing), turning and leaning with their body explicitly towards the person with an intellectual disability, or, alternatively, used humour to establish a connection.

Theme 4: People with intellectual disabilities attempting to connect with their support staff

The final theme is based on several statements from psychologists and support staff, who focused on the perspective of people with intellectual disabilities and challenging behaviour in establishing connections. Despite the fact that this perspective was rarely mentioned by the participants, the theme is nevertheless considered relevant. Two subthemes were distinguished: *participating in the activities of support staff* and *engaging in actions to become connected*.

Participating in the activities of support staff. Psychologists and support staff considered a connection to have taken place when people with intellectual disabilities participated actively in an activity together with their support staff. That is, when people with intellectual disabilities effectively responded to what support staff asked of them.

We have to buy that together and then you can get it. So, that you really do it together…, I point it out, you take it and put it in the shopping cart. [Psychologist 10]

Engaging in actions to become connected. Both groups of participants noted that, in some instances, people with intellectual disabilities actively asked for reassurance, such as by making eye contact or looking at their support worker. In some situations, people with intellectual disabilities even asked support staff questions.
And I also think it is funny, he [person with intellectual disability] *asks a question and* [name support worker] *responds to that, so that is also ... he* [support worker] *just lets him ask his question and he* [support worker] *gives him an answer. So, that* [name person with an intellectual disability] *can also respond again, so a small dialogue occurs. In that sense, they do have contact.* [Support worker 3]

Finally, several of the psychologists discerned that people with intellectual disabilities turned their body explicitly towards their support worker, in a concerted effort to connect with them.

Discussion

This study aimed to gain insight into what constitutes 'a real connection' between people with intellectual disabilities and challenging behaviour and support staff, by examining the tacit knowledge of psychologists and support staff. The first research question examined *when* psychologists and support staff considered moments of real connection to have occurred. The results indicate that there were many moments of agreement about when participants considered that a real connection had taken place between support staff and people with intellectual disabilities and challenging behaviour. Indeed, in one case, nine people selected the exact same second as indicating a moment of connectedness. The second research question, *what* psychologists and support staff considered to be a real connection, pertained to situations in which a concrete interaction was occurring (e.g. verbal or physical contact). In most of these situations, support staff played a prominent role and people with intellectual disabilities often appeared to be responsive towards the actions of support staff. Furthermore, the thematic analysis of the interpretations of professionals about *what* constituted a real connection showed that, a real connection could occur when people with intellectual disabilities and support staff were engaged in a joint meaningful activity, and, when there was a visible connection between them (verbal, eye or physical contact). In addition, the participants indicated that to be able to establish a connection with each other, support staff had to create a safe atmosphere that produced a familiar and reassuring feeling for people with intellectual disabilities. Besides this, support staff should also display an approachable attitude and be confirmative and complimentary towards people with intellectual disabilities. Finally, the results indicate that it was necessary for support staff to adopt a sensitive attitude in order to foster a connection between people with intellectual disabilities. By attuning to their needs, in terms of proximity, pace and other types of actions (e.g. the use of gestures, demonstrating the activity, etc.), the participants deemed that support staff were able to connect to people with intellectual disabilities and challenging behaviour. It is also noteworthy that both groups of participants primarily described connectedness from the perspective of support staff, with the perspective of people with intellectual disabilities and challenging behaviour rarely being mentioned. In those rare instances in which the participants did note that people with intellectual disabilities were attempting to connect, it was because they were either participating in the activity together with the support worker or explicitly attempting to connect, by, for example, asking a question or making eye contact.

These results suggest that joint engagement in an activity is considered to be a significant context for establishing connections. Active participation in daily life via engaging in meaningful activities is also a core element of multiple approaches (e.g. Positive Behaviour Support, Active support, Triple-C), which seek to support people with intellectual disabilities experience a life as close as possible to an “ordinary life” (King’s Fund, 1980). In the case of Triple-C, joint engagement in a meaningful activity is also one of the core assumptions regarding how to build a positive relationship between people with intellectual disabilities and challenging behaviour and support staff; however, this assumption needs to be underpinned by scientific evidence (Tournier et al., 2020).

Furthermore, the need for support staff to display sensitive attitudes and create a safe atmosphere was also considered to be integral to establishing a connection. Based on the interpretations of the participants, support staff were able to sufficiently meet the needs of people with intellectual disabilities and challenging behaviour, which, in turn, led to moments of real connection. In addition, the participants expressed that support staff attuned themselves to the needs of people with intellectual disabilities as a way of generating feelings of reassurance, comfort, mutuality and genuine interest. This finding is in accordance with previous research, which similarly highlighted the importance of attunement (Reuzel et al., 2017) and showed that evoking such feelings confirms the humanity of the person who is dependent upon care (Antonsson et al., 2013; Hermsen et al., 2014). When viewed in the context of ours results, this could explain why the participants considered these moments to be indicative of a real connection. Besides, our results are also in line with a recent concept mapping study by Nijs et al. (2019), which indicated that support staff should attune to the needs of people with intellectual disabilities and challenging behaviour in order to strengthen the connection. According to Simons et al. (2020), support staff should assess the support needs of people with intellectual disabilities and challenging behaviour across a range of dimensions (i.e. cognitive functioning, adaptive behaviour, participation, health, and context), and subsequently tailor their support to their clients’ needs with respect to these dimensions. Based on their systematic review, Simons et al. (2020) argued that support staff should have knowledge about people with intellectual disabilities, their own psychological resources, their own causal explanations for understanding the challenging behaviour, along with adopting an optimistic, friendly and understanding attitude, and reflecting upon how they cope with their own emotions during their work (Simons et al., 2020).

The feelings that the participants highlighted as being indicative of connections between people with intellectual disabilities and challenging behaviour and support staff share similarities with those cited by people with intellectual disabilities and challenging behaviour as being important for developing a positive relationship. Prior research has shown that people with intellectual disabilities and challenging behaviour view trust, having genuine interest, and displaying a calm approach to all be important qualities for support staff to have in terms of building a positive relationship (e.g., Clarke et al., 2019; Griffith et al., 2013; Van den Bogaard et al., 2019). However, further research is needed to learn how people with intellectual disabilities and challenging behaviour themselves experience connections with support staff. This is underpinned by the results of the current study, which showed that both psychologists and support staff primarily focused on the connection from the perspective of support staff. Including the perspectives of people with intellectual disabilities and challenging behaviour is thus necessary, because such connections are built on two-way interactions, and, hence, the experiences of both parties are of equal importance (Antonsson et al., 2013).

However, the findings of this study must be considered in light of some limitations. First, all the participants were trained in, and experienced users of, the Triple-C approach. This approach has a strong vision about how to build relationships between people with intellectual disabilities and challenging behaviour and support staff. A key assumption of Triple-C is that this relationship is predicated on carrying out meaningful activities together. Consequently, this could have implications for why participants considered engagement in meaningful activity to be a means through which people with intellectual disabilities and support staff connected with one another. In light of this, future research should thus seek to include participants with other backgrounds in the care for people with intellectual disabilities and challenging behaviour as well, in order to examine if they also consider these same moments to be indicative of real connections and provide similar interpretations.

Second, the selection of moments of agreement could be considered to be arbitrary, in that the nature of the obtained data made it difficult to compose consistent inclusion criteria. There were several reasons for this difficulty. The moments of agreement were selected for each second, and thus we did not consider the response times of the participants. This decision was made because some participants selected multiple moments of connection that were close to each other. Moreover, it was hard to decide on a strict cut-off point for what would be considered as a moment of agreement. In other words, how many participants need to select the same second in order for it to be considered a real connection?

A final limitation is that, although engaging in a meaningful activity together appears to be a significant context in which to establish connections, this study only included moments in which people with intellectual disabilities and support staff engaged in activities together. Prior to data collection, Triple-C professionals were consulted when connections between support staff and people with intellectual disabilities and challenging behaviour were likely to occur. Based on their advice, situations were recorded in which support staff and people with intellectual disabilities and challenging behaviour carried out activities together. Due to this selection procedure, we cannot be sure if a real connection only occurs in such situations. Furthermore, another effect of only including routinely occurring meaningful activities is that the invisible line referred to by the participants in this study may be familiarity with performing the same activity on numerous occasions. This may explain why both parties in the video already knew what had to be done during the activity. It may also have affected support staffs' behaviour, in that they may have been less active than normal in the video due to the fact that the person with an intellectual disability already knew what had to be done, and, as such, required less support. Despite these limitations, the present research has nevertheless shed light on both when a real connection has occurred and what precisely constitutes a real connection between people with intellectual disabilities and challenging behaviour and their support staff when engaging in meaningful activity together. Future research could focus on exploring both when a real connection occurs and what constitutes a real connection when people are either less obviously engaged in an activity together.

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CHAPTER 4

4

Family involvement in person-centred approaches for people with intellectual disabilities and challenging behaviours:

A scoping review

This chapter has been published as:
Tournier, T., Wolkorte, R., Hendriks, A. H. C., Jahoda, A., & Embregts, P. J. C. M. (2021). Family involvement in person-centered approaches for people with intellectual disabilities and challenging behaviors: A scoping review. *Journal of Mental Health Research in Intellectual Disabilities,* 1-26. https://doi.org/10.1080/19315864.2021.1959689

Abstract

Introduction

Families have a significant role in the lives of people with intellectual disabilities and challenging behaviour. However, it is not clear how actively families are involved when people with intellectual disabilities and challenging behaviour are living in out-of-home care. This scoping review explored the frequency and type of family involvement in the application of a person-centred approach in the care for people with intellectual disabilities and challenging behaviours.

Methods

Authors conducted electronic searches through six databases: Embase, Medline, Web of Science, PsycINFO, Cochrane Central, and Google Scholar (2005 to 2019) and evaluated relevant publications.

Results

Based on the 15 articles identified, only five articles report on family involvement. In addition, frequency of contact, and how family is involved appears to differ between different person-centred approaches.

Conclusion

More active family involvement in person-centred approaches for people with intellectual disabilities and challenging behaviour is recommended.

Family members of people with intellectual disabilities have a significant, lifelong role in their lives due to the unique and irreplaceable nature of family relationships (Bigby & Fyffe, 2012; Lambert et al., 2010). Although it might differ between countries (Woittiez et al., 2018), a large number of people with intellectual disabilities will continue to live with family members well into adulthood (Mansell & Beadle-Brown, 2010). During this time, the family is often the main caregiver. When people with intellectual disabilities leave the parental home they are likely to move to supported accommodation, as their intellectual disability causes significant limitations both in intellectual functioning and in adaptive behaviour (APA, 1994). From that moment on, the role as main caregiver is transferred to the service providers. A reason people with intellectual disabilities might leave their family home is because a crisis has occurred or the family member is no longer able to take care of them (Llewellyn et al., 1999). This also includes instances when family are unable to continue their support due to challenging behaviour (Llewellyn et al., 1999; Brown et al., 2011). Challenging behaviour include behaviour that challenges families, support staff and other professionals (NICE Guideline, No. 11, May 2015). Challenging behaviour is a social construction and can be defined as follows: 1) when the behaviour breaks social norms, and 2) when the behaviour occurs frequently, with a high level of severity for a long duration with significant social consequences (e.g. exclusion from the community settings or activities; Emerson & Einfeld, 2011).

Although people with intellectual disabilities might display behaviour that challenges towards their family members, it does not necessarily mean that their family bonds are any the less significant to them (Giesbers et al., 2020). It was found in a qualitative study with eight people with intellectual disabilities and challenging behaviour, that positive family relationships could have a positive effect on the behaviour of people with intellectual disabilities. Challenging behaviour decreased when the people with intellectual disabilities experienced a sense of belonging and the opportunity to participate in valued relationship roles rather than feeling that they were being “looked after” (Clarke et al., 2019). Therefore, Clarke et al. (2019) stated that maintaining family relationships should be a priority of health care facilities because of their importance to the well-being of people with intellectual disabilities and the management of their challenging behaviour.

Due to the significant role of families, it is considered important for professionals to continue to involve family members in the lives of the individual with intellectual disabilities and challenging behaviour, when they move into community or residential services (Bigby & Fyffe, 2012). The participation of family can play an essential role in setting-up effective and appropriate interventions (Gray et al., 2010). The successful participation of family requires cooperation between family and professionals (Keen, 2007; Morrow & Malin, 2004). Genuine partnership means that there needs to be shared decision-making, common goals and mutual respect, trust and honesty (Keen, 2007). Family decisions should be their own and not face undue pressure from professionals (Knox, 2000). Family members ordinarily wish to have continuing involvement in their relatives’ lives after they have left their family home, as issues relating to their care remain deeply concerning to them (Bright et al., 2018). However, previous research has found that the collaboration between families and professionals may not always be straightforward (Bright et al., 2018; Mooney & Lashewicz, 2014; Redmond & Richardson, 2003; Ryan & Quinlan, 2018). Neither families nor professionals find it easy to develop collaborative relationships (Mooney & Lashewicz, 2014). The main barriers for families are poor communication, inadequate support and coordination, a lack of information and lack of child or family centeredness (e.g. a concern with individual needs instead of what a service offers; Redmond & Richardson, 2003; Ryan & Quinlan, 2018). Professionals and health care facilities are keenly aware of the needs and challenges faced by families, yet struggle to collaborate effectively with families. They indicate to sometimes struggle with families who can be demanding and others who seem uninvolved or hard to reach. Professionals can find it sometimes difficult to attune to the different priorities and styles of care and collaboration (John, 2020; Mooney & Lashewicz, 2014). Families are sometimes convinced that support staff may fall short or miss the mark in terms of their judgement and insight into individuals' needs, thereby even contributing to challenging behaviour (Mooney & Lashewicz, 2014). Relationships between families and support staff often seem to be characterised by high levels of mistrust and misconceptions about each other (Bright et al., 2018). There is a lack of guidance available to both those working in care facilities and families about what to expect from each other and how to provide mutual support (Bigby & Fyffe, 2012).

Several residential or community settings apply a person-centred support framework. Every individual has their own specific needs and person-centred approaches attempt to personalize their support to meet these needs (Klatt et al., 2002; Sanderson, 2000). A person-centred approach aims to make the specific needs and goals of the individual as the starting point of support. It is hope that meeting an individual's needs will improve their quality of life and be associated with a decrease in their challenging behaviour (Carr et al., 2002). Person-centred approaches also adopt an open-ended approach towards the individuals with intellectual disability. They are multi-element approaches, with the aim of improving the person's quality of life (i.e. not just on changing behaviour). This means that these approaches will be delivered by multiple members of health and/or social care teams, who contribute to different aspects of people's needs (Klatt et al., 2002; Sanderson, 2000). Examples of such approaches, which are concerned with the broader context of individual's lives, are Positive Behavioural Support (PBS; Carr et al., 2002; Gore et al., 2013; McGill & Toogood, 1994), Active Support (Flynn et al., 2018; Mansell & Beadle-Brown, 2012) and Triple-C (Tournier et al., 2020). Person-centred approaches can be implemented by professionals and/or family members. The current study focuses on person-centred approaches implemented by professionals, as little is known what, if any role, family members play in the delivery of person-centred approaches to people who have left the family home.

Therefore, the current scoping review aims to provide an overview of the frequency and the type of family involvement in the delivery of a person-centred approach in the care for people with intellectual disabilities and challenging behaviour, for whom professionals are the main caregivers. The specific research questions were: 1) how many studies mentioned family in relation to the development or delivery of the intervention, 2) what was the nature of family involvement in the development of the individual's person-centred intervention? 3) what role did families play in the delivery of the person-centred interventions?

Materials and Methods

Search Strategy

A systematic search was executed in conjunction with an information specialist. The search was conducted in six databases; Embase, Medline, Web of Science, PsycINFO, Cochrane Central, and Google Scholar (first 200 hits), which were searched from January 2005 to November 2019. Table 1 provides an overview of the search terms and strategy applied in Embase using both Emtree and additional text words for "intellectual disability", "challenging behaviour" and "person-centred approach". Emtree is a controlled vocabulary thesaurus that Embase uses for indexing articles. Other databases have similar thesauri (e.g. PubMed uses Medical Subject Headings (MeSH)). Similar search strategies were used in the five other databases mentioned above.

Eligibility Criteria

Publications were included if the study concerned people with intellectual disabilities and challenging behaviour. When the study reported the delivery of a 'person-centred' approach. That is, an approach that (1) adopts an open-ended approach towards the person with an intellectual disability; (2) is a multi-element approach with the aim of improving the person's quality of life (i.e. not just on changing behaviour); (3) requires delivery by multiple members of health and/or social care teams. Last, studies were included when an outcome measure concerned challenging behaviour of people with intellectual disabilities. Publications were excluded when the study concerned people with intellectual disabilities for whom their family was the main caregiver. That is, the study concerned people with intellectual disabilities living with relatives. In addition, when the publication was not an original report, e.g. conference abstracts, letter to the editors, books or reviews it was excluded from the research. Last, studies published prior to 2005 were excluded. Although the development and use of person-centred approaches emerged in the 1980s, an evidence base for person-centred approaches was established at a later date (e.g. Robertson and colleagues, 2005) as part of the Learning Disability

Research Initiative. Moreover, these approaches were established as a key component of the provision of social care to all adults (Department of Health, 2005).

Table 1

Search Strategy Embase using MeSH Emtree and Additional Text Words

Embase final search strategy
('intellectual impairment'/mj/de OR 'mental deficiency'/mj/exp OR 'learning disorder'/mj/de OR 'mentally disabled person'/mj/de OR 'developmental disorder'/mj/de OR (((intellect* OR learning OR development*) NEXT/1 (defect* OR deficit* OR deficien* OR dysfunction* OR disab* OR impair* OR disorder* OR retard* OR handicap*)) OR ((mental*) NEXT/1 (defect* OR deficit* OR deficien* OR dysfunction* OR disab* OR impair* OR handicap*)) OR retard* OR idiocy OR (down* NEAR/3 syndrome*) OR prader-willi OR fragile-x):ti)
AND ('aggression'/de OR aggressiveness/de OR provocation/de OR threat/de OR 'violence'/de OR Assault/de OR 'exposure to violence'/de OR 'physical violence'/de OR 'verbal hostility'/de OR 'challenging behavior'/de OR 'problem behavior'/exp OR 'automutilation'/de OR hostility/de OR 'stereotypy'/de OR 'agitation'/de OR 'agitation assessment'/de OR 'disruptive behavior'/exp OR 'antisocial behavior'/de OR arson/de OR 'sexual misconduct'/de OR (aggressi* OR provoc* OR threat* OR violen* OR Assault* OR hostil* OR crime OR criminal* OR hurtful* OR ((challeng* OR problem* OR defiant* OR difficult* OR trouble* OR unaccept* OR demand* OR abuse OR abuser* OR abusive* OR inappropriat* OR maladapt*) NEAR/3 behav*) OR automutilat* OR auto-mutilat* OR (self NEXT/1 (harm* OR injur* OR mutilat*)) OR misconduct* OR (physical* NEAR/3 restrain*) OR stereotyp* OR stereo-typ* OR agitat* OR ((disrupti* OR conduct* OR problem* OR destruct*) NEAR/3 (behav* OR act OR acts)) OR misbehav* OR (withdraw* NEAR/3 behav*) OR anti-social* OR antisocial* OR arson):ab,ti)
AND ('therapy'/de OR 'early intervention'/de OR 'psychiatric treatment'/de OR psychotherapy/exp OR 'behavior modification'/de OR 'behavior therapy'/exp OR 'client centered therapy'/exp OR 'cognitive behavioral therapy'/exp OR 'cognitive rehabilitation'/exp OR 'cognitive therapy'/exp OR (support* OR intervention* OR therap* OR psychotherap* OR ((behav* OR client* OR treatment) NEAR/3 approach*) OR (behav* NEAR/3 (treatment* OR management* OR support*)) OR (comprehensive* NEAR/3 (treatment* OR support*)) OR ((multicomponent* OR multicomponent*) NEAR/3 framework)):ab,ti)
AND [2005-2019]/py NOT ([Conference Abstract]/lim) NOT ([animals]/lim NOT [humans]/lim) AND ([english]/lim OR [dutch]/lim OR [german]/lim)

Data Synthesis and Analysis

Two reviewers (TT and RW) independently screened the titles and abstracts of 750 articles (21% of 3548 articles, to meet reliability standards). The two researchers agreed on 96.3% of the papers. There was agreement to include nine papers, exclude 713 papers and disagreement on 28 of the papers. All disagreements were discussed and consensus reached. Next, a single reviewer (RW) screened the remaining publications. Full text copies of all potentially relevant articles were then obtained. Again, two reviewers (TT and RW) independently read 19 articles (22% of all the full texts). There was only disagreement on one of the papers. The remaining articles were read by one reviewer (RW). Systematic reviews were excluded but were screened to identify further relevant articles. Furthermore, the reference lists of all included articles were also screened for additional articles.

Data related to the research question were extracted from the publications. Extracted data included general characteristics of the study, the study population, the person-centred approach, family involvement and outcome measures. The data extraction form was prepared in advance by the research team and the data extraction was carried out by RW. When in doubt about any detail, a second reviewer (TT) was consulted and the issue was discussed until consensus was reached. Data are presented in table 2 with an accompanying narrative.

Results

A flow chart of the process of selecting papers for the review is shown in figure 1. After removing duplicates, 3634 studies were found in the initial search. After the first screen of the titles and abstracts, 86 papers were considered relevant and full texts were obtained. This was a large reduction of number of papers, the main reason for this reduction was that papers described the results of interventions other than person-centred approaches (e.g. pharmacotherapy, specific training such as social problem solving skills) or did not describe an outcome measure on challenging behaviour or did not target people with intellectual disabilities. After examining the full-texts of the 86 papers, a further 72 were excluded based on the eligibility criteria. One additional study was identified from the reference lists of the papers. Thus, 15 studies that matched the eligibility criteria were included in the review, which described person-centred approaches applied to people with intellectual disabilities and challenging behaviour and included an outcome measure about challenging behaviour.

Study Characteristics

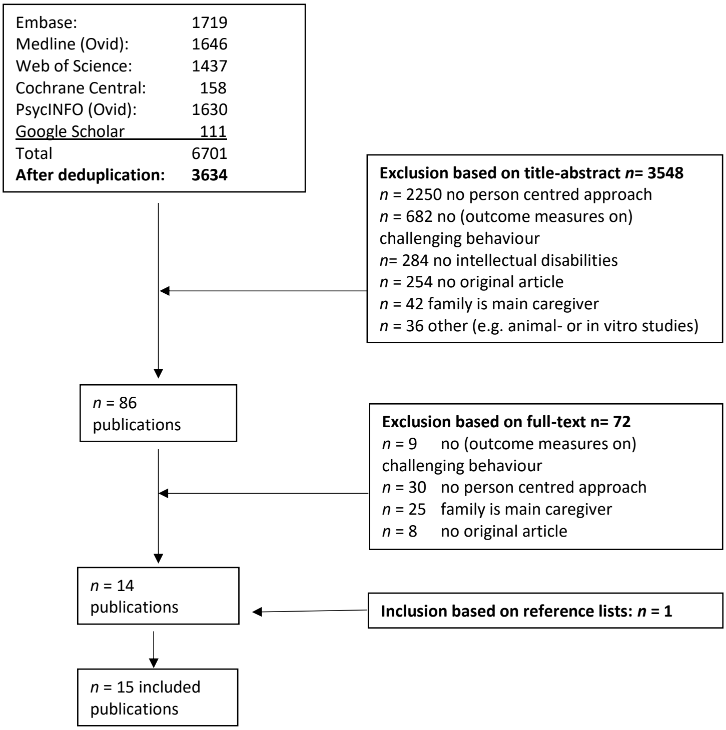
A summary of the included studies can be found in table 2. There were studies from the UK (*n* = 8), USA (*n* = 1), Australia (*n* = 2), Ireland (*n* = 1), Switzerland (*n* = 1), Taiwan (*n* = 1), and the Netherlands (*n* = 1). The articles reported on seven trials, three multiple baseline case studies, four randomized or open controlled trials, and one case report. Studies included participants with mild (*n* = 3), moderate (*n* = 7), severe (*n* = 9), and profound (*n* = 2) levels of intellectual disabilities. In ten studies, file records were used to determine the participants' level of disabilities, in one study the Adaptive Behaviour Scale was used, and four studies did not report on the level of intellectual disabilities of the participants. Participants lived residentially or in the community, either alone or together with up to eight people.

Person-Centred Approaches

The fifteen studies reported on six different person-centred approaches; five studies reported on PBS (Grey et al., 2018; MacDonald et al., 2010; MacDonald et al., 2018; McClean

Figure 1

Selection of Included Publications



et al., 2007; McGill et al., 2018), six studies on Active Support (Beadle-Brown et al., 2012; Chou et al., 2011; Jones et al., 2013; Koritsas et al., 2008; Stancliffe et al., 2010; Totsika et al., 2010), one study implemented the Programme Autisme Méthode structure for people with autism and intellectual disabilities (treatment proposing adapted and individualized schedules; Galli Carminati et al., 2007), one described the effects of the intervention On Your Own Two Feet (staff training aimed at promoting overall self-management of people with intellectual disabilities; Sandjojo et al., 2018), one implemented the Teaching Family model (De Wein & Miller, 2009), and one focused on Nidotherapy (approach that attempts to treat the problems of aggressive challenging behaviour by changing the environment to create a better fit between the person and society; Tyrer et al., 2017). The participants were followed-up for between six and 48 months. The person-centred approaches were delivered by support staff and in some studies managers were involved. One study mentioned the involvement of a remedial educationalist, whereas others described having behaviour analysts involved in writing the support plans for people with intellectual disabilities. Twelve studies reported providing training to professionals, either to learn the methods of the person-centred approach, to learn additional skills for the approach, or to learn skills that were necessary for the newly established plans for people with intellectual disabilities. Eight studies stated that a personal plan for each individual with an intellectual disability was already in place or put in place during the study, whereas seven studies did not mention a personal plan.

Family

Only five studies mentioned families in relation to the development or delivery of the intervention. Most studies described this information in the methods section of their paper. The nature of the family involvement in these five studies differed.

The trial by Beadle-Brown et al. (2012) only reported that families were informed about the approach when they were provided information about the Active Support approach. Families were only given the opportunity to ask questions about the intervention. There was no mention of the involvement of family in developing or delivering of the intervention or on the effect the intervention had on contact with family.

The trial study by Chou et al. (2011) did not mention the involvement of family in developing or delivering the intervention. The study did report on the amount and nature of family contact over a 3-month period of applying the Active Support approach, with the results showing no increase in family contact.

Three multiple baseline case studies described more active family involvement (De Wein & Miller, 2009; Grey, et al., 2018; McClean et al., 2007). Grey et al. (2018) and McClean et al. (2007) applied a Positive Behavioural Support approach and involved families in developing the intervention. They interviewed the families of people with mild to severe intellectual disabilities to obtain information about the personal support plans and goals of their relatives, who lived in group homes or residential facilities. McClean et al. (2007) also included families in multidisciplinary mental health reviews whenever these were indicated for their relative. McClean et al. (2007) reported that one participant had more contact with family as a result of the intervention.

Finally, De Wein and Miller (2009) reported on a Family Teaching Model. However, the study did not describe involvement of the family in either developing or applying the intervention. They did describe the involvement of family in reviewing the intervention. The families of the two participants with moderate and severe intellectual disabilities who live independently in the community met staff and management approximately once a month to discuss and review the progress of their goals (De Wein & Miller, 2009). They reported that the participants had more contact with family and friends after the intervention.

Ten studies did not mention the involvement of families, either in the methods or results. One of the studies did mention in the discussion that the collaboration between staff and families was greatly enhanced as a result of the intervention (Carminati et al. 2007). They stated that this opportunity was created through new programs and a reorganisation of time and space. However, no further details were given about what exactly took place regarding the collaboration with families, and what this reorganization of time and space exactly entailed.

Of note, is that none of the included studies included a lack of family involvement as a limitation of their study.

Challenging Behaviour

Ten of the included studies reported a decrease of challenging behaviour when the person-centred approach was applied (De Wein & Miller, 2009; Galli Carminati et al., 2007; Grey et al., 2018; Jones et al., 2013; Mac Donald et al., 2010; McClean et al., 2007), some of which were significant (Koritsas et al., 2008; MacDonald et al., 2018; McGill et al., 2018; Stancliff et al., 2010). The four studies that reported significant differences used standardised measures (Aberrant Behavior Checklist (Community), ICAP General Maladaptive Index, and Developmental Behaviour Checklist for Adults), whereas the studies that reported a general decrease, based their results on the recorded frequency of challenging behaviour (De Wein & Miller, 2009; Grey et al., 2018; Jones et al., 2013; Mac Donald et al., 2010; McClean et al., 2007).

Five studies did not find a decrease of challenging behaviour (Beadle-Brown et al., 2012; Chou et al., 2011; Sandjojo et al., 2018; Totsika et al., 2010; Tyrer et al., 2017). Different reasons were given by the researchers why no differences in challenging behaviour were found. For example, some participants entered the studies with low levels of challenging behaviour, making it harder to find significant decreases in challenging behaviour over the course of the study (Beadle-Brown et al., 2012; Tyrer et al., 2017), or the researchers felt they had not used measures which were sensitive to change (Beadle-Brown et al., 2012; Sandjojo et al., 2018; Totsika et al., 2010), or the fidelity of the person-centred approach was regarded as questionable (Sandjojo et al., 2018; Totsika et al., 2010).

Table 2
Study Characteristics

Author(s), year, country and quality	Study design	Study population	Person-centred approach	Family involvement	Outcome on family contact	Outcome on challenging behaviour
Beadle-Brown et al. 2012 UK	12 month trial	29 people, level of ID not reported Sex: NR Age: 44 (range 20-61) Challenging behaviour present at baseline: for some participants Type of living situation: community-based housing with 24/7 care from staff and 2-8 residents	Approach Person-centred Active Support Training staff Staff received 1-day workshop on principles of person-centred active support and 1.5-2 days hands-on training involving the manager Personal plan Not reported	Relatives received information on active support	No	Aberrant Behavior Checklist and observed challenging behaviour, no significant decrease in challenging behaviour
Chou et al. 2011 Taiwan	14 month trial	49 people with mild, moderate, severe or profound ID Sex: 31 males, 18 females Age: 32 (range 19-54) Challenging behaviour present at baseline: not reported Type of living situation: community living homes (2-6 residents) with 24/7 care from staff	Approach Active Support Training staff Two-day classroom training workshop on general principles of active support, 1-2 day classroom training including on activity and support plans, individual interactive training in the residence. Personal plan Not reported	Not reported	Social Network Index, no increase in contact with family	ICAP General Maladaptive Index, no decrease in challenging behaviour

De Wein & Miller 2009 USA	33 month multiple baseline case study	2 people with moderate or severe ID Sex: 2 males Age: 28-37 years Challenging behaviour present at baseline: all displayed physical and verbal aggression Type of living situation: community-based independent living	Approach Teaching Family Model. Information such as the individual's goals, hopes, and dreams (identified by individual with intellectual disability) as well as the individual's strengths (by staff) were identified. Information obtained from the QLP was used to target skills that would help the men to achieve their goals and that might serve as alternatives to aggression. Rewards could be earned as a motivation system. The staff member had a meeting with the individual with intellectual disability every day to discuss progress. Training staff Not reported Personal plan A quality of life plan was established	Family (i.e. parents and/or guardians) met with the teaching team and administration (and often the individual with intellectual disability) to discuss and review progress. Family was questioned on quality of life of individual with intellectual disability	One individual with intellectual disability reported increased contact with parents, resumed home visits and weekend visits with parents	Frequency of physical and verbal aggression was counted, during the TFM the challenging behaviour decreased.
Galli Carminati et al. 2007 Switzerland	21 month trial	10 people with profound ID, all diagnosed with a pervasive developmental disorder Sex: 8 males, 2 females Age: 39 (range 33-54) Challenging behaviour present at baseline: not reported Type of living situation: Programme Autisme Méthode Structurée appartments with 6 residents	Approach Programme Autisme Méthode Structurée (PAMS) develop autonomous abilities for domestic activities. Using repetition and predictability. Limited verbal communication but increased alternative communication. Leisure and training workshops. Training staff Not reported Personal plan Not reported	Not reported	No	Aberrant Behavior Checklist, challenging behaviour decreased

Grey et al. 2018 UK	24 month multiple baseline case study	7 people with mild, moderate or severe ID Sex: 5 males, 2 females Age: 14 (range 8-17) Challenging behaviour present at baseline: all displayed physical aggression Type of living situation: community group home with 24/7 care from staff (1-4 residents)	Approach Positive Behavioural Support. Including a functional assessment and personal behavioural support plan Training staff Not reported Personal plan A behavioural support plan including environmental accommodations, direct interventions, functional skills teaching and reactive strategies.	Family was interviewed by a board-certified behaviour analyst to develop interim behavioural recommendations prior to a formal behavioural support plan.	No	Frequency of physical aggression was counted and monthly reported, challenging behaviour decreased when Positive behavioural Support was applied

Jones et al. 2013 UK	22 month trial	3 people with severe ID Sex: 2 males, 1 female Age: 48 (range 46-51) Challenging behaviour present at baseline: all presented with aggression and/or self-injury Type of living situation: group home in the community with 24/7 care from staff	Approach Active Support (and positive interaction as secondary approach). Training staff All received training in the approaches, as well as in British Institute for Learning Disabilities accredited physical intervention techniques and an in-service 'understanding challenging behaviour' training'. Personal plan An individual Behaviour Support Plan was created by a specialist behaviour team, focusing on secondary prevention and reactive strategies.	Not reported	No	Frequency of challenging behaviour was counted, challenging behaviour decreased
		1 person with severe ID Sex: 1 female Age: mid-40s Challenging behaviour present at baseline: aggression and/or self-injury and territorial behaviour Type of living situation: single flat on a campus-based residential service	Approach Active Support (and TEACHH as secondary approach). Training staff All received training in the approaches, as well as in British Institute for Learning Disabilities accredited physical intervention techniques and an in-service 'understanding challenging behaviour' training'. Personal plan Not reported	Not reported	No	Frequency of challenging behaviour was counted, challenging behaviour decreased

Koritsas et al. 2008 Australia	9 month trial	12 people with moderate or severe ID Sex: 9 males, 3 females Age: 37 (range 27-57) Challenging behaviour present at baseline: not reported Type of living situation: group home	Approach Active Support Training staff AS training program for (casual) support workers. 3 days of classroom-style training and 2 days of 1-on-1 interactive training. Personal plan Not reported	Not reported	No	Developmental Behaviour Checklist for Adults, challenging behaviour decreased significantly
MacDonald et al. 2010 UK	22 month single case report	1 person with a severe ID Sex: 1 male Age: not reported Challenging behaviour present at baseline: self-injury, aggression and property destruction Type of living situation: own apartment with care of 2 support workers 24 h a day	Approach Positive Behavioural Support; a functional assessment to determine causes of the challenging behaviour and execution of the multi-element Behavioural Support Plan. Training staff Systematic staff training and 1-on-1 training by the specialist PBS team for all staff members (verbal, role-play and real-life competence training). Personal plan A multi-element behavioural support plan that includes proactive strategies (ecological changes, positive programming, focused support and reactive strategies)	Not reported	No	Frequency, severity and duration of self-injurious, aggressive, and destructive behaviour were counted, all types of challenging behaviour decreased

MacDonald et al. 2018 UK	12 month controlled trial	50 people, level of ID not reported Sex: 35 males, 15 females Age: 41 (range 18-63) Challenging behaviour present at baseline: present in some, but not all participants Type of living situation: community group homes	Approach Positive Behaviour Support; Training for managers for 1 year (2 days introduction, 8 1-day workshops). Formulation of individual plans. Training staff No, managers received training. Personal plan Yes, including at least 4 proactive strategies (ecological interpersonal; ecological activity; positive programming, either functionally equivalent or coping and tolerance; focused support, either reinforcement protocol or antecedent control strategy) and a reactive strategy.	Not reported	No	Aberrant Behaviour Checklist, challenging behaviour decreased significantly
McClean et al. 2007 Ireland	24 month multiple baseline case study	4 people with a mild, moderate or severe ID Sex: 3 males, 1 female Age: 26 (range 21-37) Challenging behaviour present at baseline: all presented with either aggression or self-injury Type of living situation: 1 participant in a group home, 4 participants in fulltime residential care in the community	Approach Positive Behavioural Support; functional assessments (informant assessments, descriptive assessments, behavioural observation, historical analysis, antecedent analysis and consequence analysis, hypothesis development and systematic observation to test hypotheses), interventions following a plan Training staff For one individual with intellectual disability, staff were trained in non-violent crisis intervention, for another individual with intellectual disability staff was trained to lower the arousal level of their response to self-injury Personal plan Multi-element behavioural support plan (environmental accommodations, skills teaching, direct interventions, reactive strategies)	In some cases, family was interviewed as part of the functional assessments. Family participated in multidisciplinary mental health reviews if these were required for their relative. One individual with intellectual disability was given more frequent opportunities to listen to mother on the phone as part of the support plan. One individual with intellectual disability was desensitized to family contact as part of the support plan.	For one individual with intellectual disability increased contact with family was reported	Frequency of challenging behaviour was counted, challenging behaviour decreased

McGill et al. 2018 UK	11 month cluster randomized controlled trial	38 people, ID Sex: 13 males, 24 females Age: 48 (range 19-84) Challenging behaviour present at baseline: 24 presented with challenging behaviour Type of living situation: residential setting (1-8 residents)	Approach Setting-wide Positive Behavioural Support; researchers formulated goals for each setting to work on, in the areas of social care (activities and skill development, health, service staff, management, relationships with families and others, communication and social Interaction, wider organization, and physical environment). Regular meetings with managers to check progress, train staff and managers where needed. Training staff Staff was trained where deemed necessary by researchers. Personal plan Not reported. Goals were set for the service, not for a single person.	All participating settings formulated standards on maintaining regular, positive contact with family members for the individuals with intellectual disability. Some settings formulated standards on establishing family contact for people with intellectual disability, and for the setting to have and safeguard contact with family Family was asked to evaluate the intervention after completion of the intervention.	No	Aberrant Behavior Checklist-Community, challenging behaviour decreased significantly
Sandjojo et al. 2018 The Netherlands	6 month controlled trial	15 people with a borderline, mild, moderate or severe ID Sex: 8 males, 7 females Age: 31 (range) Challenging behaviour present at baseline: present in some individuals with intellectual disability, unknown in how many. Type of living situation: group homes	Approach On Your Own Two Feet; supporting self-management of people with intellectual disability through coaching and focusing on positive aspects. Training staff 2 day classroom training for staff to explain and practice the methodology. Personal plan Not reported.	Not reported	No	Developmental Behaviour Checklist, no decrease in challenging behaviour

Stancliffe et al. 2010 Australia	8 month trial	41 people, level of ID not reported Sex: 27 males, 14 females Age: 44 (range 25-63) Challenging behaviour present at baseline: some participants presented with challenging behaviour Type of living situation: group homes (3-6 residents)	Approach Active Support; staff engaged with individual with intellectual disability in meaningful tasks. Training staff 3-day group classroom training and 2-hour individual interactive training Personal plan An activity and support plan including opportunity goals and protocols on how to complete any activity.	Not reported	No	ICAP general maladaptive index, challenging behaviour decreased significantly
Totsika et al. 2010 UK	6 month trial	21 people with moderate or severe ID Sex: 12 males, 9 females Age: 46 (range 28-75) Challenging behaviour present at baseline: not reported Type of living situation: community homes	Approach Interactive training component of Active Support; staff engaged participants with intellectual disability in meaningful tasks under supervision of trainers. Training staff Several months prior to the study, staff received classroom training on active support. Staff received 15 sessions of 1,5 hours of the interactive training component individually from a lead and a support trainer. Personal plan Plans were in place for most individual with intellectual disability prior to the study and not adapted specifically for the study.	Not reported	No	Behavior Problems Inventory-01, no decrease in challenging behaviour

Tyrer et al. 2017 UK	15 month cluster randomized controlled trial	85 people, level of ID not reported Sex: not reported Age: not reported Challenging behaviour present at baseline: at least 1 participant of each home presented with challenging behaviour Type of living situation: care homes	Approach Nidotherapy; consists of person-environment understanding, environmental analysis, creation of a new environmental pathway (nidopathway) and monitoring of the pathway. Training staff Written introduction on Nidotherapy, explanation of the 4 components over 6 months time Personal plan Not reported	Not reported	No	Modified Overt Aggression Scale, Problem Behaviour Check List, Quantification of Aggression Scale, no decrease in challenging behaviour

Discussion

This review concerned the frequency and type of family involvement in the application of person-centred approaches for people with intellectual disabilities and challenging behaviour who have left the family home. Studies published between 2005 and 2019 were reviewed.

The main finding of this review is that several studies reported the involvement of family in *developing* (Grey et al., 2018; McClean et al., 2007) or *evaluating* (De Wein & Miller, 2009) a person-centred approach but never in implementing it. Person-centred approaches aim to support a person in their daily life. When a personal plan is created, the input of family can be valuable as they have known a person their entire life and are aware of their likes and dislikes, and of past failures and successes (Barr, 1996; Blacher & Baker, 1992; Dunlap & Fox, 2007). This information can also be important during the evaluation phase. During this evaluation, family can act as advocates for the person with an intellectual disability (Carr et al., 2002). The family can also help to put into place the person-centred approach when the individual is at the family home. By applying a similar approach in different places, the person with an intellectual disability may experience consistency and a better understanding of situations and rules (Dunlap & Fox, 2007). This may be most helpful when families are in regular contact with a person, and good communication and coordination is needed between families and staff. Overall, there is preliminary evidence that the effectiveness of person-centred approaches increases when there is strong family involvement (Dunlap & Fox, 2007).

Not all of the studies have reported the involvement of family in developing or evaluating person-centred approaches. There may be different reasons. Such as the included studies deliberately chose not to include families, as the researchers had other factors to investigate about what contribute to implement person-centred approaches with fidelity. Another reason might be that family was involved but not explicitly mentioned in the papers. It is for example known that structural involvement of families is a significant component of PBS (Carr et al., 2002). However, only three out of seven of the included studies on PBS reported family involvement (see table 2). The role of family was not the main focus of the studies included in this review and therefore it is not possible to determine why family involvement was scarcely mentioned. This would require further research.

Limitations

The limitations of the current study need to be addressed. In particular, there are a limited number of papers in this review concerning person-centred approaches. Moreover, the focus of these papers was not to describe family involvement. Therefore, the findings may not reflect current practice in services. To fully understand the current status of family involvement of people with intellectual disabilities and challenging behaviour, further research examining current practices in services for people with challenging behaviour, with a specific focus on family involvement, would be recommended.

Implications for Research and Practice

Family has a significant role in the lives of people with intellectual disabilities and challenging behaviour (Clark et al., 2019; Giesbers et al., 2020), and preliminary results show that the involvement of family in person-centred approaches has positive effects (Dunlap & Fox, 2007). Consequently, researchers should incorporate a measure of family participation in studies investigating the effectiveness of person-centred approaches. This might provide new insights into family involvement with implications for practice.

Practice would be recommended to reflect on means to improve collaboration with family in relation to the care of individuals with challenging behaviour. This will require an individual approach as the needs of each person and the possibilities for collaboration with families will differ, which makes family involvement a complex issue (Mooney & Lashewicz, 2014; Redmond & Richardson, 2003). An example of an aspect that can complicate the collaboration between families and support staff are their personal values in respect of specific people and situations. These values are central to the successful development of services, and need to be discussed individually between families and support staff to gain insight into everyone's priorities for intervention of people with intellectual disabilities and challenging behaviour (Barr, 1996). Professionals and families should be encouraged to reflect on their input into making family involvement a reality. Identifying attributes that facilitate the development of appropriate services might be essential (e.g. shared responsibility, non-hierarchical relationships, or joint venture), while on the other hand, acknowledging and recognising factors that impede the development of such services as well (Barr, 1996).

In conclusion, this review showed that few studies reported family involvement in person-centred approaches that are applied by professionals in residential and community settings. Although collaboration between staff and family can sometimes be difficult and will always require a personalized approach, a good collaboration will often be beneficial to the treatment of a person with an intellectual disability and challenging behaviour.

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CHAPTER 5

5

Measuring emotional support in family networks: Adapting the Family Network Method for individuals with a mild intellectual disability

This chapter has been published as:
Giesbers, S. A. H., Tournier, T., Hendriks, A. H. C., Hastings, R. P., Jahoda, A., & Embregts, P. J. C. M. (2019). Measuring emotional support in family networks: Adapting the Family Network Method for individuals with a mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 32*(1), 94-105.
http://dx.doi.org/10.1111/jar.12512

Background

Informal supportive networks of individuals with intellectual disability have become increasingly important. The aim of this paper is to describe how the Family Network Method – Intellectual Disability (FNM-ID) offers a way to gather the perspective of people with mild intellectual disability on their family support.

Method

The FNM is designed to explore how individuals define their family contexts, and more specifically how they perceive existing supportive relationships in these contexts.

Results

By carefully piloting ways of questioning people with mild intellectual disability, systematic adaptations were made to the original FNM. Data obtained by the FNM-ID can be analysed using social network analysis. Thereby, the FNM-ID provides rich, theoretically significant information on emotional support in the family networks of individuals with mild intellectual disability.

Conclusions

The FNM-ID is a useful and successfully adapted tool for other researchers and professionals to systematically explore the family support experiences of individuals with mild intellectual disability.

In recent years, participation and social inclusion have dominated the policy discourse in the field of intellectual disability within western society. To enhance participation and social inclusion, and thereby the quality of life of individuals with intellectual disability (Schalock, 2004), a supportive social network is essential (Simplican et al., 2015). As a result, an emphasis has been placed on forging stronger links with their local community to increase and strengthen informal networks of support (e.g., Hewitt et al., 2013). In line with these changing societal views, researchers have paid increasing attention to the social networks of individuals with intellectual disability. Several studies have examined the characteristics of their social networks, showing that the networks of the majority of individuals are relatively small (Lippold & Burns, 2009), that friendships are often formed with other people with disabilities and that interactions between individuals with intellectual disability and those in the wider community may be mainly restricted to family members (Forrester-Jones et al., 2006; Robertson et al. 2001; Van Asselt-Goverts et al., 2013, 2015; Verdonschot et al., 2009).

Even though informal networks of individuals with intellectual disability are found to mainly consist of family members, research on family support provided to them has been scarce. For several decades, research has mainly focused on the impact of having a child with intellectual disability on parental well-being and family quality of life (Hastings, 2016). It has been extensively shown that parental and family outcomes are influenced by many factors such as child characteristics, parents' cognitive styles, and family and environmental features. More specifically, social support, especially support from family members, is an important contributing factor to positive outcomes for parents of a child with intellectual disability (Canary, 2008; Cohen et al.,2014; Hassall et al., 2005; Hastings et al., 2002; Shin, 2002; White & Hastings, 2004). However, studies on the provision of family support including directly the perceptions of individuals with intellectual disability have been rare. Research has shown that the actual amount of support may be of less importance for positive outcomes than the supported person's perception of the helpfulness of the support (Shin, 2002; White & Hastings, 2004), which also highlights the necessity of directly exploring the support experiences of individuals with intellectual disability themselves (Embregts, 2011; McDonald et al., 2013). Within the literature, support is often differentiated into emotional and instrumental support. Perceived emotional support is regarded as the most significant type of support and found to be a stronger predictor for positive physical and mental health related outcomes than instrumental support (Berkman, 1995; Thoits, 1995; Viswesvaran et al., 1999). Also, people have been found to attribute an emotional meaning to supportive behaviours that are instrumental in nature. In other words, by providing instrumental support someone may show that they are being caring and have an understanding of another person's needs (Semmer et al., 2008).

Various instruments have been used to examine social network characteristics of individuals with intellectual disability, such as the Social Network Map (Robertson et al., 2001; Tracy & Abell, 1994), the Social Network Guide (SNG; Forrester-Jones et al., 2006), the Social Support Self Report (SSSR; Lippold & Burns, 2009; Lunsky & Benson, 1997), the Social Network Questionnaire (Dagnan & Ruddick, 1997; Krauss & Erickson, 1988), the Support Interview Guide (SIG; Llewellyn & McConnell, 2002), the Functional Support Inventory (FSI; Felton & Berry, 1992; Lippold & Burns, 2009), and the Hierarchical Mapping Technique (Circles Task; Antonucci, 1986; Lippold & Burns, 2009). Using these existing instruments, researchers have been able to provide detailed information on social network characteristics, including the views of individuals with intellectual disability themselves. The instruments were used to examine the supportive relationships that existed between the person with intellectual disability and his/her network members. Most of these instruments focused on support received by the person with intellectual disability (Antonucci, 1986; Dagnan & Ruddick, 1997; Felton & Berry, 1992; Llewellyn & McConnell, 2002). Some instruments (i.e., Social Network Map, SSSR, and the SNG) also examined the support that was given by the person with intellectual disability to his/her network members, assessing the reciprocal character of the person's supportive relationships (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Robertson et al., 2001).

However, none of the existing social network instruments have examined the supportive relationships existing among all network members of the person with intellectual disability. Relationships between a person and his/her network members cannot be seen as isolated from the broader social context. Until know, research has often disregarded the social context of interdependencies among network members of individuals with intellectual disability in which, for example, intimate relationships, close friendships, or parent-child relationships are embedded. In addition, none of the methods listed above have a specific focus on assessing the family networks of people with intellectual disability – although all would potentially capture elements of support from family members.

An instrument that has been developed to explore how individuals define their family contexts, and more specifically how they perceive existing supportive relationships in these contexts, is the Family Network Method (FNM; Widmer et al., 2013). In line with a trend in sociological research, the FNM has conceptualized family relationships within the theory of social capital (Furstenberg & Kaplan, 2004; Widmer, 2006, 2007, 2016). Social capital is defined as resources that flow to individuals from their membership of a durable social network (Bourdieu, 1986). From this perspective, family relationships (i.e., family-based social capital) are expected to have a variety of positive outcomes for the individual, such as promoting physical and mental health (Kawachi & Berkman, 2001; Kawachi et al., 1999; McPherson et al., 2014; Riumallo-Herl et al., 2014). The main types of social capital, bonding and bridging social capital (Coleman, 1988; Burt, 1995), are relevant with respect to family networks. Bonding social capital refers to network closure (i.e., a group with a high density of connections and redundant ties) (Coleman, 1988). As dense networks enhance expectations, obligations, and trust among its members, support within such a network becomes collective. Traditionally, family relationships have been regarded as bonding social capital, based on the assumption that the significant family is constituted by the nuclear family (i.e., married couples and their children). However, this focus on the nuclear family ignores the fact that, due to the pluralization of life courses in late-modernity, family contexts have become more heterogeneous and open (Allan, 2008; Widmer, 2016). More recently it has been shown that family contexts based on blood ties mostly provide a bonding type of social capital, whereas family contexts based on friendships usually provide bridging social capital (Widmer, 2006, 2007). Bridging social capital refers to weaker connections between subgroups of a network that give some individuals (i.e., brokers) the potential to mediate the flow of resources between group members (Burt, 1995). To examine the social capital that is provided by the family, FNM respondents are not only asked about their own relationships with family members, but also about their views of relationships amongst the different family members who make up their network. Thereby, the FNM provides a better understanding of the family context of structural interdependencies in which individuals and their close family relationships are embedded. As the FNM captures respondents' perceptions of how their family networks are organised in terms of, for example, support provision, the FNM might be a useful instrument to question individuals with intellectual disability about their family support experiences, thereby examining the social capital their families provide.

However, the FNM was developed for use in the general population. Although there is evidence that individuals with a mild intellectual disability can be reliable informants of their support experiences (Lunsky & Benson, 1997), the instrument cannot be automatically applied to them. As a result of cognitive and language impairments, they might experience difficulties in understanding questions and communicating valid and reliable answers when using instruments developed for people without disabilities (Coons & Watson, 2013; Finlay & Lyons, 2001). Yet it has been generally recognized that individuals with intellectual disability have a valid perspective on their lives and several suggestions for questioning them in a reliable and valid way have been made in the literature (Perry, 2004). The FNM has previously indeed been used with individuals with mild intellectual disability (Widmer et al., 2008; Widmer et al., 2013). However, the exact procedure that has been used to question them has not been reported. To enhance the method's transparency and transferability for use in the population of individuals with intellectual disability, it is important to systematically report the procedures used and to document the adaptations that have been made to facilitate their understanding. Therefore, the first aim of this paper is to describe how systematic adaptions have been made to the FNM, by carefully piloting ways of questioning individuals with mild intellectual disability about their family networks, making the FNM a useful and reliable tool for other researchers and professionals. The second aim of this paper is to give a detailed description of the data that could be obtained by the FNM.

The Original Family Network Method

The original FNM consists of three parts, a detailed description is shown in table 1. In the first part, participants are asked to list their significant family members. The term 'family member' is deliberately left undefined, to allow participants to decide whom they consider as family and may wish to include as significant family members. Participants are told that the term 'significant' refers to those family members who have played a role in their life, either positive or negative, during the past year (Widmer, 2006). In the second part of the FNM, participants are asked about their perceptions of the relationships between the family members they have identified. Four aspects of the relationships between family members are examined: emotional support, instrumental support, influence, and conflicts. In the third part, socio-demographic information is collected about each listed family member, as well as information on the nature of the family tie, the duration of the relationship, and the frequency of contact.

Family Network Method – Intellectual Disability: Revised Content and Procedures

To adapt the FNM for use with individuals with intellectual disability, two pilot studies were carried out, involving a total of 19 participants with a mild (*n* = 16) or moderate (*n* = 3) intellectual disability. Participants had a mean age of 32.7 years (*SD* = 13.14, range 19 – 65 years) and 13 were male. The vast majority (*n* = 13) of participants lived in community based settings, whereas six lived in residential, more segregated, facilities. This early testing suggested that asking people with intellectual disability about multiple dimensions of support would be overly complex and may not lead to different information for each dimension. For example, difficulties arose in differentiating instrumental from emotional support. The nature of the wording might not have been understood by people with intellectual disability when trying to explain instrumental support. Also, piloting showed that focusing only on emotional support already placed a high time demand on participants. Since perceived emotional support is also regarded as the most significant type of support (Berkman, 1995; Thoits, 1995; Viswesvaran et al., 1999), the initial question about family relationships focussed on emotional support only. Therefore, during the pilot interviews, participants were asked to examine the relationships among their family members in relation to emotional support provision: 'Who would give emotional support to X [i.e., each individual included in the participant's family configuration, considered one by one] during routine or minor troubles?' (Widmer et al., 2013).

Before the pilots were carried out by the first two authors of this paper, the original FNM was translated into Dutch using a systematic forward-backward translation procedure (Cull et al., 2002). In addition, instructions for the interviewer were added to standardise the interview procedure. During the pilot interviews, one researcher was the interviewer, the second researcher observed and made notes about the procedure and difficulties that occurred during the interview. After the interview, these notes were documented in a log. The duration of the interviews varied between 15 minutes and two hours, depending on how many family members were listed, and the participant's understanding of the questions, which varied according to their level of intellectual disability and ability to concentrate. Based on the experiences of these pilot interviews, as well as the suggestions of Finlay and Lyons (2001) about overcoming difficulties when interviewing people with intellectual disability, adaptations were made to the original instrument.

Interview procedure

The FNM-ID is carried out individually with the participant at a place of their choosing, to ensure the participant's privacy and to facilitate a congenial atmosphere which might contribute to a feeling of safety. At the start of the interview, the interviewer initiates "small talk" with the participant, in which specific questions about the family network are asked. For instance, questions with respect to significant others in the participant's living situation, leisure time, and work. This small talk helps to make the participant feel comfortable and allows the interviewer to develop a picture of the participants' life and gain an initial insight into significant others in his/her network. The interviewer is able to start with the first question of the FNM-ID after observing that the participant is at ease. The first question of the FNM-ID is to talk about the family network:

1. I would like to talk to you about your family. You define for me who you consider to be your family.
   Could you tell me about your nuclear family? Who is in your nuclear family?
   Could you tell me about your extended family? With whom do you have contact (in some way)?

The interviewer writes all the names of the listed family members down on separate cards, starting with the name of the participant. On every card, a number is written as well (the participant is always number one, the first listed person is number two, the second listed person is number three, etc.), which corresponds with the number on the scoring form. If the participant mentions demographic information when talking about a person, the information is noted on the back of that person's card. The interviewer tells the participant that the names of listed family members will not be used for research; every single person receives a code after the interview and the data are processed anonymously.

The second question is about defining the significant family members from those listed at the first stage:

2. Which members of your family are significant to you? It could be no-one, a few or all of them, it is up to you how many people you choose.
   2.1. Who among them means a lot to you?
   2.2. Who is always there for you?

The interviewer checks whether the family members on the cards are considered to be significant by showing the cards (one by one) to the participant. A green and a red box are used to support the participant; cards for family members who are considered significant are put in the green box, the cards of the family members who are considered not significant, are put in the red box. Alternative questions (for example question 2.1 and 2.2) can be asked (in a fixed order) when a participant is not able to answer the main question. If these additional questions are not sufficient, strategies can be used to help participants to answer the question (see table 1). These questions and strategies were added to standardise the procedure of the FNM-ID and to enhance the reliability of the instrument. Subsequently, all the cards in the green and red box are put back on the table again and the interviewer moves on to the third question, which is about emotional support. This question concerns whether a participant receives and/or gives emotional support to his/her listed persons; and whether emotional support is provided among all the listed people.

3. If X is feeling out of sorts, who is there for X?
   3.1. If X is not having such a good day, who supports X?
   3.2. If X is feeling out of sorts, who listens to X?
   3.3. If X is feeling out of sorts, who reassures X?

The interviewer checks whether the family members give emotional support to the participant by showing the cards (one by one) again to the participant. Again, the red and green box are used to support the participant and additional questions are available. After this is completed, the participant is asked to provide his/her perceptions of the relationships among the network members, answering the same questions about emotional support for every single person (using the same procedure with the cards and the boxes). If the main question or the additional questions are not sufficient to obtain answers, strategy C can be used (see table 1). After this, demographics of all the listed people are collected and written on the back of the card of the concerning person. Table 1 provides an overview of the demographic data collected.

Finally, a fourth question about significance of the participant to his/her family members is asked:

4. To which of your family members are you significant? It could be no one, a few or all of them, it is up to you how many people you choose.

4.1. To whom do you mean a lot?
4.2. For whom are you always there?

The interviewer checks whether the participant considers themselves significant to every family member in the network by showing the cards of all members (one by one) to the participant. Again, additional questions (4.1 and 4.2) are available in case the main question is not sufficient and the boxes are used.

Based on these two pilots, table 1 summarises, per topic, the adaptations and rationale of adaptations between the original FNM and the FNM-ID.

Social Network Measures obtained from the FNM-ID

In this part of the paper, we will illustrate the measures that give insight into people with mild intellectual disability's perceptions of their family configurations, based on the data obtained from the FNM-ID. As in the original FNM, analysis concerns the significant family network (family members that are selected at step two of the FNM-ID). Different software packages can be used to analyse social network data, for example UCINET (Borgatti et al., 2002) or R software packages like Statnet (Handcock et al., 2016). Using these packages, measures can be calculated for the significant family network of the participant as a whole (network measures) or for specific persons in the network (centrality measures). Network measures give a better understanding of family configurations of people with mild intellectual disability, whereas centrality measures give information about how individual family members are located or embedded in the overall family network (Hanneman & Riddle, 2005).

1. *Network measures.* Several measures about the family network can be calculated: i.e., size, density, average degree, arc reciprocity, and index of components. The size of the network represents the number of family members listed by the participant. Density of a network can be calculated by dividing the number of supportive ties (connections) among all the family members by the maximum number of potential supportive ties if all the family members were connected. In highly dense connected family networks, most or all family members are connected with each other, providing a bonding type of social capital. Average degree calculates the average number of supportive ties of the family members in a network; it divides the total number of supportive ties that exist in the network by the number of network members The arc reciprocity represents the proportion of reciprocal relationships within a network: of all the support that is given from one family member to another, what proportion is reciprocated? The 'index of components' measures how many subgroups there are in a network.

Table 1

Original FNM and FNM-ID: Description, Differences and Rationale of Adaptations

Topic	Original FNM	FNM-ID	Rationale for adaptations
FNM guide in general	Names of family members are written down on a list.	• Cards are used to write down the names of the family members • Demographics are written on the back of the cards • Green and red boxes are used to differentiate first between significant and not significant family members and later between family members who provide support and those who do not provide support.	Supportive (visual) techniques were added to the protocol. According to Boster (1994) a card sorting method makes it easier to judge the similarities among large numbers of items. The names of the listed family members were written down on small paper cards (one card for each person) so they can be presented on the table to give a better overview of the listed family members compared to writing down a list of names. As demonstrated in earlier studies (e.g., Forte et al., 2011; Pownall et al., 2017), asking the participants to select and post the cards helped to scaffold their task and ensure they were making active judgements. Also, the cards put the participant more in charge of the decision making. Also, a red and a green box were used to support answering the questions and to ensure participants are making active choices and to make the choice more tangible.
Start of the interview	Officially not in the original FNM guide	• Start small talk with the participant. Specific questions about the family network are asked. For instance, significant others in the living situation, leisure time or work.	
Introductory talk about family	Officially not in the original FNM guide	1. Talk about the family network, give instruction and ask the two following questions: I would like to talk to you about your family. You define for me who you consider to be your family. • Could you tell me about your nuclear family? Who is in your nuclear family*? • Could you tell me about your extended family? With whom do you have contact (in some way)? *In Dutch the word "gezin" is used for the nuclear family, a commonly used word, which typically refers to parents and their children. The right terminology in English for individuals with mild ID needs some further thought.	During the pilot the researchers noticed that participants would think more about family members they recently saw or spoke to instead of their whole family. Therefore, an introduction to the FNM was added, in which participants were asked to talk about their family. The aim of establishing rapport and opening up the topic of family more broadly was to ensure that participants would think about their whole family when answering the question 'who is in your family?' and not just people they saw lately. Also, the instruction 'you tell us who you think of as family' was added to the first question because the researchers were interested in finding out about the participants' own definition of family.

Defining significant family members	Respondents are first asked to give a list of persons that they consider as significant family members. They are instructed that the term 'significant' refers to those people in their family who have played a role, either positive or negative, in their life during the past year. A statement is read to respondents that further emphasizes that they should not only refer to the people of their family who are significant to them because they love them or respect them, but also to those who have upset them or have made them angry during the last year. The term 'family' is left undefined and respondents are asked to use their own definition of what they intend by 'family'.	2. Define the significant family members: 2.1. Which members of your family are significant to you? It could be no one, a few or all of them, it is up to you how many people you chose. 2.2. Who among them means a lot to you? 2.3. Who is always there for you? Strategy A: • Ask the participant permission to take a picture of him/her. • If 'yes': take a picture and print this picture. If 'no': a pictogram of a man/woman is shown to the participant. The interviewer explains that the image represents the participant. • The participant is asked to put the cards of the family members that are most significant/closest to the individual next to the image. • If the participant is not able to indicate the most significant people, ask for the most significant five. • If the participant is not able to indicate the most significant five people, ask them one by one (e.g. who the foremost significant person is / who is number one, who else is significant?) Strategy B: • Ask the participant about a significant event. • Ask the participant: if this event takes place, who of your family members should definitely come/be there? • If the participant is not able to list the most significant people, ask for the most significant five. If the participant is not able to list the most significant five people, ask them one by one (e.g. who is foremost significant person / who else etc.)	We noticed that the explanation about 'significant family members' was too complicated and confusing for people with ID. Participants asked for further explanation before they were able to answer the question. Therefore, the explanation about 'significant' family members ('Significant refers to people who have played a role, either positive or negative, in your life during the past year') was omitted from the adapted approach, enabling participants to give their own interpretation of significance. When defining the significant family members, the instruction 'it could be no one, a few or all of them, it is up to you how many people you chose" was added. During the second pilot, the interviewers experienced that participants sometimes already made a selection when listing their family members (i.e., participants did not list their whole family but just a selection of significant members). By adding the instruction that all family members could be considered significant, the researchers tried to avoid over-selecting significant family members. Furthermore, the instruction that none of the family members could be considered significant is added to decrease the chance of social desirable answers.

Emotional support	Who would give emotional support to X during routine or minor troubles? (E.g.: when X is sad, when X had a bad day, who would help him/her, console him/her, etc.) (The original FNM asks these questions only about significant family members).	3. Defining the emotional support of relationships: 3.1. If X is feeling out of sorts, who is there for X? 3.2. If X is not having such a good day, who supports X? 3.3. If X is feeling out of sorts, who listens to X? 3.4. If X is feeling out of sorts, who reassures X? Strategy C: • Ask: Does X ever feel out of sorts? Ask the interviewer to think back and tell about the last time that happened. Ask about the persons who supported X in that situation. Ask about persons who help X in similar situations.	
Demographic questions	Gender Age Level of education The nature of the family tie The duration of the relationship Where does the person live Frequency of contact face-to-face Frequency of contact in other ways (telephone, internet)	• Gender **Is X male or female?** • Age (categorised into decades) **How old is X?** • Nature of the family tie What is your family tie with X? • Duration of relationship → only if the participant lists someone who isn't a family member (categorised into decades) For how long have you known X? • Place of residence Does X live in the same village/city as you? • Frequency of contact (categorised: every day, every week, every month, less than once a month) How often do you see X face-to-face? How often do you have contact with X in other ways? (Telephone, internet).	Answering the questions about demographics was found to be difficult for people with ID. The researchers noticed that participants were not able to answer the questions precisely which, in some cases, made them feel insecure and irritated. Since a rough estimation about these characteristics is sufficient enough, categories were made for the demographic questions about age, duration of the relationship, place of residence and frequency of contact. The question about level of education of family members appeared to be too difficult to answer for most participants, therefore it was decided to eliminate this question.
Significance of the person with ID	Officially not in the original FNM guide	4. Defining significance of the person with ID to the family members: 4.1. To which of your family members are you significant? It could be no-one, a few or all of them, it is up to you how many people you chose. 4.2. To whom do you mean a lot? 4.3. For whom are you always there?	Since it might also be valuable to measure another element of the reciprocity of significance within relationships, a new question was added at the end of the interview; the participant is asked to whom they think they are a significant other.

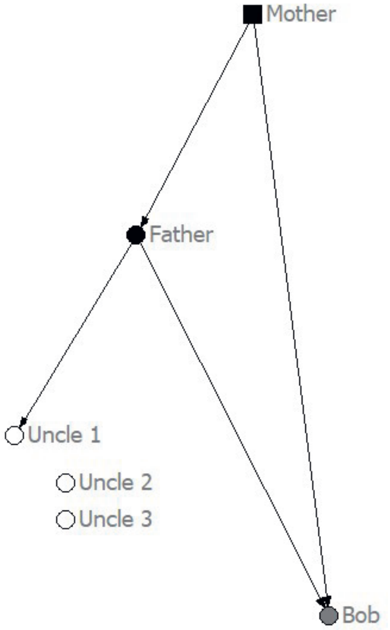
2. *Centrality measures.* Per family member, centrality measures can be computed, qualifying the position of a person in a network. The degree centrality of a family member refers to the number of supportive ties a person has. This measure can be specified as in- or out-degree. The in-degree of a person is the number of supportive ties that represent the support received from other family members. The out-degree is the number of support ties in which a person gives support to other family members in the network. Betweenness centrality describes the intermediary position of a person in the family network. Betweenness centrality is about how many pairs of family members would have to go through to the person in order to reach one another (in the minimum number of hops). Family members with a high betweenness centrality mediate the flow of support among network members, providing a bridging type of social capital.
3. *Attribute measures.* The FNM-ID obtains demographic information of all the listed family members and the person with intellectual disability: these data are called attributes. Attributes are calculated for either the full family network (e.g., 40% of the family network is male) or the nodes' in- or out-degree (e.g., 10% of the people who provide support live in the same place of residence).
4. *Graphs.* Networks can be visualised using a variety of software methods including NetDraw (part of the UCINET software package). The network and centrality measures can be combined with attributes, and can be visualised by using different colours, shapes or sizes.

FNM-ID Networks: Two Illustrative Cases

Two cases have been selected to illustrate possible differences between family configurations of people with mild intellectual disability and the potential utility of the FNM-ID. Pseudonyms are used to protect anonymity. The first case describes the family configuration of a 27 year old male (Bob) living in the community in the Netherlands. He received support within a clustered care setting and had set times for one-to-one support, but he was able to ask for additional support at any time during a 24 hour period. This participant listed five family members at step one of the FNM-ID; his father, mother, and three uncles. According to Bob, two of his uncles did not have an emotional support connection to anyone in the network (no arcs are pointing to or from the uncles). Bob only considered his parents as significant (see figure 1). The size of Bob's significant network was three (see table 2); Bob, his father, and his mother who were also the members who provided him with emotional support (the in-degree measure for Bob was 2). Bob was not supporting his parents in return (out-degree measure is 0, arc reciprocity is .00) As there are no reciprocal supportive relationships in the significant network, the density has a score of .50.

Figure 1

Family Configuration for Bob



Legend for figure 1

❍	= male
☐	= female
Grey	= Bob
White	= significant
Black	= not significant

Due to the little support among the family members the average degree of the network is 1.00. The betweenness centrality for Bob is .00, indicating that he is not an intermediary for the other network members.

Table 2

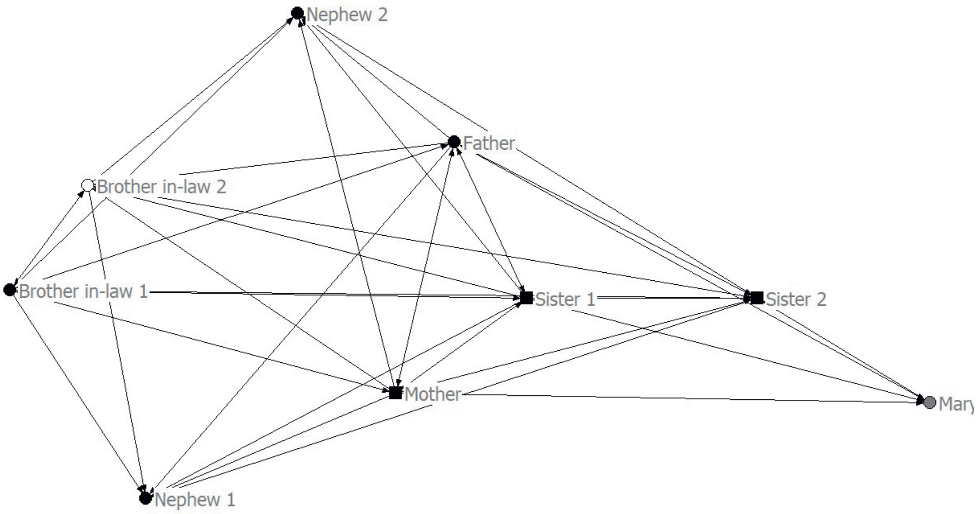
FNM-ID Significant Network Measures for Bob and Mary

Measure	**Bob**	**Mary**
Network size	3	8
Density	.50	.66
Average degree	1.00	4.63
Arc reciprocity	.000	.70
Indegree	2	4
Outdegree	0	3
Betweenness centrality	.00	.00

The second case is of a 33 year old female (Mary), also living in a clustered care setting in the community in the Netherlands. At step one of the FNM-ID she listed her mother, father, two sisters, two brother-in-laws, and her two nephews. Except for one brother-in-law, Mary considered all of them as significant, making the size of the significant network eight. Mary has a quite dense network (Figure 2). Figure 2 shows that Mary has three emotional relationships that are reciprocal (see two sided arcs); with her mother and with her two sisters. Her father is giving her emotional support as well, but Mary feels that she is not supporting him. According to Mary, the other listed family members are emotionally supported by other family members. For example, her mother is supported by the father, sister 1 and 2, Mary herself and brother in-law 1.

Figure 2

Family Configuration for Mary



Legend for figure 2
❍ = male
☐ = female
Grey = Mary
White = significant
Black = not significant

As a result of the large number of supportive relationships between the family members, the density score of this network is .66 (table 2). As previously indicated, the density can be calculated by dividing the number of ties (connections) among the nodes by the maximum number of potential ties. As a result, the score will always vary between 0 (no support between family members) and 1 (all family members are supporting each other). Therefore, a score of .66 indicates a relatively high density. Because of this supportive network, the average degree is 4.63, and many of these supportive relationships are reciprocal (arc reciprocity is .70). Mary has a betweenness centrality of .00, meaning that no family members have to pass her to reach one another.

In addition to information about the size of a network and the supportive relationships between the family members, the attributes of the family members can also be analysed. Attributes can be, for example, age, gender, place of residence or nature of the family tie and can be calculated by the 'composition'. In table 3, the network compositions with respect to the attribute 'nature of the family tie' for Bob and Mary are shown. The 'raw score for the whole network' represents the number of each type of family member within the significant network of the person with ID. Bob's network includes two parents (proportion of 1.00) and receives support from both them (proportion is 1.00; in-degree). This network composition shows that Bob is highly dependent on his nuclear family when it comes to emotional support. This information might be valuable, for example, to understand the sustainability of his family network; when his parents pass away, there will be no other network members available who have a history of providing Bob with emotional support. Mary's network consists of two parents, two siblings, two extended family members and one in-law family member (see table 3 for proportion scores). Mary is supported by her two parents and two siblings and provides support (out-degree) to one parent and two of her siblings. Again, this composition shows Mary's vulnerable position in the family network. If her parents pass away, only 50% of her emotionally supportive family relationships will remain.

Table 3

Significant Network Composition Attribute 'Nature of the Family Tie' for Bob and Mary

Attribute	Participant		Whole network raw score (proportion)	In-degree raw score (proportion)	Out-degree raw score (proportion)
Nature of the family tie	Bob	Parent	2 (1.00)	2 (1.00)	0 (.00)
	Mary	Parent	2 (.29)	2 (.50)	1 (.33)
		Sibling	2 (.29)	2 (.50)	2 (.67)
		Extended family	2 (.29)	0 (.00)	0 (.00)
		In-law family	1 (.14)	0 (.00)	0 (.00)

Conclusion

The FNM-ID enables a systematic exploration of the way in which individuals with mild intellectual disability define their family contexts, as well as the social capital these contexts provide. Research has neglected the direct perspectives of individuals with intellectual disability with respect to family support. Their informal supportive networks, which to a great extent are shaped by family members, have become increasingly important in a time of austerity and cuts to services. Therefore, gaining insight into their family context may play an important role in facilitating their social participation and inclusion.

Based on thorough piloting, the original FNM has been successfully adapted to better suit the cognitive and linguistic needs of individuals with mild intellectual disability (Finlay & Lyons, 2001). Although the intention was to include people with a moderate intellectual disability in these developments, in our piloting the instrument remained too complex despite the adaptations. In particular, these participants found taking the perspective of another family member too complicated and cognitively challenging. This finding might be due to the degree of their disability. Future research should explore ways of questioning people with moderate intellectual disability about their family networks.

The FNM-ID not only offers a way to gather the perspective of people with mild intellectual disability about their family support, but also provides rich, theoretically significant information about their family networks. In addition, the FNM-ID provides information about the person's perception of the relationships amongst all family network members. Thus, the FNM-ID provides a broader understanding of the family context of structural interdependencies in which individuals with mild intellectual disability and their close family relationships are embedded (Widmer et al., 2013). Findings of earlier family research has already shown that supportive relationships between a person with intellectual disability and his/her family members cannot be seen as isolated from the broader family structure. More specifically, higher levels of social support for parents of children with a disability, especially support from family members, lead to more positive outcomes in those parents, who in turn, might better relate emotionally to their children (Boyd, 2002; Hastings et al., 2002; Trute et al., 2008).

After systematically adapting the FNM for use with individuals with mild intellectual disability, the next step is to apply the FNM-ID in research in which substantial samples of individuals with mild intellectual disability are questioned about their family contexts. This is crucial to generate new knowledge on, for example, patterns of family configurations of individuals with mild intellectual disability, the type and amount of family-based social capital available to them, and the relationship between family resources and outcome measures such as the individual's subjective well-being and mental health.

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CHAPTER 6

6

Perspectives of people with intellectual disability about their family networks: A comparison study with key support worker proxy reports

This chapter has been published as:
Tournier, T., Hendriks, A. H. C., Jahoda, A., Hastings, R. P., Giesbers, S. A. H. & Embregts, P. J. C. M. (2020). Perspectives of people with intellectual disability about their family networks: A comparison study with key support worker proxy reports. *Journal of Intellectual & Developmental Disability,* 1-12. https://doi.org/10.3109/13668250.2020.1827143

Background

The Family Network Method – Intellectual Disability (FNM-ID) was used to compare perspectives of people with mild intellectual disability and their support workers on family networks of people with intellectual disability.

Method

138 participants with mild intellectual disability and support workers were interviewed, using the FNM-ID. Paired *t*-tests were used to examine differences in perspectives. Multiple regression analyses were used to examine divergence in perspectives.

Results

People with mild intellectual disability perceived their family networks to be larger and to provide more support than support workers did. Living in a residential setting and having higher levels of externalising behaviour were associated with differences in perspectives, whereas a higher level of internalising behaviour was associated with more similar views.

Conclusions

Individuals with intellectual disability and support workers are unlikely to provide the same information about family networks of people with mild intellectual disability. Behavioural and emotional problems were associated with divergence in perspectives.

Family members have a significant role in the lives of people with intellectual disability. Their unconditional love, lifetime commitment, and emotional closeness bring significant and unique qualities to their relationships (Bigby & Fyffe, 2012). In some cases, people with intellectual disability do not live with their family but in community or residential care (Brown et al., 2011), which has implications for their relationship with family if they are more distant from their significant others. Support staff may have, therefore, a significant role to help maintain the links people with intellectual disability have with their family members (McConkey & Collins, 2010).

To be able to carry out this supporting task, staff need to understand the existing family network and family ties of individuals they support. Knowledge about family relationships of people with intellectual disability is crucial as it is associated with positive outcomes in assisting the people with intellectual disability with developing, maintaining, and enhancing relationships (Van Asselt-Goverts et al., 2015). Therefore, knowing who are represented in the family networks is significant information for support staff, to have a good understanding of the social needs and preferences of people with intellectual disability. However, there is uncertainty whether support staff are always well informed about the families of people with intellectual disability, or know who the individual with intellectual disability has contact with (Bigby, 2008).

In intellectual disability research, practitioners and researchers often rely on proxy reports partly because it can be more challenging to obtain self-reported information (Scott & Havercamp, 2018) due to, among other factors, the cognitive demands of providing self-report information (Bertelli et al., 2017; Fujiura, 2012). Working with proxy-reports to obtain data about people with intellectual disability may be a partial solution to the self-report problem. However, the data may be limited as it is more difficult for a proxy to report on the personal perspectives of another individual on topics such as mental health, quality of life, and relationships. For example, Koch et al. (2015) compared self- and proxy reports of the Quality of Life (QoL) of 102 people with intellectual disability, using the World Health Organization Quality of Life-BREF (Skevington et al., 2004). Results showed that people with intellectual disability scored their QoL significantly higher compared to the proxy reports in all five domains, with large effect size differences in the psychological and social domain and medium sized differences in the physical, environment, and disability domains. Schmidt et al. (2010) used the same measure and found significant but only moderate associations for the five life domains, including the subjective domains, between the self- and proxy QoL-assessment of 614 adults with intellectual disability and their proxies (including professional caregivers).

There is also a growing body of literature that highlights the discrepancies between self- and proxy reports for other subjective data in the population of people with intellectual disability (Lunsky & Benson, 1997; Lunsky & Bramston, 2006; Scott & Havercamp, 2018). Lunsky and Benson (1997) compared the perspectives of people with intellectual disability and support staff on social support. Staff rated the support people with intellectual disability got from family or from staff and friends significantly lower than people with intellectual disability themselves. Scott and Havercamp (2018) found that staff rated friendship support significantly lower than family or staff support while self-report of people with intellectual disability indicated that friends provided as much support as staff or family. Lunsky and Bramston (2006) showed that staff rated the stress people with intellectual disability experience higher than did people with intellectual disability themselves.

Despite the possible divergence between proxy informants and the self-report of the person with intellectual disability, proxy responses are commonly used in intellectual disability research (Scott & Havercamp, 2018). Key support workers may be used as proxy informants because they are familiar with the person with intellectual disability, which may give them more confidence to report about the person's life experiences and preferences (Cummins, 2002). Although researchers have examined self-proxy report agreement about social support, research has rarely focused on other dimensions of family relationships, despite the fact that family has a significant role in the lives of people with intellectual disability (Bigby & Fyffe, 2012). We were not able to find studies comparing self-reports about family relationships with staff proxy-reports, but there has been research comparing how people with intellectual disability viewed their family networks with family members' views. Widmer et al. (2010) compared the perceptions of people with intellectual disability and psychiatric disorders and their family members on the family relationships of the individuals with intellectual disability. The family networks were measured using the Family Network Method (FNM) to assess the characteristics of the family network and the perceived emotional support within the whole family network (Widmer et al., 2013). Widmer et al. (2010) found that both respondent groups perceived that the person with intellectual disability both received and gave emotional support in their family network. However, family members thought the individuals had smaller family networks and less emotional support within the family network than did the participants with intellectual disability themselves.

The FNM was adapted by Giesbers et al. (2019) into the Family Network Method – Intellectual Disability (FNM-ID) to measure family networks of people with intellectual disability and to estimate relationships among all the family members in terms of reciprocal emotional support. The term emotional support refers to love and caring, sympathy and understanding, and/or esteem and value from others (Thoits, 1995). As the FNM-ID can be completed by different stakeholders, including people with intellectual disability themselves, professionals and family, the aim of this study was to examine if support staff's own views agree with people's own views about their family networks.

In existing research on staff as proxies and self-reports on personal experiences and perspectives of people with intellectual disability, differences have been noted but the factors that might contribute to, or are associated with, divergence or convergence of ratings have hardly been examined. We found one study of Schmidt et al. (2010) which showed it was possible to predict the differences between perspectives on QoL of people with intellectual disability and proxies (relative or support worker) by two variables. First, when the proxy knew the individual with intellectual disability well, their perspectives on QoL were more similar. Second, when the severity of disability was higher (measured with the World Health Organization Disability Assessment Schedule; Üstün & World Health Organization, 2010), the smaller were the differences between the individual with intellectual disability and the proxy report.

The second aim of the current study was to consider individual characteristics or factors, which might make it more or less difficult for support staff to develop insight into people's perspectives regarding their family networks. Four factors were selected: gender, living situation, mental health, and challenging behaviour. Gender was selected because men tend to hold more instrumental attitudes, whereas women hold more emotionally responsive attitudes, and seem to disclose emotions more easily (Bakker et al., 2002; Ogus et al., 1990). Thus, females with intellectual disability may share more emotional information with support staff, potentially making staff better informed.

Living situation was included because this may have influence on the amount of support a person receives. We included participants who lived more independently in the community, in group homes or clusters of apartments with outreach support for a part of each day but where support staff were available at other times if necessary. We also included participants who lived in a residential facility, a site with multiple group homes for people with intellectual disability, and where support staff present all the time. This has implications for the frequency of contact someone has with support staff. When people have regular contact with each other, and know each other for a longer period, proxies seem to be better able to act as a proxy reporter (Schmidt et al., 2010).

Mental health and challenging behaviour were included as possible correlates of divergence in perspectives because both factors may affect the relationship between the individual and their support staff. Challenging behaviour of people with intellectual disability towards support staff or themselves can raise strong feelings for support staff, such as annoyance, anger, fear, sadness, and despair (Hastings & Remington, 1995; Bromley & Emerson, 1995). These unpleasant feelings may lead to avoidance and a depersonalised attitude towards people with intellectual disability and challenging behaviour (Hastings & Brown, 2002; Mitchell & Hastings, 2001). Therefore, challenging behaviour may be associated with a more distant relationship between the support worker and the individual with intellectual disability, which might adversely affect staff knowledge of the individual's family relationships. Alternatively, support staff and family may work more closely together in the support of individuals with intellectual disability and challenging behaviour. Family members may, for example, provide support staff with information about changes in the behaviour of their relative (Bright et al., 2018). Family members might also be involved in assessing risks and organising visits home. This closer collaboration could contribute to a better understanding of the family networks by support staff. Mental health issues can also lead to avoidant or stigmatising behaviour from professionals towards people with intellectual disability (Araten-Bergman & Werner, 2017; Ouellette-Kuntz et al., 2003), which may also affect the closeness of the relationship between an individual with intellectual disability and their support worker and divergence in perspectives about family support.

In the current study, the perspectives of people with intellectual disability and their key support workers on the family networks of people with intellectual disability were compared. We explored: (1) the characteristics of the family networks of people with intellectual disability, by examining both their own perspective and the perspective of their key support workers using an adapted version of Widmer's (Widmer et al., 2013) Family Network Method (the FNM-ID; Giesbers et al., 2019), and (2) divergence in perceptions of the person with intellectual disability and their key support worker associated with the presence of internalising and/or externalising behaviour problems, challenging behaviour, gender, and the person's living arrangement.

Method

Participants

Participants were people with mild intellectual disability (IQ 50-70; *n* = 138) and their key support workers (*n* = 138). The participants with mild intellectual disability ranged in age between 18 and 40 years (*M* = 28.2 years; *SD* = 6.14). Most of the participants had a Dutch cultural background (*n* = 127, 92.0%), 78 were male (56.5%), and 62 (44.9%) were officially diagnosed by a certified clinician with a psychiatric or developmental disorder, with autism the most common category (*n* = 33, 24.1%). Most of the participants lived in a facility in the community (*n* = 116, 84.1%), the others lived in a residential facility (*n* = 22, 15.9%). Most of the support workers taking part were female (81.2%) and their mean age was 41.9 years (range 23–63 years). The mean length of time that support workers had been working in care was 18.6 years (range 3-45), and 128 participants (92.8%) had received specific training in the field of social work or health care, 82 participants (64.1%) of whom had intermediate vocational training (education which focuses on necessary knowledge and skills for a chosen occupation) and 46 participants (35.9%) of whom had a higher professional education and training (education which focusses on theoretical and practical training or focus on training in academic disciplines).

Measures

Family Networks

To measure support in the family networks of people with mild intellectual disability the Family Network Method – Intellectual Disability (FNM-ID; Giesbers et al., 2019) was used. The FNM-ID maps the significant family network and is used to estimate relationships among all the family members in terms of reciprocal emotional support. Participants with mild intellectual disability as well as their staff member were individually asked about their perception of the family support network of the individual with mild intellectual disability.

For this study, we used four steps from the FNM-ID. The first step is to map the family network of the person with intellectual disability. Participants were asked to provide a list of all individuals whom they considered to be a family member to the person with intellectual disability. The term “family” was deliberately left undefined to identify the participants’ personal definition of family. The second step was to make a selection of family members who were considered to be significant to the participant with intellectual disability from all the listed family members. In the third step, the participant was asked which family members provide support when the participant with intellectual disability feels “out of sorts”. They can make a selection from all the listed family members in step one. In the final step of the method, demographic information (e.g., age, gender, nature of the family tie) on each listed family member were collected.

Cognitive Ability

Because IQ scores of the participant were often missing, or obtained using unidentified or outdated IQ tests, a brief screening was carried out to check whether a participant met the inclusion criteria of mild intellectual disability. No Dutch Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler, 2011) was available, and so two subtests (Vocabulary and Matrix Reasoning) of the Dutch Wechsler Adult Intelligence Scale (WAISIV-NL; Wechsler, 2012) were administered. These two WAIS-IV-NL subtests correspond with the two-subtest form of the WASI-II. An estimation of IQ scores was made based on the subtest standard scores of the two WAIS-IV subtests. A participant was excluded from the study when both WAIS-IV-NL standard sub-test scores were indicative of a level of cognitive ability above or below the mild intellectual disability range (taking the standard error into account). Participants who scored in the intellectual disability range on only one subtest were included in the study, because people with intellectual disability often have a varied intelligence profile.

Behavioural and Emotional Problems

The Adult Behaviour Checklist (ABCL; Achenbach & Rescorla, 2003) was used to measure behavioural and emotional problems. This questionnaire examines a broad range of behavioural and emotional problems: anxious/depressed, attention problems, withdrawn, aggressive behaviour, somatic complaints, rule-breaking behaviour, thought problems, intrusive. In the current study, we used the scores concerning internalising behaviour (i.e., anxious/depressive problems, somatic complaints, and withdrawn behaviour) and externalising behaviour (aggressive behaviour, rule-breaking behaviour, and intrusive behaviour). The ABCL was completed by a proxy informant; the key support workers. Key support workers were asked to rate how the items had been of the participants over the past 6 months. A 3-point response scale was used, "not true" (0), "somewhat or sometimes true" (1), and "very true or often true" (2). Tenneij and Koot (2007) found that the internal consistency coefficient Cronbach's alpha of the ABCL scales, for people with intellectual disability, ranged from 0.69 to 0.95 (mean alpha = 0.84). Furthermore, they showed that the inter-rater reliability, assessed by the intra class correlation coefficient, ranged from 0.57 to 0.76 (mean = 0.68).

Behaviour Problems Inventory

The Behaviour Problems Inventory-01 (BPI-01) is a questionnaire that was designed to assess challenging behaviours in individuals with intellectual disability. The items fall into one of three subscales: Self-Injurious Behaviour (14 items), Stereotyped Behaviour (24 items), and Aggressive/Destructive Behaviour (11 items). Each item is rated on a frequency scale (0 = never to 4 = hourly), and a severity scale (0 = no problem to 3 = severe problem; Rojahn et al., 2001). In the current study, a working definition of challenging behaviour was used to determine if a participant with intellectual disability had shown significant challenging behaviour during the past two months (Bowring et al., 2017). For the working definition, self-injurious behaviour was determined as challenging if any related item was rated as severe and as occurring at least weekly, or when any related item was rated as moderate but had occurred at least daily. Aggressive–destructive behaviour was determined as challenging either if items were rated as severe and occurred at least weekly, or when the items were rated as moderate but occurred at least daily. Stereotyped behaviour was determined to be challenging if the behaviour occurred at the highest rated frequency (hourly). Participants were then categorised in terms of whether they showed any significant challenging behaviour (one or more of Self-injurious, Aggressive–destructive behaviour, or Stereotypy) or no significant challenging behaviour.

The Dutch version of the BPI-01 has good psychometric properties based on frequency scores. The internal consistency of the total scale as well as of two out of three subscales is good. The internal consistency for the total BPI-01 scale was .89 and for the subscales: Self-Injurious Behaviour .63, Stereotyped Behaviour .85, and Aggressive/Destructive Behaviour .88 (Dumont et al., 2014). Good intra-class correlations were found for the total scale as well as the subscales of the Dutch version of the BPI-01; the items in the same group resemble each other. The total scale was .93 ($p < .05$), intra-class correlations for the subscales were: Self-Injurious Behaviour .86 ($p < .05$), Stereotyped Behaviour .90 ($p < .05$), and Aggressive/Destructive behaviour .93 ($p < .05$) (Dumont et al., 2014).

Procedure

Approval was provided by the Ethics Committee of Tilburg University (EC-2015.46). A stratified sampling procedure was carried out within five service providers that offer long-term care to individuals with intellectual disability in the Netherlands. First, the total number of people with mild intellectual disability who met the inclusion criteria was identified for each service provider. Inclusion criteria to participate in the study were: (1) aged 18–40 years, (2) mild intellectual disability (IQ 50–70), and (3) receiving professional support at least once a week for at least 6 months. The limit for inclusion was set at 40 years old, since parents of older individuals with intellectual disability are likely to be elderly and less able to provide support (Bigby, 2008), potentially influencing the study findings. Then, a randomly selected sample of 10% of each service provider was drawn from individuals who met inclusion criteria. Because the group of selected individuals who met inclusion criteria differed in size per service provider, the number of selected participants per service provider varied from 14 to 50.

Participants with mild intellectual disability were approached in consultation with their key support workers. In total, key support workers of the 354 selected individuals with mild intellectual disability were contacted by telephone. During this telephone call the aim and procedure of the study were explained and the researcher did an extra check of the inclusion criteria. An information letter about the study was sent to the key support worker and they were asked to discuss the letter with the selected individual with mild intellectual disability if they wanted to participate in the study. The letter contained information about the aim of the study, the financial reward for participation (ten euro cash), and confidentiality of the data. One hundred and fifty people with mild intellectual disability (42.4%) agreed to take part in the study. The main reason for non-participation was that participants were not interested in taking part in the study (57.4%). In some cases (32.4%), the support worker and/or psychologist advised against participation in the study (e.g., because it was expected that talking about the family would be too demanding). The researchers always checked with key support workers if an individual with mild intellectual disability did not have the capacity to decide about participating in the study. Some participants had a legal guardian under Dutch law (a parent or professional) who was then legally empowered to make decisions for the individual with mild intellectual disability. When inviting people with mild intellectual disability to participate in the study, a small group (10.3%) did not participate because their relatives or guardians did not give permission. Legally, we had to comply with the guardian's decision.

An appointment was made to meet with those who agreed to take part in the study. Depending on the participants' preference, the interviews were administered at the participants' home or at an office of the service provider. The first and the fifth author and a research assistant (all psychologists), were qualified to administer all included measures. They carried out the face-to-face interviews, which usually took between 45 min and 1 h. Nine times (6.0% of the cases) a second appointment was necessary to complete the interview, due to concentration difficulties. To put the participant at ease, the interview always started with small talk. Next, a standard consent procedure was followed to make sure the participant was able to give consent (Arscott et al., 1998). After explaining the research project to the participant (both written and verbally), the researcher determined whether the participant could recall the information by asking them five questions: (i) What will I be talking to you about?, (ii) How many times will I be talking to you?, (iii) Are there any good things about talking to me?, (iv) Are there any bad things about talking to me?, (v) What can you do if you decide that you do not want to talk to me anymore? If the participant was unable to answer the questions, the researcher gave further explanations using more accessible language until the participant had an understanding of the key elements of the study. Once consent was obtained, the WAIS-IV subtests were administered. Then, demographic information about the participant was obtained. The researcher read each item out loud and the participant replied verbally or typed the answer into a computer (when the participant replied verbally, the researcher typed the response into a computer). Then, data about the family network of the participant were collected using the FNM-ID, following the interview protocol described earlier. When the participant gave permission, this part of the data collection was audio recorded, to ensure all data were captured.

With the consent of participants, the researcher also planned an interview with the key support worker. Key support workers were visited individually for 45–60 min. After informed consent was obtained, key support workers were questioned using the FNM-ID about their perceptions of the family network of the person with intellectual disability. Then, the ABCL and BPI-01were computer- administrated. Proxy-report were used here instead of self-report to reduce the demand placed on participants with mild intellectual disability. Additional information about officially diagnosed psychiatric or developmental disorders according to file records were obtained. These records were checked by the key support workers and reported to the researcher. If necessary, the psychologist was contacted as well to provide additional confirmation. Key demographic information about the key support worker was collected as well.

The current study only included data from dyads of participants with mild intellectual disability and their key support workers. Data from nine participants with intellectual disability were excluded from the study because their IQ scores indicated that their cognitive abilities were above or below the mild intellectual disability range. In addition, data from the FNM-ID for one participant were excluded from the study; scores on all but one measures were found to be extreme outliers (3SDs or more above the mean). Therefore, 138 complete dyads of people with mild intellectual disability and key support workers were included in the current analysis.

Data analysis

The family network data were entered into Excel. Subsequently, the Excel files were imported in Statnet a software package of R (R Core Team, 2011) to calculate the social network measures (Handcock et al., 2016). For both groups, people with intellectual disability and the key support workers, the social network measures were calculated separately. A selection of social network measures was made, based on the social capital theoretical framework (Sapin et al., 2016; Widmer, et al., 2010). First, the *size* of a network was calculated, so the number of family members within the network of the participant. In this study, both the total size of the family network and the size of the selection of "significant" members were used. Furthermore, the measures *in-degree* and *out-degree* were calculated. These represent how many relationships with received (in-degree) or given (out-degree) emotional support the person with intellectual disability had with other family members (Giesbers et al., 2019). We also calculated what proportion of the emotionally supportive relationships consisted of reciprocal support (*dyad reciprocity*; Hanneman & Riddle, 2005). Last, the *composition* of the total family network was summarized in terms of the number per type of relationship which were listed during the interviews. For example, a participant listed two parents, one sibling and two professionals.

In the second phase of data analysis, the network measures were exported to SPSS and paired samples *t*-tests were conducted to examine differences in the characteristics of the family networks perceived by the participants with intellectual disability and their key support workers. A standardized mean difference effect size for paired designs, *d* was calculated using *t[2(1–r)/n]1/2* (Dunlap et al., 1996). A conservative value of 0.80 was used to estimate *r* in that equation.

In the third phase of data analysis, dyad difference scores were calculated for four measures that revealed significant differences at the second step (i.e., size of the family network, size of the significant family members within the family network, and in- and out-degree). Because individual scores within a dyad are nested data involving two levels (individual – dyad) (Gonzalez & Griffin, 2012), difference scores were only used at the dyadic level of the analysis. Then, factors that may account for different perceptions between participants with intellectual disability and their key support workers on divergent network measures were examined using multiple regression analyses with the dyad's difference score of the network measures as the dependent variable. The predictors for each regression model were the gender of the participant with intellectual disability, the living situation (residential or community), whether the person had at least one significant challenging behaviour, and the level of internalising and externalising behaviour. As it is not assumed that all dyads have the same mean, therefore, the mean score of the dyad on the dependent variable was included as a predictor, to correct for different dyad mean scores. This approach is called the residual change approach (Castro-Schilo & Grimm, 2018).

Results

Group differences in network perception

Paired samples *t*-tests were conducted to examine differences in the characteristics of the family networks perceived by the participants with mild intellectual disability and staff members. The results show significant differences on four out of five network measures.

Network measures

Participants with mild intellectual disability perceived both their total family networks, *t*(137) = –7.20, *p* = <.001, and their significant family networks, *t*(137) = –5.88, *p* = <.001, to be larger in size than did staff members (table 1). Both results have small effect size.

Table 1

Mean Numbers of the Network Measures for Participants, t, df, p, d

	Variable	**Mean (*SD*)**		***t***	***p***	***d***
		Individuals with intellectual disability	**Staff members**			
Full network	Size	9.98 (6.28)	6.28 (2.98)	-7.20	< .001	-0.388
Significant network	Size	7.18 (4.86)	4.96 (2.24)	-5.88	< .001	-0.317
Measures for individuals with intellectual disability	In-degree	2.34 (1.60)	1.59 (1.07)	-4.77	< .001	-0.257
	Out-degree	2.37 (3.54)	1.46 (1.83)	-2.80	<.006	-0.151
	Dyad-Reciprocity	0.29 (0.33)	0.33 (0.38)	-0.99	.322	-0.053

Individual network measures

Significant differences were found between the perceptions of participants with mild intellectual disability and key support workers in the amount of support. Participants with mild intellectual disability perceived that they had more relationships with family members in which they received support (i.e., in-degree), than staff members perceived, *t*(137) = –4.77, *p* = <.001. This also applied to the perceived given support (i.e., out-degree) by the participant with mild intellectual disability, *t*(137) = –2.80, *p* = .006. All the significant differences for the individual network measures were associated with a small effect size. No significant group differences were found in the perceptions of the reciprocity of the family relationships of participants with mild intellectual disability, *t*(137) = 0.99, *p* = .322.

Composition of family networks

Differences in the perspectives of people with intellectual disability and key support workers on the total size of the family networks were analysed in more detail, by comparing the different types and numbers of listed family members. Table 2 presents the number of relationships per type of the relationship, as listed per group of participants. The results show that the significant difference in full network size may be attributed primarily to two types of relationships. Participants with mild intellectual disability listed more extended family, *t*(137) = –7.21, *p* = <.001, and family members in-law, *t*(137) = –2.25, *p* = .026, than did key support workers, both associated with a small effect size. Both participant groups listed the same number of children in the family networks.

Table 2

Number of Listed Relationships in the Family Network, t, df, p, d

	Mean (*SD*)		***t***	***p***	***d***
Type of relationship	**Individuals with intellectual disability**	**Support staff**			
Partner	0.13 (0.34)	0.11 (0.31)	-1.00	.319	-0.054
Parent	1.56 (0.60)	1.59 (0.58)	-1.07	.287	-0.058
Child	0.02 (0.15)	0.02 (0.15)	#	#	
Sibling	1.59 (1.24)	1.46 (1.16)	-1.57	.120	-0.085
Extended family	4.59 (5.27)	1.51 (1.67)	-7.21	< .001	-0.388
Family in-law	0.68 (1.10)	0.48 (0.95)	-2.25	.026	-0.121
Step family	0.48 (1.12)	0.39 (0.76)	-1.03	.305	-0.021
Foster family	0.36 (1.96)	0.25 (1.58)	-0.81	.421	-0.019
Friends	0.21 (0.64)	0.11 (0.41)	-1.66	.099	-0.089
Professionals	0.10 (0.54)	0.12 (0.59)	-0.36	.723	-0.019
Volunteer	0.08 (0.70)	0.06 (0.38)	-0.69	.493	-0.037
Other	0.18 (0.61)	0.17 (0.54)	-0.13	.897	-0.007

The *t* and *p* value could not be computed because the standard error of the difference is 0.

Correlates of divergence

To examine the differences in perceptions on the family network (table 1) between people with mild intellectual disability and their key support workers, multiple regression analyses were conducted with possible predictors. Multiple regression models for total size of the family networks, *F*(6, 131) = 18.420, *p* = <.001, R^2 = .46, the number of significant members in the family networks, *F*(6, 131) = 22.76, *p* = < .001, R^2 = .51, the amount of in-degree, *F*(6, 131) = 5.54, *p* = <.001, R^2 = .20, and out-degree *F*(6, 131) = 11.58, *p* = < .001, R^2 = .35 were statistically significant overall.

Examining the possible predictors in more detail, for all four network measures the dyad's mean score added statistically to the prediction (table 3). For all network measures, a higher score on the dyadic mean score was associated with a larger difference in perspective on the network measure. This means, for example, that when the participant with mild intellectual disability listed more family members (total size) the chance that the key support worker did not list all the same family members increased. The differences between the perceptions of people with intellectual disability and key support workers are larger when family sizes increased. The same applied for the number of significant family members. When participants with mild intellectual disability thought they received (in-degree) support from more family members, it was more likely that key support workers listed fewer family members who were supportive. This was also the case for the perceived given support (out-degree).

Another notable result was that proportionally more predictors were significant for the differences in perspectives on the size of the significant family network. When participants with intellectual disability lived in a group home or apartment located in the community with full time staffing support, staff were more likely to agree who they considered as significant family members, as compared to key support workers for people with intellectual disability living in more segregated, residential settings. When the individual with mild intellectual disability showed more externalising behaviour, the differences in the number of listed significant family members between people with mild intellectual disability and support key workers became larger. People with intellectual disability listed more significant family members than did support key workers. When the individual with mild intellectual disability showed more internalising behaviour, the differences in the number of listed significant family members by people with mild intellectual disability and staff members became smaller.

Table 3
Summary of Multiple Regression Analyses for Variables Predicting Dyad's Difference Scores

	Size total (n =138)			**Size significant (n =138)**			**In-degree (n = 138)**			**Out-degree (n = 138)**		
Variable	***B (SE)***	***t***	***p***	***B (SE)***	***t***	***p***	***B (SE)***	***t***	***p***	***B (SE)***	***t***	***p***
Gender	-0.183 (0.815)	-0.224	.823	-0.043 (0.568)	-0.077	.939	-0.180 (0.305)	-0.592	.555	-0.095 (0.562)	-0.169	.866
Living setting	1.556 (1.103)	1.410	.161	1.608 (0.769)	2.091	.038	0.238 (0.412)	0.579	.564	0.867 (0.767)	1.129	.261
Challenging behaviour	-1.309 (0.953)	-1.374	.172	-0.591 (0.666)	-0.888	.376	-0.830 (0.356)	-2.333	.021	-0.121 (0.668)	-0.182	.856
Internalising behaviour	-0.085 (0.050)	-1.694	.093	-0.080 (0.035)	-2.279	.024	-0.025 (0.019)	-1.333	.185	0.015 (0.035)	0.431	.667
Externalising behaviour	0.029 (0.041)	0.704	.482	0.065 (0.029)	2.231	.027	0.027 (0.016)	1.723	.087	-0.021 (0.029)	-0.715	.476
Dyadic Mean Score	1.010 (0.100)	10.064	.000	0.980 (0.089)	11.059	.000	0.667 (0.148)	-4.503	.000	1.067 (0.135)	7.907	.000

Note. Constant = -3.27 (Size total), 0.98 (Size significant), -0.35 (In-degree), -1.08 (Out-degree)

Discussion

The results of the present study showed that people with mild intellectual disability perceived their family networks to be larger and to provide more support than their key support workers did. These findings suggest that there is some divergence in the perspectives of people with mild intellectual disability and key support workers about the characteristics and the support in family networks. There was notable disagreement about extended family members (e.g., aunts, uncles, nieces) and family in-law (typically partners of the brothers and sisters of the person with mild intellectual disability). People with intellectual disability and key support workers reported similar numbers of nuclear family (partner, parents, children, siblings). Extended and step family members may be less visible for key support workers, although people with intellectual disability consider them as significant. In fact, the current study explicitly allowed people with intellectual disability to define their significant family themselves. The fact that support workers did not know about (or potentially did not recognize) the importance of extended family suggests that they could be made more aware of extended family and consider relationships with extended family as a way to improve the social networks of people with intellectual disability.

An explanation for the differences in listed family members might be that people with mild intellectual disability typically meet members of those two family groups outside the context of the service provider (e.g., at the homes of their parents or of their brother or sister). We only included participants who lived apart from their family in long-term care. Therefore, support workers may not have an opportunity to meet all the family members of individuals they support, which may make it more difficult to provide a complete proxy-report using the FNM-ID. This suggestion is also in line with the findings of Scott and Havercamp's (2018) research: staff members felt ill-equipped to rate the relationships of people with intellectual disability as they stated they were unaware of friendships/intimate relationships or had never seen the person interact with a friend/ significant other. The results of this study seem to confirm this assumption, as participants who resided in a residential facility differed more from their support workers' perspectives regarding significant family members, than participants who lived in a community setting. Given that we examined other predictors of divergence in perspectives (including several service user factors), the setting effect might be related to the fact that key support workers who work in residential facilities have less insight into significant other family members, perhaps because families visit and contact their relative with intellectual disability less. There may also have been other characteristics of the people with intellectual disability associated with this setting difference that were not measured in the current study. All of these possibilities could be explored in future research.

Another finding was that the participants with mild intellectual disability estimated that they were more emotionally supportive to family members and received more emotional support from their family members than their support key workers estimated. This might indicate that the validity or accuracy of the key support workers when reporting on the emotional support in family networks of people with mild intellectual disability is questionable. A potential other explanation for these different perspectives might be that a positive illusory bias inflated the self-perceptions of people with intellectual disability. Earlier research showed that people with intellectual disability may be at risk of greater biases in perceptions of social relationships because other individuals' feelings are often misunderstood (Lavin & Doka, 1999). This is in line with Lunsky and Benson's (2001) research, which found that people with mild intellectual disability had difficulties with interpreting social situations as well as the emotions of others. Based on video vignettes, 50 people with intellectual disability were asked to interpret different social situations. The results suggested that interpretations of social support were based in part on prior conceptions about social support. For example, people who perceived their own support as low and also reported high levels of loneliness, rated the video vignettes as less supportive than people who viewed their own situations more positively. In addition, people with intellectual disability rated the video vignettes more positively than did the 40 support members who also participated in the study. Another hypothesis for this putative self-inflated perception of people with mild intellectual disability might be that it is difficult to admit that their social networks are small, or they might feel lonely. It may serve a self-protective function; helping to maintain a positive self-image. Such a function has been observed in children with externalizing behaviour problems, who tend to inflate their status in, and the quality of, social relationships with both peers and family members (Barry, 2011). Nonetheless, social networks can be conceptualized as cognitive structures, based on the assumption that "perceptions are real in their consequences, even if they do not map one-to-one onto observed behaviours" (Krackhardt, 1987, p. 128).

The difference in the perceived number of significant family members, between people with mild intellectual disability and their key support workers, was found to be related to the internalising and externalising behaviour of the person with mild intellectual disability. That is, the difference in perspectives became larger when the person with mild intellectual disability showed higher levels of externalising behaviour. In contrast, the differences in perspectives reduced when the person with mild intellectual disability showed higher levels of internalising behaviour. An explanation for these differences might be that support staff develop different attitudes towards people with externalising versus internalising behaviour (Van Dam et al., 2011). Previous research has shown that support staff had a warmer and more supportive attitude towards people with internalizing problems, and a more structured and controlling attitude towards adolescents with externalizing problems (Van Dam et al., 2011). A supportive attitude towards people with internalising behaviour might lead to a better understanding of individuals' needs and wishes, and a greater awareness of their supportive social relationships. When staff are more focussed on controlling the (externalising) behaviour of the person with intellectual disability, they might have less insight into the nature of their social support. It may also be the case that people with a mild intellectual disability who display externalising behaviour have fewer mutually supportive relationship than their peers. Limited emotional support might be a result as well as a cause of externalising behaviour (Schuiringa et al., 2015). However, this pattern was not found in our study. Moreover, challenging behaviour predicted more agreement about the emotional support received from family members. The higher level of agreement could be due to the fact that the measure of challenging behaviour includes self-injurious behaviour and stereotyped behaviour (cf. externalising behaviour). In contrast to aggression, self-injurious and stereotyped behaviour pose less threat to staff and evoke more sympathy and understanding (Noone et al., 2006).

Some limitations with the current study need to be discussed as they relate to the generalizability of the current findings. First, only 42.4% (*n* = 150) of the randomly selected people who met the inclusion criteria agreed to take part in the study, so there is a risk of non-response bias. Unfortunately, no data were available for the non-respondents, and so biases in the sample selection cannot be quantified. Second, all participants lived in a facility managed by a service provider where they received regular staff support (from a few visits each week to 24/7 support). Future research should address the perceptions of individuals with mild intellectual disability who live independently at their own home, with and without support. Furthermore, a distinction can be made between emotional and instrumental support. This study focused on emotional support, as it has been found to be a stronger predictor for physical and mental health-related outcomes (Berkman, 1995; Thoits, 1995). It would be useful in future research to also look at perspectives on instrumental support in family networks.

There are several findings from the current study that add to our understanding of how people with mild intellectual disability perceive the emotional support in their family networks compared to the perceptions of their key support workers. In particular, we contributed to literature suggesting that the perspectives of staff and people with intellectual disability may differ but importantly we examined factors that might be associated with diverging perspectives. Support workers could become more aware that the living setting or the behaviour someone displays might bias their perspective on someone's family network and perceived emotional support. Divergence in perspectives might be detrimental because better informed support workers might be better able to support individuals with intellectual disability to maintain links between them and their family members. Second, support staff should be aware that people with intellectual disability might rate their social support differently than people without intellectual disability, due to their "support schemas" based on their previous experiences (Lunsky & Benson, 2001). Last, if key support workers are consulted as proxies for the FNM-ID measure specifically, the data should be interpreted with caution especially when key support workers have known the individual for a limited amount of time and/or see that person in one context only. Moreover, when self-report is not feasible, it may be useful to gather proxy reports from more than one source if possible, to obtain a fuller picture of the person's life and experiences.

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CHAPTER 7

Brief report: Family networks of people with mild intellectual disability with and without challenging behaviour

This chapter has been accepted for publication as:
Tournier, T., Hendriks, A. H. C., Jahoda, A., Hastings, R. P., & Embregts, P. J. C. M. (in press). Brief report: Family networks of people with mild intellectual disability with and without challenging behaviour. *Journal on Developmental Disabilities*.

Abstract

Differences in perceived emotional support in family networks of people with mild intellectual disability with and without challenging behaviour were explored by using a self-report measure. One hundred and thirty eight participants (78 men and 60 women, average age 28.2 years old) with mild intellectual disability were interviewed using the Family Network Method – Intellectual Disability to assess their emotionally supportive family relationships. The instrument maps the perceived emotional support among all the family members in the family networks of people with mild intellectual disability, with and without challenging behaviour. The results suggest that challenging behaviour may not be *strongly* associated with the family network characteristics and emotional support in family networks of people with mild intellectual disability. A few, and generally small, differences were found between the family networks of people with or without challenging behaviour. However, one moderate sized group difference was found: those with challenging behaviour reported less mutual support in their whole family network.

The informal support networks of people with intellectual disability mainly consist of family members (Forrester-Jones et al., 2006; Lippold & Burns, 2009; Van Asselt-Goverts et al., 2013). Family members have a significant role in the lives of people with intellectual disability (Binnendyk et al., 2009). Family relationships are usually typified by emotional closeness, unconditional love, and a long-term perspective (Bigby & Fyffe, 2012), and can therefore be a potent source of meaning in life and contribute to a sense of belonging (Krause, 2007; Lambert et al., 2010).

Family relationships are also important specifically for people with intellectual disability and challenging behaviour. Positive family relationships can provide them a sense of belonging and valued roles and relationships, for example as a sister or an aunt (Clarke et al., 2019). Thus, there is no reason to imagine that family would be any less important to individuals with challenging behaviour. However, the assumption behind the present research is that the family networks of people with mild intellectual disability and challenging behaviour may be different to the family networks of people with mild intellectual disability without challenging behaviour. For example, people with intellectual disability and challenging behaviour are more likely to live in services or secure accommodation that are distant from their family (Bigby, 2012; Robertson et al., 2001). Challenging behaviour of an individual with intellectual disability can also cause stress in family members (Hastings, 2002; Lecavalier et al., 2006), which might have impact on the quality of family relationships, and the family network (Greenberg, Seltzer et al., 2006; Orsmond et al., 2003). In addition, family members of individuals with challenging behaviour might avoid or reduce the time they spend engaged with the person with intellectual disability or engage in increased negative interactions (Floyd & Phillippe, 1993; Schuiringa et al., 2015), potentially leading to reduced relationship quality. Families of people with challenging behaviour may also become more socially isolated from others, including family members, because they feel limited where they can go with their child (Fox et al., 2002).

To our knowledge, there has been no research examining the family networks of people with mild intellectual disability and challenging behaviour, and certainly none based on self-reports. Self-reports and active participation in research for people with intellectual disability have been increased as they became more recognised as experts on their own lives, experiences and feelings (McDonald et al., 2013; Lunsky & Benson, 1997). In addition, there is a growing body of evidence that highlights the discrepancies between self- and proxy reports for subjective data (e.g. experienced stress or support) in the population of people with intellectual disability (Lunsky & Benson, 1997; Lunsky & Bramston, 2006; Scott & Havercamp, 2018; Tournier et al., 2020). Therefore, it is important to use self-report measures to examine subjective themes such as emotional support in family networks.

Researchers in the field of intellectual disability have mainly focused on the effects of singular aspects of social (including family) networks, such as total network size (Lippold

& Burns, 2009), or the amount of perceived support (Forrester-Jones et al., 2006). However, social networks are a significant source of social capital (Furstenberg & Kaplan, 2004). The social capital theory defines the possession of a durable social network as a source of socially supportive relationships (Bourdieu, 1986). From this theoretical perspective, when focusing only on singular dimensions of networks, one will fail to capture the multi-dimensional nature of networks (e.g. a dense network with many reciprocal supports; Fiori et al., 2006).

A social capital perspective can also be applied to family networks. An instrument that measures the multi-dimensional nature of family networks is the Family Network Method (FNM; Widmer et al., 2013). The FNM maps who participants consider to be their family members and assesses how they perceive the relationships between these family members (Widmer et al., 2013). To ensure the instrument was accessible for the use in the population of individuals who have a mild intellectual disability, the method was adapted by Giesbers et al. (2019) as the Family Network Method-Intellectual Disability (FNM-ID).

Therefore, the aim of the present study was to assess whether people with mild intellectual disability who have challenging behaviour perceive their family networks differently than those without challenging behaviour. We used the FNM-ID to gather data about the properties of family networks.

Method

Participants and Procedure

The participants were recruited to a large study examining people with mild intellectual disabilities' perceptions of their family networks (Giesbers et al., 2020). A stratified sampling procedure was used to recruit participants with mild intellectual disability within five service providers in the Netherlands. Inclusion criteria to participate in the study were: 1) age between 18 and 40 years; 2) mild intellectual disability; and 3) support at least once a week by paid support staff for at least 6 months. For each service facility, the total number of people with mild intellectual disability who met these inclusion criteria was determined. Then, per service provider, a sample of 10% of the population was selected for the study. In total, 138 participants (78 men and 60 women), with an average age of 28.2 years old (range: 18-40; *SD* = 6.16) participated in the study. The majority of participants lived more independently in the community (*n* = 116) in group homes or clusters of apartments with support for a part of each day, or where support staff were available at other times if necessary. The remaining participants (*n* = 22) lived in residential facilities (i.e., a site with multiple group homes for people with intellectual disability, and where support staff were present all the time).

Approval for the study was obtained by the Ethics Committee of Tilburg University (EC-2015.46). Data were collected by face-to-face interviews at the participants' homes, or at the service providers' offices. First, two WAIS-IV subtests (matrix reasoning and vocabulary) and a demographic information questionnaire were administered. The FNM-ID (Giesbers et al., 2019) was used to obtain the participants' descriptions of their family networks. Finally, demographic information was obtained. With the participants' consent, the researcher also completed the Behaviour Problems Inventory-01 (BPI-01; Rojahn et al., 2001) with their key worker (i.e. an appointed support worker who takes care of personal matters for the person with an intellectual disability, such as contact with family, organising an annual care review).

Measures

Family Networks

To measure the perception of people with mild intellectual disability about the support in their family networks, the FNM-ID (Giesbers et al., 2019) was used. The FNM-ID maps the family network and relationships among all the family members in terms of (reciprocal) emotional support and a variety of social network variables can be coded. The instrument was adapted based on thorough piloting, involving 19 participants with mild intellectual disability, and the FNM-ID was adjusted to meet the cognitive and linguistic needs of people with mild intellectual disability (Giesbers et al., 2019). The FNM-ID adopts a broader concept of family, that is, whom do people with mild intellectual disability themselves consider as family? Moreover, the measure maps the relationships among all family members (e.g., father – mother; mother – sister; grandpa – aunt). As a result, a broader understanding of the family context of structural interdependencies is obtained, which gives insight into how the relationships between people with mild intellectual disability and their family members are embedded (Widmer, 2016).

Challenging Behaviour

The Behaviour Problems Inventory-01 (BPI-01) is a questionnaire that was designed to assess challenging behaviours in individuals with intellectual disability. The items fall into one of three sub-scales: Self-Injurious Behaviour (SIB), Stereotyped Behaviour (SB), and Aggressive/Destructive Behaviour (ADB). Each item is rated on a frequency scale (0 = never to 4 = hourly), and a severity scale (0 = no problem to 3 = severe problem; Rojahn, et al., 2001). To operationalise the definition of the presence of challenging behaviour during the preceding two months, we used the working definition from a recent population-based study of challenging behaviour (Bowring et al., 2017). This working definition can be used to code challenging behaviour measured by the BPI-01. SIB is considered "challenging" when it is either rated as severe and occurs at least weekly, or when it is rated as moderate but occurs at least daily. ADB is "challenging" when it is either rated as severe and occurs at least weekly, or when it is rated as moderate but occurs at least daily. SB is considered "challenging" when it occurs at the highest rated frequency. Overall, challenging behaviour is present if at least one behaviour is defined as challenging according to these three definitions (Bowring et al., 2017). The Dutch version of the BPI-01 has good internal consistency reliability (Dumont et al., 2014). The internal consistency for the total BPI-01 scale was .89, and for the subscales Self-Injurious Behaviour .63; Stereotyped Behaviour .85; and Aggressive/Destructive Behaviour .88 (Dumont et al., 2014). The instrument has good intra-class correlations for the total scale as well as the subscales of the Dutch version of the BPI-01. The total scale was .93 ($p < .05$), intra-class correlations for the subscales were: Self-Injurious Behaviour .86 ($p < .05$), Stereotyped Behaviour .90 ($p < .05$), and Aggressive/Destructive behaviour .93 ($p < .05$) (Dumont et al., 2014).

Data analysis

The UCINET software package (version 6.623) was used to analyse the family network data (Borgatti et al., 2002). Several social network measures were derived, based on the social capital theoretical framework (Sapin et al., 2016; Widmer et al., 2010), see table 1.

Table 1

Overview of the Computed Social Network Measures

Network measures	**Definition**
Size	The number of family members within the participant's network. Participants were invited to list all people whom they considered as family, even if they were not an official family member (e.g. friends, staff).
Size of significant family members	A sub-set of the total family size measure: family members who have played a role in their life in the past year.
Density	The number of connections between family members compared to the maximum possible numbers of connections that could exist between all the family members.
Arc reciprocity	The proportion of emotional supportive relationships in the whole family network which are reciprocal. In other words, how many family members have supportive relationships that are reciprocal?
Dyad reciprocity	The proportion of emotional supportive relationships of the individual with intellectual disability, which are reciprocal. For example, a score of .5 means that a person receives support from two people and support one of these people him/herself.
In-degree	The number of family members who provide emotional support to the individual with intellectual disability.
Out-degree	The number of family members who receive emotional support from the individual with intellectual disability.
One step outreach centrality	The number of distinct family members within one link of the individual with intellectual disability. This means how many other people a given person can reach in one step in their family network.

Network measures were exported to SPSS-24 and independent samples *t*-tests were conducted to examine differences in the characteristics of the family networks perceived by the participants with mild intellectual disability with and without challenging behaviour. The Cohen's *d* effect size was calculated using $(M_1 - M_2)/[S^2_{pooled}]$ (Cohen, 1988).

Results

Thirty-six participants (26.3%) met the definition for having challenging behaviour. Table 2 presents the demographic characteristics per subgroup.

Table 3 summarises group differences and the results of independent samples *t*-tests comparing FNM-ID scores. Participants with challenging behaviour had lower scores on all network variables, though all differences bar one were non-significant and the effect sizes were negligible to small. One statistically significant difference did emerge: reciprocal emotional support in the whole family network of participants with challenging behaviour (arc reciprocity) was lower compared to participants without challenging behaviour with a moderate effect size (M =.39, SD = .34, p =.013, d = 0.47).

Table 2

Demographics of Participants per Subgroup

Variable		**Individuals without challenging behaviour *(n = 102)***		**Individuals with challenging behaviour *(n = 36)***	
		***n* (%)**	***M (SD)***	***n* (%)**	***M (SD)***
Sex	Male	59 (57.8)		19 (52.8)	
	Female	43 (42.2)		17 (47.2)	
Living situation	Community	90 (88.2)		26 (72.2)	
	Residential	12 (11.8)		10 (27.8)	
Cultural background	Dutch	93 (91.2)		34 (94.4)	
	Other	9 (8.8)		2 (5.6)	
Age in years			28.55 (6.07)		27.19 (6.32)

Table 3

Mean Scores for the Network Measures

		Mean *(SD)*		*t*	*p*	Cohen's *d*
	Variable	**Individuals without challenging behaviour *(n = 102)***	**Individuals with challenging behaviour *(n = 36)***			
Network measures - Full network	Size	10.30 (6.51)	9.06 (5.56)	1.03	.307	0.20
Network measures - Significant network	Size	7.42 (4.87)	6.50 (4.84)	0.98	.330	0.19
	Arc reciprocity	.54 (.29)	.39 (.34)	2.50	.013*	0.47
	Density	.37 (.24)	.34 (.23)	.57	.568	0.13
Individual measures - full network	In-degree	2.45 (1.66)	2.03 (1.38)	1.37	.174	0.28
	Out-degree	2.60 (3.87)	1.72 (2.25)	1.28	.202	0.28
	Dyad-Reciprocity	.29 (.32)	.26 (.34)	0.49	.627	0.09
Individual measures - significant network	One step outreach centrality	.37 (.38)	.29 (.36)	1.14	.258	0.22

Note. * $p < .05$

Discussion

In contrast to our initial expectations, the results suggest that there are only small differences between the family networks of people with mild intellectual disability with and without challenging behaviour. The impact of challenging behaviour on the quality of family relationships may not have substantial effect on the structure of family networks and emotional support within the family network as perceived by individuals with intellectual disability themselves. However, caution is needed in interpreting these findings due to the small sample size of participants with challenging behaviour, and the fact that all participants (with and without challenging behaviour) resided in a health care service supported by professionals and not in their family home. Future research should include a larger sample of people with intellectual disability and challenging behaviour, who also live with their family to investigate if our preliminary results are replicated.

One network measure differed significantly between the two groups, with a moderate effect size. Arc reciprocity, the mutual support between all the family members in the network, was reported as higher in the family networks of people with intellectual disability without challenging behaviour. This suggests that in the family networks of people with intellectual disability and challenging behaviour there is less reciprocal support. A potential reason for this difference might be that people with mild intellectual disability and challenging behaviour who live in a health care service are less aware about the emotional support family members provide to each other. They may be spending less time at their family home compared to people without challenging behaviour and therefore have less opportunity to witness the support between their family members. Widmer et al. (2010) suggested that witnessing broader family relationships affects the perceptions of people with intellectual disability. Relationships that were not directly connected to the participant with intellectual disability were not typically recognised by them. Another possible explanation for the finding is that less emotionally supportive wider family contexts may be associated with increased risks for challenging behaviour (McPherson et al., 2014). Without replication and further exploration, these competing explanations cannot be reconciled.

Whatever the direction of association, maintaining positive family relationships is likely to be beneficial for the quality of life of people with intellectual disability and challenging behaviour (Clarke, et al., 2019). Therefore, it can be valuable for support staff to assist people with intellectual disability and challenging behaviour with developing, maintaining, and enhancing their family relationships. Providing emotional support to others might also be valuable for people with intellectual disability and challenging behaviour; it may enhance feelings of self-worth and self-esteem (Forrester-Jones & Barnes, 2008; Liang et al., 2001). Finally, a better balance between given and received emotional support might be beneficial for people with intellectual disability and challenging behaviour. Earlier research outside of the field of intellectual disability showed that an over-benefited position (with more received than given support) may lead to a less positive outcome in terms of mental health and well-being than an under-benefited position (Fyrand, 2010; Thomas, 2010).

Key Messages from this Article

People with Disabilities. Whatever your support needs, staff in services should help you to have the positive relationships with your family members that you want to. It is good to be able to help people in your family as much as they help you.

Professionals. People with mild intellectual disability and challenging behaviour perceive that the quality of their family relationships is quite similar to those of people without challenging behaviour. It is important not to assume that challenging behaviour always makes life worse for people with intellectual disability.

Policymakers. Given the importance of increasing social capital to support everyone's well-being, it is likely to be important to promote mutually supportive family relationships for people with challenging behaviour.

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CHAPTER 8

8

Family network typologies of adults with intellectual disability: Associations with psychological outcomes

This chapter has been published as:
Tournier, T., Hendriks, A. H. C., Jahoda, A., Hastings, R. P., Giesbers, S. A. H., Vermulst, A. A., & Embregts, P. J. C. M. (2021). Family network typologies of adults with intellectual disability: Associations with psychological outcomes. *Journal of Applied Research in Intellectual Disabilities 34*(1), 65-76. https://doi.org/10.1111/jar.12786

Abstract

Background

Based on self-reported social capital, different typologies of family networks of people with intellectual disabilities were examined. Associations between behavioural and emotional problems or well-being and typologies were investigated.

Method

137 participants with mild intellectual disability were interviewed using the Family Network Method-Intellectual Disability to assess their emotionally supportive family relationships. Data on participants' well-being and behavioural and emotional problems were also gathered. Latent class analysis was used to identify family typologies based on social network measures.

Results

Four distinguishable typologies were identified, two supportive and two less supportive. A small association was found with behavioural and emotional problems and one of the supportive typologies. Associations with constructs of well-being were found for both supportive and less supportive typologies.

Conclusions

A variety of family types were found, with implications for sensitive professional support.

Supportive social relationships, including those of family, may have a positive influence on health and well-being of people with and without intellectual disabilities (Antonucci, 2001; Scott & Havercamp, 2018). Relationships serve many functions, including providing an outlet for frustrations and fears and giving assistance and encouragement in times of difficulty (Scott & Havercamp, 2014). In the field of intellectual disability, researchers have examined the association between various outcomes and social networks, mainly analysing the effects of particular aspects of a social network such as total network size (Lippold & Burns, 2009) and the amount of perceived support (Forrester-Jones et al., 2006). However, the structures in which these social relationships are embedded matters (Faber & Wasserman, 2002). The degree to which an individual is integrated into a broad social network is directly linked with well-being and mental health (Cohen & Wills, 1985; Sapin et al., 2016). As such, social networks are a significant source of social capital (Furstenberg & Kaplan, 2004). Social capital theory describes the possession of a durable social network as a source of socially supportive relationships (Bourdieu, 1986). Based on this theory, treating network characteristics as individual dimensions (e.g. size of a network) will fail to capture the multi-dimensional nature of networks (e.g. a dense network with many reciprocal supports; Fiori et al., 2006).

Most research about family networks of people with intellectual disability has only examined the person with an intellectual disability's view of their own relationships with other family members and not the (reciprocal) relations between all network members (Lippold & Burns, 2009; Robertson et al., 2001; Van Asselt-Goverts et al., 2013). There is a small qualitative literature about people with intellectual disabilities' perspectives on mutual care, between them and their family members. In one study (Walmsley, 1996), 22 adults with an intellectual disability were interviewed about their lives, and giving and receiving care. Results suggested that the participants did not view themselves as being dependent on family care. Instead, they saw themselves as having family roles which allowed for a sense of reciprocity and mutuality. Williams and Robinson (2001) compared the perspectives of 40 parents with those of 45 (young) adults with an intellectual disability. Based on the interviews, they found that many people with intellectual disabilities and their parents did not feel that there was mutual support. Parents generally defined themselves as carers who took responsibility and exercised control. Both of these studies suggest that a more holistic approach is required, taking into account the complex web of interdependence within families; a model that recognizes mutually supportive relationships and considers the resources needed by the whole family. To capture the multi-dimensional nature of family networks, approaches such as the Family Network Method are required (Widmer et al., 2013). The Family Network Method is an instrument that maps who the participant considers to be their family members. In addition, it assesses how the participant perceives the relationships between these family members (Widmer et al., 2013). This method has been adapted by Giesbers et al. (2019) as the Family

Network Method-Intellectual Disability (FNM-ID) to ensure it is accessible and meaningful for use in the population of individuals who have an intellectual disability.

Initial results using the FNM-ID showed that there is likely to be considerable variation in the perceived family networks of people with intellectual disabilities, in terms of size and (reciprocal) emotional support (Giesbers et al., 2020). Examining family typologies can have practical implications, as different types of families might require different professional support. There has been very little research about family network typologies in the field of intellectual disabilities. The few studies published have been focused on parents' perceptions instead of the perception of the person with intellectual disabilities themselves (Mink et al., 1984; Mink et al., 2002). One previous study did take the perspectives of people with intellectual disability into account, to identify typologies of their family networks. Widmer et al. (2013) explored the different family roles instead of the significant emotional support they provide. Widmer et al. (2013) performed a cluster analysis and described four family configurations: professional, kinship, nuclear and friendship family configurations. However, Widmer et al. (2013) did not distinguish who is providing or receiving emotional support to/from the person with intellectual disability, which is the essence of social capital (Bourdieu, 1986).

Given the lack of family network typology studies, based on self-reports of people with intellectual disabilities, the current study examined whether different typologies of perceived family networks can be distinguished in terms of emotional support. Previous research has also shown associations between dimensions of family-based social capital and the behaviour problems (McPherson et al., 2014) and living situation (Widmer et al., 2013) of people with intellectual disabilities. Therefore, a secondary aim of the current study was to examine associations between types of family networks and the personal characteristics of the individuals with intellectual disabilities, their behavioural and emotional problems, and their well-being.

Method

Participants

The 137 participants had a mean age of 28.2 years (*SD* = 6.16, range 18–40); 56.2% of the participants were male, 92.0% had a Dutch cultural background, and 44.9% were officially diagnosed by a certified clinician with a psychiatric or developmental disorder, with autism the most common category (24.1%). Most of the participants lived in a facility in the community (83.9%), and the others lived in a residential facility (see table 1). The mean age of staff was 41.96 years (range 23-63), 26 were male (19.0%), the average work experience was 18.62 years (range 3-45), and 92.7% (*n* = 127) had received specific training in the field of social work or health care, of which 63.8% (*n* = 81) involved an intermediate vocational training and 35.4% (*n* = 45) higher professional education and training.

Table 1

Demographic Information for the 137 Participants with Intellectual Disabilities

	N	Percent (%)	Mean	*SD*
Sex				
Male	77	56.2		
Female	60	43.8		
Age in years			28.20	6.16
Place of residence				
Community	115	83.9		
Residential	22	16.1		
Living condition				
Individually	47	34.3		
With others	90	65.7		
Cultural Background				
Dutch	126	92.0		
Other	11	8.0		

Procedure

After approval by the Ethics Committee of Tilburg University (EC-2015.46), participants were randomly selected using a stratified sampling procedure within five service providers for people with intellectual disabilities in the Netherlands. For each service provider, the total number of people with intellectual disabilities who met the inclusion criteria was identified. Then, a sample of 10% of the population who met the inclusion criteria of each service provider were selected for the study. Inclusion criteria to participate in the cross-sectional study were as follows: (a) age between 18 and 40 years; (b) mild intellectual disability; and (c) support at least once a week by paid support staff for at least 6 months. Participants were approached through their key support worker. A total of 354 individuals were selected randomly and invited to participate, and 42.4% agreed to take part in the study (*N* = 150). Reasons for nonparticipation included no interest (*n* = 117, 57.4%) and objections from relatives or guardians (*n* = 21, 10.3%). For some individuals, the support worker or psychologist advised against participation in the study (*n* = 66, 32.4%).

When the person with intellectual disability agreed to participate, an appointment was made. Depending on participant preference, face-to-face interviews were carried out at the participants' homes or at the service providers' offices. The researcher carefully explained the purpose of the study, the procedure and the confidentiality of the information. A standard consent procedure (Arscott et al., 1998) was then followed to assess the capacity of the participant to give consent to take part in the research. Participants were given a written and verbal overview of the research project, and the researcher asked them the five questions developed by Arscott et al. (1998), to determine whether they could recall information about the study. When the participant demonstrated sufficient recall, a written consent form was signed. If the participant could not answer the questions, the researcher explained the project again in more accessible terms, until the participant was able to understand the key aspects of the research project. Once consent was obtained, Wechsler Adult Intelligence Scale-IV subtests were carried out. Demographic information was obtained from the participants, and the Personal Wellbeing Index-Intellectual Disability was completed as a questionnaire. Then, the FNM-ID was used to interview the participant about their family network. The administration of the FNM-ID was audio-recorded if the participant gave permission.

After the interview, participants were given a ten euros in recompense for their time. Eleven participants were excluded because their scores on the cognitive assessments were above or below the mild intellectual disability range. Two individuals were excluded because they were not able to answer the questions, leaving a total of 137 participants.

With the participant's consent, their key support worker was interviewed to obtain information about the participants' behavioural and emotional problems and to check additional information about officially diagnosed psychiatric or developmental disorders obtained from personal records.

Measures

Family Networks

The Family Network Method-Intellectual Disability (FNM-ID) was used to measure the family networks of people with intellectual disability. The FNM-ID makes it possible to analyse emotionally supportive relationships, by asking participants to estimate relationships among all their family members. Emotional support refers to a belief that love and caring, sympathy and understanding, and/or esteem and value are available from significant others (Thoits, 1995). The instrument is composed of multiple steps; participants are first asked to provide a list of all individuals whom they consider to be a family member at the time of the interview. The term "family" is deliberately left open to allow the participants to apply their own definitions. Subsequently, participants are asked to list all family members that are significant to them from the listed family members. Finally, they are asked to describe which family members provide emotional support to the participant and to each other from the list of family members, by asking them the question: "If X is feeling 'out of sorts', who is there for X?" (i.e. X represents each individual included the participant's family configuration, considered in turn). Socio-demographic information on each listed family member is collected, as well as information on the nature of the family tie, the duration of the relationship (if not a relative) and the frequency of contact.

To characterize the family networks of individuals with intellectual disability, seven social network measures are computed from the FNM-ID (table 2), which are related to a social capital theoretical perspective (Sapin et al., 2016; Widmer et al., 2010) and are of interest in terms of the lives of people with intellectual disability.

Table 2

Overview of the Computed Social Network Measures

Type of network	Network measures	Definition
Total family network measures	Size	Number of family members within the network of the participant with intellectual disability
	Density	An indicator of how close a network is; how many network members support each other on average. Density is defined as the ratio between the number of existing supportive relationships between the family members divided by the total number of possible supportive relationships between the family members
	Arc reciprocity	Proportion of supportive relationships between family members that are reciprocal. The focus of this measure is on the number of supportive relationships that are involved in reciprocal relations, relative to the total number of actual relations
Individual family network measures	In-degree	Number of relationships in which the person with intellectual disability receives support
	Out-degree	Number of relationships in which the person with intellectual disability provides support
	Dyad reciprocity	Number of dyads (in which the person with intellectual disability is an actor) with reciprocal relationships, divided by the total number of adjacent dyads (in which the person with intellectual disability is an actor)
	One step outreach centrality	Number of distinct family members within one link of a given person (i.e. how many other people a given person can reach in one step)

Cognitive Ability

To check whether a participant met the inclusion criteria of mild intellectual disability, a brief screening IQ-score, based on standard scores and standard errors, was derived because file scores of the participants were often missing, outdated or obtained using unidentified IQ tests. The subtests “Vocabulary” and “Matrix Reasoning” from the Dutch version of the WAIS-IV (WAIS-IV-NL) were used (Wechsler, 2012). These subtests correspond with the subtests of the Wechsler Abbreviated Scale of Intelligence-II (WASI-II; Wechsler, 2011). As no Dutch version of the WASI-II was available, the two corresponding WAIS-IV subtests were used. The raw scores were turned into standardized scores per participant; then, a 95% confidence interval was calculated per subtest with help of the standard measurements of errors. When a participant had a standard score in the intellectual disability range on both subtests (according to the 95% confidence interval), the participant was deemed as having a mild intellectual disability. People with intellectual disabilities often have a varied intelligence profile. Therefore, participants who score on only one subtest in intellectual disability range were also included in the study. Participants who scored above the intellectual disability range on both subtests were excluded.

Well-being

Subjective well-being was measured using the Personal Wellbeing Index-Intellectual Disability (PWI-ID; Cummins et al., 2010). Participants with intellectual disability were asked to report their satisfaction with their life as a whole, and on seven life domain items: standard of living, health, achieving in life, relationships, personal safety, community connectedness and future security. Items were rated on a 5-point response scale, with anchor points of "completely dissatisfied" (1), "neutral" (3) and "completely satisfied" (5). For analysis, individual item scores were used. In previous research, the scale items had item-total correlations higher than the recommended minimum of 0.30 (McGillivray et al., 2009).

Behavioural and Emotional Problems

The Adult Behaviour Checklist (ABCL; Achenbach & Rescorla, 2003) was used to measure behavioural and emotional problems. This questionnaire examines a broad range of behavioural and emotional problems: anxious/depressed, attention, withdrawal, aggression, somatic complaints, rule-breaking and intrusive thoughts. Although the ABCL was developed for the general population, a study on the psychometric properties for the use of this instrument with people with intellectual disability has been conducted. Tenneij and Koot (2007) found that the internal consistency coefficient Cronbach's alpha of the ABCL scales, for people with intellectual disabilities, ranged from 0.69 to 0.95 (mean alpha = 0.84); and inter-rater reliability, assessed by the intraclass correlation coefficient, ranged from 0.57 to 0.76 ($M = 0.68$). In the current study, the present authors used the scores on the eight subscales. Key support workers were asked to rate whether these items were true of the participants over the past 6 months using a 3-point response scale: "not true" (0), "somewhat or sometimes true" (1) or "very true or often true" (2). Total scores for each scale were converted into T-scores.

Demographics

Demographic information (participants' sex, age, living situation and cultural background) was obtained during the interview, or afterwards from the participant's file (with consent of the participant).

Data analysis

The family network data were entered into Excel and then imported and analysed in UCINET (version 6.623), a software package for the analysis of social network data (Borgatti et al., 2002). To identify empirically meaningful family typologies based on the FNM-ID variables, the present authors used latent class analysis (LCA) in Mplus (Muthén &

Muthén, 1998-2015). LCA is a probabilistic version of traditional non-hierarchical cluster analysis. The inputs for LCA were the seven social network variables (table 2) standardized as *z*-scores. To identify the ideal number of classes (family typologies), several criteria were used. The first criterion, the measure of parsimony, was the Baysian information criterion (BIC; Kass & Raftery, 1995). A lower BIC value indicates improvement of model fit with k classes relative to a model with k-1 classes. If the BIC values increase in model k + 1, the preceding number of classes k is most optimal. The second criterion was the classification quality of the model. High average posterior probabilities indicate how well the participant is classified into their class. The entropy measure is a combined index of the posterior probabilities, and high values are preferred with a maximum value of 1. There are no statistical criteria to decide what is low or high. The third criteria were two likelihood ratio tests: Vuong–Lo–Mendell–Rubin likelihood ratio test (VLMR-LRT) and the adjusted Lo–Mendell–Rubin likelihood ratio test (LMR-aLRT) (Muthén & Muthén, 1998-2015), indicating whether the present k-class solution was better than the foregoing k-1 class solution. Significant values ($p < .05$) of the likelihood ratio tests indicated that the present model (k) was superior to the previous (k-1) model. The fourth criterion was the utility of the classes based on practical and theoretical considerations (Porcu & Giambona, 2017).

After choosing the most ideal number of classes, the stability of the solution was verified by bootstrap sampling (Efron & Tibshirani, 1993). Five thousand bootstrap samples of size $N = 137$ were generated by sampling with replacement from the original data set. For each bootstrap sample, a LCA was conducted and at the end, all samples are combined to construct confidence intervals (95% CI) for the parameter estimates.

The 95% bootstrap CIs are also used to interpret each of the k classes. A standardized social network variable with a 95% CI including positive as well as negative values is interpreted as having an average level within a class and is denoted by 0. Intervals containing only positive values with mean estimates below .50 are considered as above average and denoted by +. Intervals with only positive values and a mean estimate between .50 and 1.00 are considered as rather high and denoted by ++. A mean estimate above 1.00 with only positive values is seen as high and denoted by +++. Similar criteria are applied for negative intervals.

After the number of classes was identified, the second step was to test differences between the classes with respect to demographic variables, well-being, and behavioural and emotional problems. Differences across classes with categorical or binary variables were tested with a chi-square test as described by Lanza et al. (2013) and differences across classes with continuous variables with a chi-square test as described by Asparouhov and Muthén (2014). Both tests are available in Mplus. An overall chi-square test was carried out for all four classes together. A significant result was followed by chi-square tests comparing each two class combinations.

Results

Latent Class Analysis

Latent class analyses with 1–5 classes were performed, because after the fifth class the different parameter values became worse. BIC values, entropy values, numbers in each class, posterior probabilities and p-values for two likelihood ratio tests are displayed in table 3. With increasing numbers of classes, the BIC value decreased. However, there was no turning point with an increasing BIC value. Based on this criterion, it was not possible to decide the optimal number of classes, but the decrease in BIC value is very low from class 4 to class 5. The entropy measure was highest with $k = 3$ classes. In fact, the entropy values are high for all class solutions (>0.95), so this criterion is not useful for deciding the number of classes. Both likelihood ratio tests indicated that a 2-class solution would be better than a 3-class solution. In the 4-class model, a distinctive meaningful group emerged based on face validity. The two classes in the 2-class solution resembled the first two classes of the 3-, 4- and 5-class solutions. The third class of the 3-class solution resembled the third class in the following solutions. The fourth class in the 4-class solution resembled the fourth classes in the 5-class solution. The fifth class in the 5-class solution did not resemble the first four classes.

Based on statistical criteria, the 4-class solution would be better than the 5-class solution because the posterior probabilities of the 5-class solution are even lower, and there is only a small decrease in the BIC value. However, based on face validity, the 4-class solution would also be the best fit because four characteristic groups emerged. The fifth class did not show new differential characteristics and the number of average scores on the network measures increased compared to the other classes. The entropy value for the 4-class solution was high (.958) with high posterior probabilities (.973 - .988) indicating that the participants were correctly classified in their classes. Based on the combination of all criteria used, a 4-class solution was chosen.

Description of the Four Classes

To be able to describe the four different classes and depict them with illustrative graphs (NetDraw, Borgatti, 2002), the raw mean scores for each of the classes on the seven social network variables were calculated (table 4).

To give a global impression of what the classes look like, the descriptions of the four classes are supported by example graphs of the perceived networks for individual "typical" participants. These four participants were selected as examples because they had individual scores that approached the mean scores on the social network measures for their class.

Class 1 (*n* = 79) can be described as an overall small network (mean 6.37 people), with a small number of supportive relationships (*M* = 1.97, *SD* = 1.47), and the person with intellectual disability

Table 3

Latent Class Models with up to five Classes

LCA	Classes	*n*	Posterior Probability	VLMR-LRT *p* value	LMR-aLRT *p* value
Class = 1	1	137	1.00		
BIC = 2783					
Classes = 2	1	88	.98	.000	.000
BIC = 2473	2	49	.99		
Entropy = 0.966					
Classes = 3	1	86	.99	.059	.064
BIC = 2395	2	35	.99		
Entropy = 0.972	3	16	.98		
Classes = 4	1	79	.99	.185	.191
BIC = 2359	2	35	.99		
Entropy = 0.970	3	14	.99		
	4	9	.97		
Classes = 5	1	68	.98	.393	.403
BIC = 2340	2	22	.94		
Entropy = 0.958	3	14	.98		
	4	8	.99		
	5	25	.98		

rarely provides support (*M* = 0.67, *SD* = 0.98). The person with intellectual disability has very little reciprocal support (*M* = 0.11, *SD* = 0.21), and they cannot reach many family members in their network directly (*M* = 0.10, *SD* = 0.16). Figure 1 is an example of a participant of class 1 who only gets support from his parents. His sister and brother-in-law are also listed in his family network, but they are not providing or getting any emotional support from the participant. This network characterizes more than one half of participants. It represents a small network and impoverished experience in terms of family-based social capital.

Class 2 (*n* = 35) represents small networks (*M* = 4.57, *SD* = 1.70) but scores high on density (*M* = 0.61, *SD* = 0.22) and reciprocity for the whole network (*M* = 0.78, *SD* = 0.22). The person with intellectual disability receives and gives somewhat more support (*M* = 2.23, *SD* = 1.33; *M* = 2.69, *SD* = 1.28) compared to participants in class 1. Participants in class 2 can relatively easily reach most other people in their network (*M* = 0.76, *SD* = 0.24). The example shows a small but dense family network. The participant reported that he is supporting every family member in his network and also receives emotional support from all of them. Overall, this class seems to describe a small but supportive family network (figure 2).

Table 4

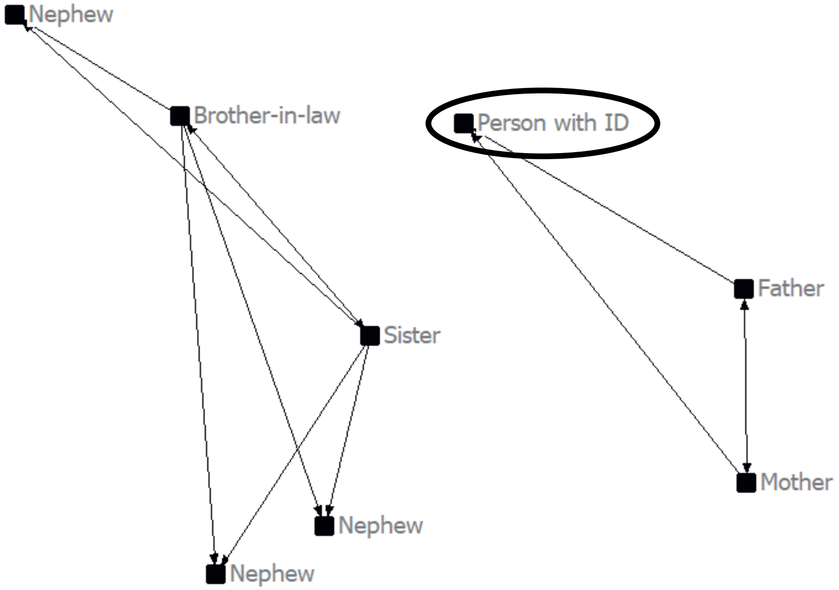
Means scores, 95% Bootstrap Confidence Intervals and Typology of four Family Network Classes

	Class 1 *N*=79				**Class 2 *N*=35**				**Class 3 *N*= 14**				**Class 4 *N*= 9**			
	M (SD)	**95% BCI**		**Score category-sation**	***M (SD)***	**95% BCI**		**Score category-sation**	***M (SD)***	**95% BCI**		**Score category-sation**	***M (SD)***	**95% BCI**		**Score category-sation**
Size	6.37 (3.17)	-.35	.02	0	4.57 (1.70)	-.67	-.37	--	9.43 (4.05)	-.01	1.13	0	20.56 (4.42)	1.01	3.46	+++
Density	.25 (.14)	-.58	-.31	-	.61 (.22)	.66	1.43	+++	.49 (.21)	-.01	1.09	0	.09 (.05)	-1.24	-.54	---
Arc reciprocity	.34 (.26)	-.70	-.28	-	.78 (.22)	.59	1.16	++	.69 (.14)	.30	.88	++	.39 (.24)	-.97	.17	0
Dyad reciprocity	.11 (.21)	-.72	-.35	--	.66 (.28)	.75	1.45	+++	.44 (.18)	.19	.83	+	.16 (.18)	-.74	.16	0
One step outreach centrality	.10 (.16)	-.79	-.53	--	.76 (.24)	.82	1.34	+++	.86 (.15)	1.08	1.59	+++	.17 (.17)	-.80	.01	0
In-degree	1.97 (1.47)	-.44	.03	0	2.23 (1.33)	-.36	.28	0	4.57 (1.40)	.88	1.94	+++	2.22 (1.20)	-.54	1.06	0
Out-degree	0.67 (0.98)	-.62	-.42	--	2.69 (1.28)	.01	.41	+	9.07 (2.56)	1.88	3.31	+++	3.00 (3.04)	-.45	1.65	0

Note 1: *M*=mean; 95% BCI = 95% Bootstrap Confidence Interval; Score categorization = interpretation Mean and 95% CI
Note2: +++ = high, ++ = rather high, + = above average, 0 = average, - = below average, -- = rather low, --- = low

Figure 1

Example of a Family Network of a Participant in Class 1



Class 3 (*n* = 14) applies to a small number of people. The network has a moderate size (*M* = 9.43, *SD* = 4.05) and density (*M* = 0.49, *SD* = 0.21). It also has the largest number of supportive people (*M* = 4.57, *SD* = 1.40) and people who are supported by the person with an intellectual disability (*M* = 9.07, *SD* = 2.56). Individuals with an intellectual disability also have a direct connection to most people in their network (*M* = .86, *SD* = .15). Hence, the graph shows that the person with intellectual disabilities is centrally placed in his network. Overall, this class represents a large type of family with close relationships that include the person with an intellectual disability (figure 3).

Class 4 (*n* = 9) applies to a very small number of people but was reasonably stable across the multiple solutions. Class 4 is represented by a large family (*M* = 20.56, *SD* = 4.42) with fewer connections (*M* = 0.09, *SD* = 0.05) and limited reciprocity (*M* = 0.39, *SD* = 0.24). The person with intellectual disability is supported by a small proportion of the network (*M* = 2.22, *SD* = 1.20) and, in turn, supports few family members (*M* = 3.00, *SD* = 3.04). The individual example shown in figure 4 has a substantial family network. However, he is only a member of a small sub-section of the network. In this sub-section, he enjoys mutually supportive relationships with family members. It is notable that four nieces who are listed do not get any emotional support from the other family members. This is a large type of family network, whose members do not appear to enjoy close relationships. The person

Figure 2

Example of a Family Network of a Participant in Class 2

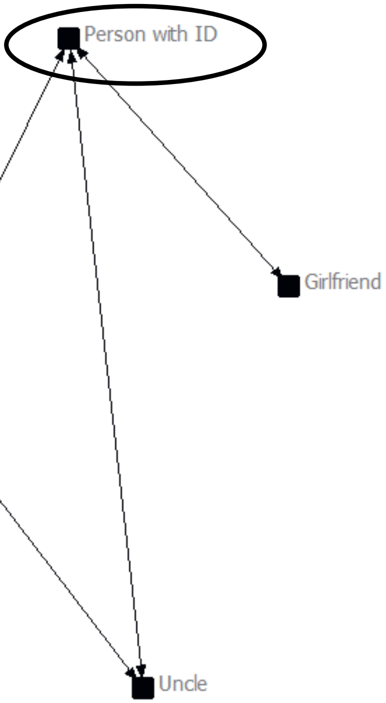
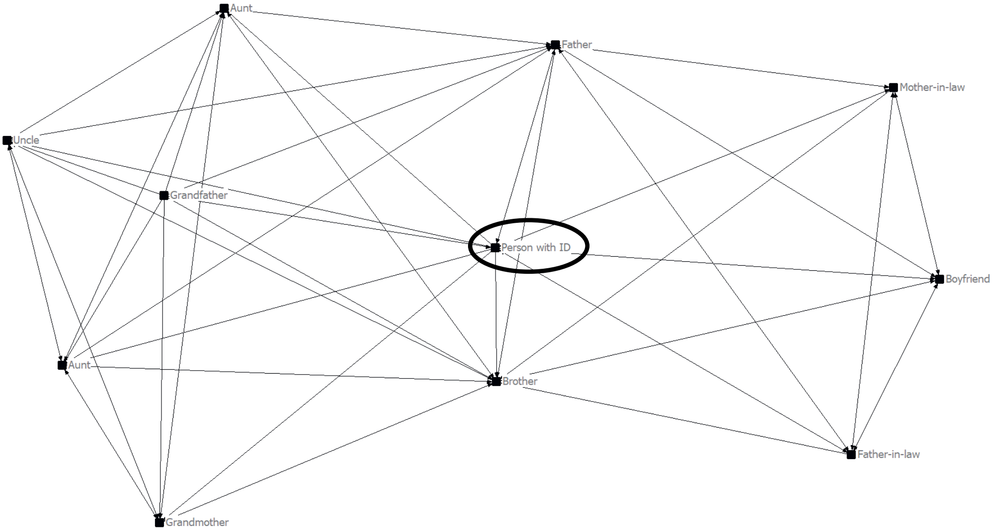


Figure 3

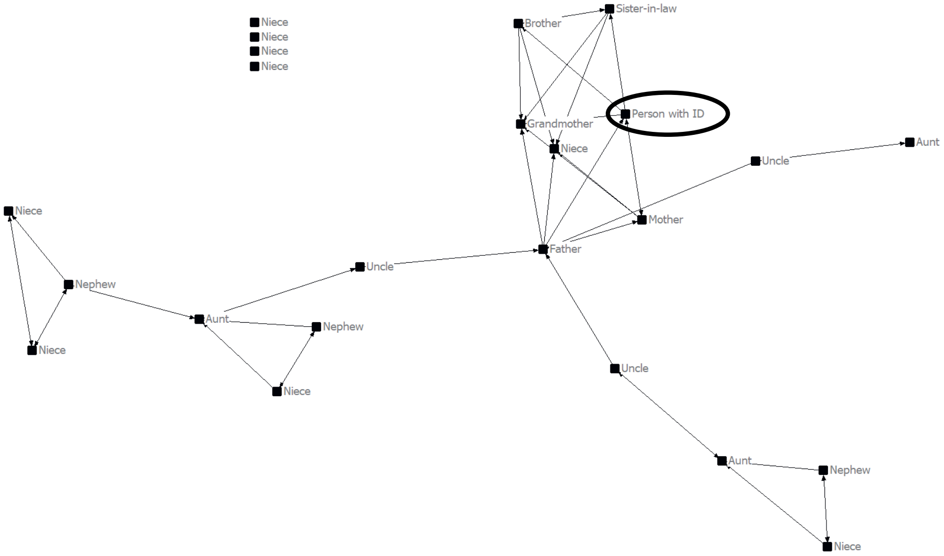
Example of a Family Network of a Participant in Class 3



with an intellectual disability only view themselves as having connections with a small part of the family network (they can reach on average .17 of them in one step).

Figure 4

Example of a Family Network of a Participant in Class 4



Comparisons across Classes

To test differences across the four classes, the present authors used a chi-square test for categorical/binary outcomes (Lanza et al., 2013) and a chi-square test for continuous outcomes (Asparouhov & Muthén, 2014), as presented in table 5. Significant differences across the four classes were found for cultural background, $\chi^2(3) = 12.08$, $p = .007$, well-being within personal relationships, χ2(3) = 14.79, $p = .002$, community connectedness, χ2(3)= 8.16, $p = .043$, thought problems, $\chi^2(3) = 8.22$, $p = .042$, rule-breaking behaviour, $\chi^2(3) = 8.19$, $p = .042$, and intrusive behaviour, $\chi^2(3) = 10.32$, $p = .016$. For the outcomes with an overall significant difference across classes, centrality measures (proportions or means) for each class were calculated and post hoc chi-square tests used to examine which classes were different from each other. The most distinct class is class 3. This class only has participants from a Dutch cultural background, and they had the highest well-being scores for their personal relationships and the highest scores for rule-breaking and intrusive behaviour. Class 4 is also notably different. Participants in this class had the highest scores for thought problems and the highest scores for community connectedness. Finally, participants in class 1 were the least satisfied with their community connectedness and personal relatedness. Participants in this class, on the other hand, displayed the lowest levels of behavioural and emotional problems.

Table 5
Centrality measures (proportions and means) and standard deviations for Demographic, Well-being and Behavioural and Emotional Problem Variables with test results for differences between classes

	Class1	**Class 2**	**Class 3**	**Class 4**	**Overall chi-square test**		**post hoc chi-square test**		**Classes differing**
	($n = 79$)	**($n = 35$)**	**($n = 14$)**	**($n = 9$)**	**$\chi^2(3)$**	**p**	**$\chi^2(1)$**	**p**	
Sex (proportion female)	.40 (.49)	.49 (.53)	.43 (.52)	.58 (.52)	1.32	.724			
Living situation (proportion living individually)	.32 (.45)	.46 (.52)	.35 (.51)	.11 (.32)	6.21	.102			
Residential (proportion with residential facility)	.13 (.32)	.17 (.37)	.36 (.49)	.11 (.34)	3.32	.357			
Cultural background (proportion Dutch participants)	.91 (.43)	.92 (.30)	1.00 (.00)	.89 (.32)	12.08	.007	7.20	.007	3 vs. 4
Age	28.57 (6.25)	28.57 (6.13)	23.22 (8.51)	31.08 (5.93)	7.28	.064			
Well-being – life as a whole	3.92 (.85)	3.95 (.92)	4.07 (.62)	4.10 (1.19)	.55	.908			
Well-being – standard of living	4.38 (.74)	4.28 (.72)	4.36 (.73)	3.36 (1.37)	4.72	.194			
Well-being – health	3.85 (1.05)	3.89 (.86)	3.78 (.95)	3.88 (1.30)	.13	.988			
Well-being – achieving in life	4.20 (.69)	4.26 (.82)	4.07 (.71)	4.11 (.59)	.81	.847			
Well-being – personal relationships	4.12 (.79)	4.41 (.66)	4.72 (.46)	4.32 (1.01)	14.79	.002	14.55	.000	1 vs. 3
Well-being – personal safety	3.91 (.85)	3.93 (1.02)	4.21 (.88)	3.89 (1.10)	1.38	.710			
Well-being – community connectedness	3.99 (.87)	4.35 (.59)	4.21 (.78)	4.46 (.51)	8.16	.043	6.00 5.28	.014 .022	1 vs. 2 1 vs. 4
Well-being – future security	3.97 (.79)	4.06 (.74)	4.21 (.95)	4.08 (.86)	.97	.809			

Anxious/depressed	9.43 (5.60)	10.37 (7.67)	10.69 (5.92)	12.23 (6.98)	1.89	.596			
Withdrawn	5.81 (3.73)	5.49 (4.15)	6.30 (4.37)	5.42 (3.64)	.45	.929			
Somatic complaints	3.08 (4.04)	5.16 (4.22)	3.03 (2.31)	5.59 (5.23)	6.69	.082			
Thought problems	2.52 (2.18)	2.92 (2.99)	3.14 (3.15)	6.46 (4.18)	8.22	.042	7.67 5.62 4.14	.006 .018 .042	1 vs. 4 2 vs. 4 3 vs. 4
Attention problems	13.23 (5.70)	13.61 (7.05)	17.33 (6.01)	16.15 (6.29)	6.81	.078			
Aggressive behaviour	9.06 (7.03)	10.45 (7.24)	11.80 (6.72)	10.74 (7.99)	2.48	.478			
Rule-breaking behaviour	5.37 (7.87)	6.03 (5.34)	10.20 (5.65)	8.18 (13.08)	8.19	.042	7.70 5.57	.006 .018	1 vs. 3 2 vs. 3
Intrusive	3.30 (2.80)	4.22 (3.18)	5.58 (2.64)	4.70 (2.47)	10.32	.016	8.55	.003	1 vs. 3

Note: Only significant overall chi-square tests with $p < .05$ were followed with chi-square-post-hoc tests.

Discussion

The present authors used social capital-informed research methods to characterize the family network typologies of people with mild intellectual disability, using their self-reports about family members' emotional support. Through latent class analyses, four family network typologies were identified based on seven self-reported social network measures. The four distinguishable family network typologies show that people with intellectual disability have a variety of family contexts with distinct social capital. Class 2 and class 3 appear to be the most supportive family networks, in which the person with mild intellectual disability is part of a close (reciprocally supportive) family group. In contrast, participants in classes 1 and 4 may experience less family-based social capital. Participants in class 1 had a small family network in terms of both size and support. They are also the least satisfied with their personal relationships and their community connectedness. Class 4 may represent large family networks but they are not perceived to be close, although the participants in this class do score well on community connectedness.

The insights obtained from analysing these different types of perceived family groups might have practical use for professionals when looking at ways to strengthen, maintain or expanding the social capital of people with intellectual disabilities. For example, in the case of class 1, expanding the size of the network and the (reciprocal) supportive relationships might have a positive influence on their subjective well-being and mental health. Participants in class 4 could take more advantage of their available connections to become more connected with their extensive family network. However, caution is needed here because the distance might be there for a reason. For example, family relationships could be distant due to a family member being abusive or difficult family relationship; or certain characteristics or actions of the individual with intellectual disabilities may have influenced the nature of their relationship (Greenberg et al., 2006).

Although classes 2 and 3 are both supportive family typologies, participants in class 3 seem to be happier with their personal relationships. A possible explanation might be linked to their extended family networks and reciprocal relationships. The reciprocal nature of relationships can improve and strengthen the connections (Baumeister & Leary, 1995) and have a positive effect on the self-worth of people with intellectual disability (Milner & Kelly, 2009). In turn, this might contribute to the high score for well-being in terms of personal relationships. At the same time, participants in class 3 also scored highest on the subscales rule-breaking and intrusive behaviour of the ABCL. Typically, people with intellectual disability who have behavioural and emotional problems are among the most disadvantaged and socially excluded in society (Emerson, 2001). The results for class 3 seem at odds with earlier research. There may be at least two possible hypotheses for this result. First, the inflated self-perceptions of people with behavioural problems have been attributed to an illusory positive bias (Barry et al., 2011). Another potential explanation could be that people who are more aggressive are less passive and more demanding, and so are better at maintaining relationships with family members. These hypotheses, and others, could be explored in future in-depth research with people with intellectual disabilities who have families matching the class 3 typology.

Limitations of the current study should be mentioned. First, the present authors focused on emotional support because it has been found to be a stronger predictor for physical and mental health-related outcomes (Berkman, 1995; Thoits, 1995). However, different results may be obtained if the focus is on instrumental support. Second, no rating of the quality of emotional support was included. Quality of social relations may have an impact on well-being. Positive aspects of supportive relationships appear to provide a sense of security, increasing individuals' positive feelings about themselves and their world (Antonucci, 2001). Future research could replicate the current methods with a focus on instrumental support and the quality of emotional support—to examine the replicability of the typologies identified. Third, there were some limitations concerning sampling and recruitment. Only 42.4% (*n* = 150) of the participants who were initially identified agreed to take part in the study meaning that the resulting sample was unlikely to have been representative of the population studied. Unfortunately, no data were available for the non-respondents. Therefore, it was not possible to quantify biases in the sample selection. The present authors only included participants who lived apart from their family in long-term care and who were supported by staff. Their distance from family members and the nature of their support may have had a significant impact on their perceptions of family. In future research, it would be important to examine family typologies in populations living in different contexts, and cultures, and with more representative samples.

The current study was exploratory, and yielded insights about family network typologies of people with mild intellectual disability from their own perspectives. The findings showed that their social capital is low on average but that there is some variability. In terms of practical implications, these findings suggest that people with intellectual disability have different support needs in terms of strengthening or extending their social capital.

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CHAPTER 9

General discussion

The Current Thesis

This thesis had two linked pathways concerning the contextual and relational nature of challenging behaviour, two elements which can both affect the challenging behaviour of a person with an intellectual disability (Bowring et al., 2019). First, a person-centred approach that places great emphasis on the context and relationships of people with intellectual disabilities and challenging behaviour was examined: the practice-based Triple-C approach. Despite being widely used in service facilities in the Netherlands to support people with intellectual disabilities and challenging behaviour, the scientific evidence underpinning Triple-C is still lacking and there is a variety in how the method is applied in practice. Therefore, the first aim of this thesis was to try to make the multicomponent Triple-C approach and its application in practice more explicit. In addition, the underlying mechanisms and theoretical foundation were examined. The framework of the Medical Research Council (Campbell et al., 2000; Craig et al., 2008) was used to provide guidance in the evaluation of this multicomponent approach. The outcomes of this evaluation will contribute to the further development of Triple-C in two ways: first, Triple-C practitioners will be able to apply the approach more systematically, and second, the theoretical foundation is necessary to be able to execute future empirical research into the approach.

The second pathway of this thesis was to obtain a better understanding of the family relationships of people with intellectual disabilities and challenging behaviour who reside at service facilities. Because another significant aspect of the contextual and relational background of challenging behaviour is the context of a person's day-to-day relationships. The current focus of Triple-C is solely on the relationship between a professional and an individual with an intellectual disability and challenging behaviour, which might be explained by the fact that Triple-C is only used in service settings. That is, people with intellectual disabilities and challenging behaviour who are supported by Triple-C reside at community or residential facilities. However, people with intellectual disabilities and challenging behaviour who reside at service facilities consider their family as a significant part of their day-to-day relationships (Clarke et al., 2019). This is because people with intellectual disabilities and challenging behaviour often have life long and close relationships with family, even if they are not living with family anymore (Clarke et al., 2019). In turn, family members have known their relative with challenging behaviour their entire life and are familiar with their likes and dislikes, and past failures and successes (Dunlap & Fox, 2007). Despite the significance of family, it was not clear if, and how family remain involved when people with intellectual disabilities and challenging behaviour reside at service facilities, where person-centred approaches such as Triple-C are applied. When family involvement is considered, first it should be clear *whom* people with intellectual disabilities and challenging behaviour consider as family themselves, because there might be a difference in perspectives between professionals and people with intellectual disabilities and challenging behaviour. Therefore, the second pathway investigated family involvement in the lives of people with intellectual disabilities and challenging behaviour when they reside at a service facility. This included how people with intellectual disabilities themselves perceive their family based social capital, and how challenging behaviour is associated with this capital.

In this final chapter, the main findings of the thesis are summarized and integrated. The strengths and limitations of the thesis are discussed, along with and implications for future research, policy, and practice.

Main Findings and Interpretations

The Triple-C Logic Model (Chapter 2)

The focus of the first pathway was to make the multicomponent Triple-C approach and its application in practice more specific by trying to make the implicit knowledge of Triple-C professionals more explicit. A systematic process was necessary to generate the evidence to underpin the Triple-C approach, which was found in a framework described by the Medical Research Council (MRC). This framework provides guidance in developing or evaluating complex interventions and emphasises the importance of starting with theory and building a clear understanding of how an intervention is proposed to have its effects (Campbell et al., 2000; Craig et al., 2008). Interventions are considered complex when they consist of a number of separate elements which seem fundamental to the proper functioning of the intervention, although the "active ingredient" of the intervention that is effective is difficult to specify (Campbell et al., 2000). Triple-C is considered as a complex approach as it comprises multiple components that need to be executed on different levels of an organisation. In the field of intellectual disabilities, these types of approaches are also labelled as multicomponent approaches (Carr et al., 2002).

According to the MRC, high-quality evidence for complex interventions is described as going through five different phases: (1) the 'Pre-Clinical' or theoretical phase, (2) the modelling phase, (3) the exploratory trial, (4) the main trial, and (5) long term surveillance. In the case of Triple-C, it transpired that the existing theoretical basis and the understanding of the approach were not clear enough to execute an effectiveness study (MRC framework phase 3, 4 or 5; Campbell et al., 2000). Therefore, the first two phases of the MRC model were necessary to identify the underlying mechanisms and the outcomes of Triple-C. Within the MRC framework, the theory and modelling phases are presented separately. However, refining theory through modelling activities is likely to be iterative (Campbell et al., 2000; Craig et al. 2008). In Chapter 2, we illustrated how this iterative process of the first two phases was executed by using different research methods such as interviews, focus groups, and content analysis of published accounts.

Subsequently, a way of presenting the outcomes at a glance was needed, which was found in terms of a logic model. Logic models are related to program theory, which can be an informative way to clearly display multicomponent approaches (McLaughlin & Jordan, 2010; Shakman & Rodriguez, 2015). In the case of Triple-C, it was helpful to describe the assumptions underlying the approach, the intervention components at a staff and organisational level, and the mechanisms of impact in more detail (i.e. what needs to be done by Triple-C professionals?). Consideration was also given to how these elements are expected to lead to intended outcomes for people with intellectual disabilities, support staff and organisation. Further, the logic model clearly shows what is needed in different layers of an organisation to implement the approach adequately. As a result, the Triple-C logic model and the accompanying description that were produced could be important for future implementation and research. That is to say, the logic model makes the key dimensions and processes more explicit, which helps to ensure the fidelity with which the approach is implemented. In turn, this provides the basis for researching the effectiveness of Triple-C, starting with an exploratory trial (phase 3) and leading to long term surveillance (phase 5). Finally, the logic model provides a means of communicating the rationale of the Triple-C approach and its activities to a wider audience. Despite this thorough process to describe Triple-C more explicitly, the results of this study also helped to uncover elements of the approach that had not been operationalised. This included details about what support staff need do in practice. In the third chapter of this thesis, we further elaborated on one of the practical elements of the approach.

Working on a Relationship, a Significant Pillar of Triple-C (Chapter 3)

The Triple-C logic model can be considered as a first step to make the approach and the outcome measures more explicit. To make this explication more concrete, and to help guide the daily actions of Triple-C support staff, an observational study was carried out concerning a specific element of Triple-C in practice, 'the unconditional professional supportive relationship'. The results of the Triple-C logic model study (Chapter 2) revealed that Triple-C professionals consider this as a significant 'pillar' of the approach.

The assumption of Triple-C is that the person with an intellectual disability and challenging behaviour and the support worker build a relationship by carrying out meaningful activities together. To start this process, a real connection between the person with an intellectual disability and challenging behaviour and the support worker is needed. A real connection can be considered as a functional, pleasing, and important connection to people with intellectual disabilities, which enables support staff to gain insight into, and respond to the needs of people with intellectual disabilities and challenging behaviour (Carr et al., 2016; Hermsen et al., 2014; Reinders, 2010). An observational study was used to examine what a 'real connection' includes, according to Triple-C professionals. To obtain the most competent Triple-C knowledge, participants for this study were selected by the founders based on their good practice. A specific method based on video reviews of daily practices was adopted, to give words to the tacit knowledge of these Triple-C professionals (Burford, 1993).

Based on their tacit knowledge, Triple-C psychologists and support staff selected situations where concrete interactions (e.g. verbal or physical contact) took place, as moments of a real connection. Most of the time the support worker had a prominent role and the person with an intellectual disability and challenging behaviour often seemed responsive towards the actions of the support worker. Based on thematic analyses of the professionals' views about a real connection, the joint engagement in a meaningful activity was considered as a significant context to establish this connection. In addition, a real connection was considered when there was a visible connection in terms of verbal, eye or physical contact. Furthermore, participants mentioned pre conditional factors that were considered necessary for those being observed to be able to connect with each other. This included the need for support staff to create a safe atmosphere by establishing a familiar and reassuring feeling. In line with this safe atmosphere, support staff should display an approachable attitude, they should confirm the positive behaviour of the person with an intellectual disability and give compliments. Furthermore, Triple-C psychologists and support staff considered that the sensitive attitude of support staff was key to their connections to people with intellectual disabilities and challenging behaviour. For example, by adjusting their proximity towards the person with an intellectual disability or slowing down their actions. Finally, specific actions were viewed by psychologists and support staff to be helpful in fostering connectionions with people with intellectual disabilities and challenging behaviour. These actions included, giving instructions, using gestures, demonstrating (a part of) the activity themselves, or using objects to illustrate what needed to be done in the activity.

The Involvement of Family (Chapter 4)

Part of the second pathway of this thesis was to examine the involvement of family when people with intellectual disabilities and challenging behaviour reside at a service facility, as it is not clear how family remain involved despite their significant role in people's lives (Clarke et al., 2019). This is despite the fact that many services claim to implement person-centred approaches (Klatt et al., 2002; Sanderson, 2000). Therefore, a scoping review was carried out to gain more insight in the family involvement in person-centred approaches (Chapter 4). Six databases were searched electronically to conduct relevant publications from January 2005 to November 2019.

Our main finding was that researchers rarely report on the inclusion of family in person-centred approaches to support people with intellectual disabilities and challenging behaviour. Where researchers did describe the involvement of family in person-centred approaches, there was considerable variation. For example, the involvement of family varied between receiving information about the person-centred approach (Beadle-Brown et al., 2012), to attending monthly meetings in which the progress of the person with intellectual disabilities and challenging behaviour was discussed (De Wein & Miller, 2009). However, due to the lack of information about family involvement in studies about person-centred approaches, caution is needed to draw firm conclusions based on these preliminary results. There might be a number of reasons why family involvement was rarely reported. For example, researchers might have deliberately chosen not to include family, as they were focussed on other factors concerning the implemention of person-centred approaches. Family may have been involved, even though they were not explicitly mentioned in the papers. Finally, it might have been the case that family were not involved in these applied approaches. Whatever the reason, these sparse descriptions seemed to be a missed opportunity for researchers and professionals to learn from each other about family involvement in person-centred approaches, and to learn how to build better collaborations with family (Mooney & Lashewicz, 2014; Redmond & Richardson, 2003). This knowledge would be valuable, as practice demonstrates that family involvement can be complex due to the different needs of people with an intellectual disability and challenging behaviour with regard to family involvement, and the possibilities of family to collaborate (e.g. personal circumstances of family members) with support staff (Mooney & Lashewicz, 2014; Redmond & Richardson, 2003). Therefore, suggestions to improve the cooperation between family and support staff will be discussed in the implication section of this chapter.

Adapted Measure to Map Family Networks (Chapter 5)

Before support staff can involve family successfully in person-centred approaches, they need to know *who* should be involved; whom do people with intellectual disabilities and challenging behaviour themselves consider to be their (significant) supportive family members? Therefore, to measure the perceptions of people with mild intellectual disabilities with and without challenging behaviour of their family networks, the Family Network Method (FNM; Widmer, 2013) was adapted into the Family Network Method – Intellectual Disability (FNM-ID; Giesbers et al., 2019). Adaptations were made to meet the cognitive and linguistic needs of people with mild intellectual disabilities (Finlay & Lyons, 2001). A piloting process, involving 19 participants with mild intellectual disabilities was completed. The FNM-ID allows people with mild intellectual disabilities to map their family networks and the family support within these networks. A broader concept of family is adopted by the FNM-ID, which means that it gives insight in who people with mild intellectual disabilities themselves identify as family. In addition, the measure maps the relationships among all family members (e.g., mother – father; father – uncle; grandma – uncle). These results give a broader understanding of the family context of structural interdependencies in which the relationships between people with mild intellectual disabilities and their family members are embedded (Widmer, 2016).

As little is known about the details of family networks of people with mild intellectual disabilities and challenging behaviour who reside in service facilities, the data obtained with the FNM-ID was used to gain a better understanding of this topic. That is, the perceptions of people with mild intellectual disabilities and challenging behaviour were compared to the perceptions of their key support worker (Chapter 6). Moreover, the perceived family networks of people with mild intellectual disabilities with and without challenging behaviour were compared (Chapter 7); and family network typologies based on perceptions of people with mild intellectual disabilities (and challenging behaviour) and possible associations with behavioural and emotional problems were investigated (Chapter 8).

Comparison of Perspectives (Chapter 6)

The perspectives of people with mild intellectual disabilities and their support staff on the concept of 'family', and (reciprocal) supportive relationships between family members and the individual with an intellectual disability, were compared. It was found that participants with mild intellectual disabilities perceived their family networks to be larger and more supportive than did their key support staff. The results showed that the key support staff did not know the individuals' extended family networks. A possible explanation for this gap in their knowledge might be that people with mild intellectual disabilities meet their extended family outside the service context.

Furthermore, people with mild intellectual disabilities considered themselves more emotionally supportive and they thought they received more emotional support than their key support staff perceived. There might be several reasons for these different perspectives. First, the validity or accuracy of the key support staff when reporting on the emotional support in family networks of people with mild intellectual disabilities might be questionable, as people with mild intellectual disabilities might meet these family members outside the service facility. Second, there might be biases in the perceptions of people with intellectual disabilities regarding their social relationships, because they may misunderstand other individuals' feelings (Lavin & Doka, 1999). This can be caused due to people with mild intellectual disabilities' difficulties with interpreting social situations and other people's emotions (Lunsky & Benson, 2001). A third possible explanation for the differences in perspectives might be that people with mild intellectual disabilities find it hard to admit that their social network is small, or they might feel lonely. In this way, perceiving a more supportive network may serve a self-protective function, which helps to maintain a positive self-image (Barry, 2011).

In addition, it was found that when people with mild intellectual disabilities displayed more externalising behaviour, the differences in perspectives with key support staff became larger. On the other hand, when people with mild intellectual disabilities displayed more internalising behaviour, their perspectives on the family network were more comparable with key support staff. However, the presence of more 'challenging behaviour' predicted more agreement between people with mild intellectual disabilities and key support staff about the emotional support received from family members. This higher level of agreement could be an artefact of the measure that was used to examine the challenging behaviour: the Behaviour Problems Inventory-01 (Rojahn et al., 2001), which includes stereotyped behaviour and self-injurious behaviour. The measure that was used to examine the externalising behaviour, the Adult Behaviour Checklist (Achenbach & Rescorla, 2003), does not include these constructs. In contrast to aggression, stereotyped behaviour and self-injurious behaviour pose less threat to staff and evoke more sympathy and understanding (Noone et al., 2006), which may lead to a better understanding of their family networks.

Based on these results, it can be concluded that the perspectives of support staff and people with mild intellectual disabilities differ and that there are factors that might be associated with these diverging perspectives, such as living setting and the type of challenging behaviour. If support staff are better informed about the family networks of people with mild intellectual disabilities and challenging behaviour then they will be in a better position to support individuals with mild intellectual disabilities to maintain, strengthen or expand connections between them and their family members.

Family Networks and Challenging Behaviour (Chapter 7)

Challenging behaviour causes differences in perspectives on family networks between people with mild intellectual disabilities and support staff. When people with intellectual disabilities display challenging behaviour, this affects the perspectives of support staff (Chapter 6). However, it was not clear whether there were differences in perspectives between people with mild intellectual disabilities with and without challenging behaviour. To learn more about the influence of challenging behaviour on family networks, the family networks of these two groups were compared as well.

Based on the results of this study there almost seem to be no differences between the perceived family networks of people with mild intellectual disabilities with and without challenging behaviour. This suggest that challenging behaviour may not have major impact on how people with mild intellectual disabilities perceive the structure of their family networks and the emotional support provided. Only one small difference was found with a moderate effect size: participants who display challenging behaviour perceive less mutual support within their family network as a whole. A potential reason for this difference is that when people with mild intellectual disabilities and challenging behaviour reside in a home of a service provider, they might be less aware of the emotional support family members provide to, or receive from each other.

Family Network Typologies (Chapter 8)

Even though the results of Chapter 7 indicated that there seem to be no significant differences between the perceived family networks of people with mild intellectual disabilities with and without challenging behaviour, there might be differences in support needs regarding maintaining, strengthening, or expanding family relations. In addition, differences in family networks may have implications for the involvement of family in person-centred approaches. Therefore, in the last study of this thesis (Chapter 8), we examined if family networks of people with mild intellectual disabilities could be classified into typologies.

Four different family network typologies were found, based on seven social network measures, using the FNM-ID. Although the findings demonstrate that the social capital of people with mild intellectual disabilities tends to be low, there is variability. Two typologies were characterised as supportive family networks (typology 2 and 3), in which people with mild intellectual disabilities were part of a close (reciprocally supportive) family group. The two other family network typologies showed less supportive family networks. That is, one typology was characterised by small family networks with less emotional support (typology 1). Participants who were classified as belonging to this network were also the least satisfied with their community connectedness and their personal relationships. The other less supportive type of family networks was larger, but offered limited emotional support (typology 4). Participants with this type of family network scored well on community connectedness.

A notable result of this study was that participants of one of the supportive typologies (typology 3) also scored high on the subscales rule breaking behaviour and intrusive behaviour of the Adult Behaviour Checklist (Achenbach & Rescorla, 2003). This was not expected, as people with mild intellectual disabilities who display behavioural or emotional problems are among the most socially excluded in society (Emerson, 2001). Explanations for this result might be that people with challenging behaviour have been attributed to an illusory positive bias (Barry et al., 2011) which results in inflated self-perceptions, or it could be that people who are more aggressive and demanding, are less passive and as such better at maintaining relationships with family members. However, caution is needed here, as these are hypotheses that should be explored in future in-depth research with people with mild intellectual disabilities who have families matching the class 3 typology.

The results of this study suggest two practical implications, first that people with mild intellectual disabilities have different support needs in terms of strengthening or extending their social capital. That is, some people with mild intellectual disabilities could be supported in expanding their social networks, while others should be supported in maintaining their current family relationships. Second, the possibilities of family involvement in the person-centred approach might differ per typology. Some family network typologies might have more potential family members who could be involved in caring for their relative than other typologies, which is a valuable insight for support staff who may wish to foster the active involvement of family in person-centred approaches.

Strengths of the Thesis

Three Sources of Knowledge

The results of this thesis are based on different sources of knowledge: scientific knowledge; professional knowledge; and knowledge by experience. Knowledge based on science (i.e. evidence-based knowledge) has long been regarded as the ultimate source of knowledge for quality improvement in care. In recent years, a new vision on knowledge has been embraced. In addition to scientific knowledge, the practical knowledge of professionals and the experiential knowledge of people with intellectual disabilities and their relatives are considered to be valuable sources of knowledge as well, and are considered as equal to scientific knowledge (Embregts, 2017, 2018). The integration of these three sources of knowledge is referred to by the term evidence-based practice (Sackett et al. 1996; Van Yperen et al., 2017). One of the strengths of this thesis is that the three sources of knowledge come together. That is, in the process to operationalise Triple-C more explicit (Chapter 2 and 3), the (implicit) knowledge of professionals was examined systematically. The studies concerning the family networks of people with mild intellectual disabilities with and without challenging behaviour (Chapter 6, 7 and 8) are based on the perspectives of people with mild intellectual disabilities themselves, and their support staff. Developing new scientific knowledge combined with practical knowledge of professionals and experiential knowledge of people with mild intellectual disabilities, creates multiple opportunities. Such as indicating potential effectiveness of approaches developed in practice by professionals in a brief period of time compared to developing completely new interventions, and disclose specific knowledge which only can be acquired by experience.

Perspectives of People with Mild Intellectual Disabilities and Challenging Behaviour

Including the perspectives of people with mild intellectual disabilities and challenging behaviour on their family networks in this thesis was considered a strength as well, because people with mild intellectual disabilities are experts on their own lives, experiences and feelings (McDonald et al., 2013; Lunsky & Benson, 1997). These valuable insights cannot be obtained from another source. In addition, challenging behaviour is related to the context and day-to-day relationships of people with intellectual disabilities (Bowring et al., 2019). In this way, family relationships can affect (both positively and negatively) the behaviour of people with mild intellectual disabilities. To gain more insight about which family members could affect the behaviour of people with mild intellectual disabilities, it is necessary to understand who people with mild intellectual disabilities and challenging behaviour consider as (significant) family. Finally, including the perspectives of people with mild intellectual disabilities on their own family network has become more significant due to the cuts in professionals support (Malli et al., 2018; Miettinen, 2012). These cuts have resulted in people with mild intellectual disabilities becoming more reliant on their informal supportive networks for their social capital (Simplican et al., 2015). Which makes it more important to know whom they consider as family and, if necessary, strengthen or expand these relationships.

Methods and Techniques

It is considered a strength to use different scientific research methods (e.g. interviews, focus groups, self-report questionnaires, video reviews) to obtain the different types of knowledge of professionals and experts by experience. In addition, in the case of building the Triple-C logic model, an iterative approach was adopted, in combination with different research methods (interviews, focus groups, content analysis). There was also a process of reflection with different stakeholders (scientists and practitioners) to avoid blind spots or overlooking significant elements of the Triple-C approach. Despite these strengths, several limitations should be mentioned. A number of general limitations will be addressed, along with suggestions for future research.

Limitations and Implications for Future Research

Investigating a Multicomponent Approach

First, the MRC framework was a helpful guide to investigate the multicomponent Triple-C approach. It provided guidance to determine what was necessary to take the first step in translating a practice-based approach into an evidence-based approach. However, investigating an existing practice-based approach might cause blind spots; elements of the approach that are not mentioned by Triple-C professionals or questioned by scientists. Since only Triple-C professionals were consulted in the studies, and published accounts of the founders of Triple-C were analysed (Chapter 2 and 3), we cannot be sure we missed elements that are a part of the Triple-C theoretical framework, of which Triple-C professionals might be not aware of. In the study about connectedness (Chapter 3) for example, the joint engagement in a meaningful activity was mentioned often by Triple-C professionals. Since carrying out joint meaningful activities is one of the three pillars of the approach, this might have caused a bias in their perspectives. It is not clear if professionals from another background in the care for people with intellectual disabilities and challenging behaviour, would also consider joint activity as key to connecting to a person with an intellectual disability and challenging behaviour. Therefore, it would be recommended to involve professionals who have experience in different approaches from Triple-C in future research. Their perspectives on the support of people with intellectual disabilities and challenging behaviour might help to detect other significant apsects in the support of people with intellectual disabilities that are not included in the current description of Triple-C.

Concerning the source of knowledge by experience, the perspectives of people with intellectual disabilities and challenging behaviour themselves were not taken into account when developing the logic model. A piece of work to consider feedback from people with intellectual disabilities and challenging behaviour would be an important step before further research will be conducted to test the effectiveness of the Triple-C approach. This also applies to the connectedness between support staff and people with intellectual disabilities and challenging behaviour. The connectedness study (Chapter 3) only included the perspectives of Triple-C professionals. It would be valuable to obtain the knowledge and perspectives on what people with intellectual disabilities consider to be a real connection with support staff.

In general, it would be recommended to revisit the logic model at intervals, as missing elements might become visible over time, as a result of further research into Triple-C. Moreover, there is a need to identify the relationships between the different elements in the logic model, and to formulate more specific hypotheses about which elements might relate to certain processes and outcomes. When the relationships between the different elements in the logic model are clearer, then the last phases of the MRC framework (the exploratory trial, the main trial, and the long term surveillance research) can be completed. These last phases would focus on the effects of the intervention, which would provide robust evidence about the effectiveness of the Triple-C approach.

Sampling and Recruitment

There were limitations concerning the research about people with mild intellectual disabilities' perspectives on their family networks. In the first instance, the generalisability of these results is limited due to included target population. The focus was only on people with mild intellectual disabilities with and without challenging behaviour, and, therefore, the results cannot be generalised to for example people with borderline intellectual functioning or moderate intellectual disabilities. At the start of this research, it was also intended to include participants with moderate intellectual disabilities. However, when piloting the FNM-ID it turned out that the instrument remained too complex for those with moderate intellectual disabilities, despite the different adaptations that were made. Taking the perspective of another family member was particularly complicated and proved too cognitively challenging for participants with moderate intellectual disabilities. This limited generalisability is unfortunate, because the Triple-C target population range from severe to borderline intellectual disabilities and means that the findings about family networks could only be generalised to a part of the Triple-C target population.

In addition, the participants with mild intellectual disabilities all lived in services with frequent support (at least once a week). None of the participants lived at their family home or independently. Earlier research has shown that residing in a service facility (far) away from the family home makes it difficult to have regular contact with family (Eley et al., 2009). Furthermore, the results of the study of White et al. (2020) showed that the inability of family members to readily ‘pop in’ and meet their relative, represented a significant concern as family members could not easily see how the person was managing. In turn, this necessitated their reliance on proxy accounts, although family did not always perceive proxy informants as reliable. These concerns are in line with our results that support staff lack knowledge about the family networks of people with mild intellectual disabilities who reside at service facilities. Future research should include people with mild intellectual disabilities who live at their family home or independently, to examine how the person’s living situation affects the support staff’s knowledge about their family networks.

Moreover, the number of participants with challenging behaviour in the family network studies, according to the so called ‘working definition’ of Bowring et al. (2017) of the Behaviour Problems Inventory-01 (Rojahn et al., 2001), was low. Although, the proportion of participants with challenging behaviour in the study is approximately similar to the proportion in the whole population of people with intellectual disabilities who have challenging behaviour (Bowring et al., 2017). Despite this representative sample, future research on the perceived emotional support in family networks of people with intellectual disabilities should have larger sample sizes of participants who display challenging behaviour, to allow more robust conclusions to be reached.

Emotional Support and Challenging Behaviour

The last limitation concerns the studies about family networks. These studies only included the construct of emotional support. However, based on the literature, two types of support can be distinguished: emotional and instrumental support. The original FNM obtained information about these two types of support, as well as conflict and influence (Widmer et al., 2013). The FNM-ID only measures perceived emotional support. This decision was made based on results of the pilot of adapting the FNM for people with mild intellectual disabilities. It was found that asking participants about emotional and instrumental support was too complex, and did not lead to different results for each dimension. This was because people appeared to attribute an emotional meaning to instrumental support (i.e. when someone provides instrumental support, she shows that she cares for the other person; Semmer et al., 2008). For this reason, it was decided to solely focus on emotional support. Nonetheless, it would be interesting to find a reliable way to examine the instrumental support people with mild intellectual disabilities think that they give and/or receive as well, and to investigate if the experiences of emotional and instrumental support are distinct, overlap, or interact.

Another limitation is that the FNM-ID only focusses on the positive emotional support family members give or receive from each other. However, results of earlier research showed that negative dimensions of family relationships, such as conflicts, are significantly related to psychological wellbeing (Widmer et al., 2018). Family can be a source of support, but also a source of stress and conflict. As challenging behaviour or mental health issues can be sources of stress as well (Hastings, 2002; Lecavalier et al., 2006), it might be assumed that challenging behaviour would have a negative impact on family relationships (Greenberg et al., 2006; Orsmond et al., 2003). However, the results of the family network studies in the current thesis do not suggest that challenging behaviour or mental health affect the family networks negatively. More robust evidence could be obtained if the studies in the current thesis were replicated with larger sample sizes of people with mild intellectual disabilities and challenging behaviour.

Implications for Policy and Practice

The findings from the studies presented in this thesis have implications for policy and practice. Based on findings of the first pathway (research to the Triple-C approach), the logic model should contribute to clearer communication among professionals that will result in better training, a shared understanding of the approach and a better delivery. The results of the study presented in Chapter 2 emphasise that the elements in the logic model do not represent a 'menu' of options. Rather, to implement Triple-C effectively, the combined use of all of these elements is strongly recommended. This also includes the need for different levels of an organisation to be involved in the delivery of the Triple-C approach. For example, one should not focus only on training and coaching support staff to carry out meaningful activities together with the person with an intellectual disability and challenging behaviour. There also needs to be work on the organisational features of a service facility to create an optimal and safe climate for the support worker that makes it possible to engage in these meaningful activities. A practical tool that can help professionals (i.e. the psychologist, manager and team captain) to check whether the preconditions are met at all layers of an organisation is the *Triple-C logic model index* (Van Wouwe et al., 2021). This index can be used by professionals to reflect on their work, organisation, and support towards their Triple-C teams of support staff. The *Triple-C logic model index* makes it possible to apply the approach more systematically in practice and give professionals guidance at times of uncertainty. This applies to both professionals who are just starting to work with the Triple-C approach, as well as to experienced Triple-C professionals who want to stay on top of their own actions.

Further, the results of Chapter 3 give insight in how support staff could make a connection with people with intellectual disabilities and challenging behaviour, which could add to the practical execution of the pillar 'unconditional professional supportive relationship'. To create or maintain a real connection, support staff should create a context where they work on a meaningful activity together with the person with an intellectual disability, whereby support staff have a sensitive and approachable attitude and create a safe atmosphere. A range of specific actions (e.g. use humour, giving instructions, using gestures, etc.) are suggested which can be used by support staff to establish or maintain a connection with people with intellectual disabilities and challenging behaviour. It is recommended to use the results of this study in training and coaching of Triple-C support staff. For example, support staff can have more guidance when they learn which specific actions can be used to become connected with people with intellectual disabilities and challenging behaviour. Beside training and coaching of these concrete actions, the attitude of support staff towards people with intellectual disabilities and challenging behaviour are also important. Based on the outcomes of our study, Triple-C professionals deemed it significant that support staff had a respectful, kind, and calm attitude in order to be able to connect to people with intellectual disabilities and challenging behaviour.

The results of the second pathway of the thesis, concerning the involvement of family, also have implications for practice. The support of people with intellectual disabilities and challenging behaviour can be more effective and more sustainable if they are designed and implemented by all individuals who are in regular contact with the individual with an intellectual disability, such as family members and support staff (Dunlap & Fox, 2007). The results of our scoping review (Chapter 4) suggest that it is not obvious that family are involved in person-centred approaches. In the case of Triple-C, which can be considered as a person-centred approach, the involvement of family is not explicitly mentioned in the logic model (Chapter 2). It would be a valuable addition to the current Triple-C approach to secure the involvement of family by explicitly including them in the description and application. Inevitably, this requires a detailed description of how Triple-C professionals could involve family in the development and application of the Triple-C treatment. It is not self-evident that all professionals know how to collaborate with family (Bright et al., 2018; Mooney & Lashewicz, 2014; Redmond & Richardson, 2003; Ryan & Quinlan, 2018). A start could be made by encouraging support staff and psychologists to reflect on how they can make family involvement a reality, such as operating with a more open and transparent system of which family could be a part of (Doody, 2011). Further, it is advised that both parties (family and professionals) identify what they consider is needed to collaborate in an optimal way, such as a clear allocation of tasks and responsibilities. When both parties stick to these agreements, a relationship of trust can be developed (Barr, 1996). By regular (physical) meetings, family and support staff can discuss and exchange their needs and wishes and learn more about each priority for supporting people with intellectual disabilities and challenging behaviour (Barr, 1996). Family, for example, express the need support staff to be perceptive and responsive to the personality of their relatives, and some of them would like help to navigate their way through the cumbersome bureaucracy of organsiations (Mooney & Lashewicz, 2014; Olivier-Pijpers et al., 2020). Finally, family and support staff should be encouraged to discuss factors that impede the development of their collaboration. This would include their personal values in respect of specific situations, like the personal hygiene of the person with an intellectual disability (Barr, 1996).

The current Triple-C approach solely focuses on people with intellectual disabilities and challenging behaviour who reside in settings where they are supported by support staff. However, people with intellectual disabilities and challenging behaviour may also be living for part of the time with their family. Therefore, it would be beneficial to educate family members in Triple-C to use the approach. When people with challenging behaviour reside partly at a service facility, and partly at their family home, applying Triple-C in both settings could lead to more consistent support, for example by using the same daily program or the way others respond to the person's challenging behaviour. Earlier research suggested that multiple 'mediators' (e.g. support staff and family) in different contexts can generalise intervention effects through less intensive strategies that are more easily deliverable in natural settings (Harvey et al., 2009). Another possible situation is that family want their relative with challenging behaviour to reside at their family home as long as possible. In this case, it would be valuable for family to be trained and coached regularly by Triple-C professionals at their own home. This includes family having training and coaching on-the-job just like Triple-C professionals. Besides this training and coaching, a contextual fit of the support plan in a family setting is required, requiring a match with family values and goals, family resources, and embedded into existing routines and activities. Lucyshyn et al. (2002) suggest that under these conditions, commitment to change, implementation fidelity, plan maintenance and generalisation will be improved, and challenging behaviour of the relative with an intellectual disability can be addressed.

A last implication for practice, based on the results of the second pathway of this thesis, is that professionals should be more aware of whom people with mild intellectual disabilities and challenging behaviour consider as (significant) family. This knowledge is considered significant for support staff and psychologists to be able to involve family more sustainably in the lives of people with mild intellectual disabilities and challenging behaviour. The perceived emotional support within the family networks of people with mild intellectual disabilities and challenging behaviour living in service facilities do not differ from those of people with mild intellectual disabilities without challenging behaviour, although the type of challenging behaviour that is displayed may have an effect on how well support staff know the person's family network. Differences in perspectives between people with intellectual disabilities and support staff might be harmful for family relationships, as better informed support staff might be more able to support people with mild intellectual disabilities and challenging behaviour to maintain, strengthen, or expand contact with their family members. Furthermore, the results showed that people with mild intellectual disabilities have a variety of family contexts with distinct social capital in terms of emotional support. This means that people with mild intellectual disabilities have different support needs in terms of maintaining, strengthening, or expanding their family networks. Therefore, it is recommended that support staff should have sufficient time to immerse themselves in the family networks of people with mild intellectual disabilities and challenging behaviour, to help them foster meaningful social contacts with significant others and to experience a sense of belonging and the opportunity to participate in valued, equal relationships (Clarke et al., 2019; Giesbers et al., 2019; McConkey & Collins, 2010). A practical tool, which can help people with mild intellectual disabilities and challenging behaviour and their support staff to learn more about the family networks, is the web application '*Familie enzo*' (Giesbers et al., 2020). This digital tool maps the family networks of people with mild intellectual disabilities step by step. They can create their own avatar and then add all their family members and significant others to their network. The web application then asks a number of questions: who is important to you, who will help you if you are not having such a good day, and who will you help if others are not having a good day. People with mild intellectual disabilities can work independently with the application with help of the accessible language, and the attractive interface and reading function. When all questions have been completed, a clear overview of the network will appear. This overview can be printed as a family portrait or used as input for a conversation with for example support staff. The results can help support staff to actively involve and strengthen the network, if there is a need. For example, by making a plan together with the person with a mild intellectual disability about whom he/she would like to see more often, in which way, and when. To secure this step in the support to people with mild intellectual disabilities and challenging behaviour, it is recommended to fill out the *Familie enzo* application once a year for two reasons. First, to evaluate the process on expanding, strengthen or maintaining the social capital of people with mild intellectual disabilities and challenging behaviour, and second, to check whether the knowledge of support staff about the social capital of the individual they are supporting is accurate.

In Conclusion

Based on the two pathways of this thesis (I: investigating the Triple-C approach, and II: involvement of family), it can be concluded that the development of the Triple-C logic model is a significant start to apply Triple-C more systematically in practice and to underpin the approach with scientific evidence. Despite this first step, future research will be needed to continue this process; underpinning Triple-C with more robust research to become an evidence-based approach. Furthermore, based on the results of the second pathway, it would be a valuable addition to involve family structurally in the application of Triple-C. The support of people with intellectual disabilities and challenging behaviour would be more effective and sustainable when they are designed and implemented by both family and professionals (Dunlap & Fox, 2007).

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Summary

This thesis had two linked pathways concerning the contextual and relational nature of challenging behaviour, two factors which can affect the challenging behaviour of a person with an intellectual disability. First, a person-centred approach that places emphasis on the context and relationships of people with intellectual disabilities and challenging behaviour was examined: the practice-based Triple-C approach. Despite being widely used in service facilities in the Netherlands to support people with intellectual disabilities and challenging behaviour, the scientific evidence underpinning Triple-C is still lacking and there is inconsistency in how the method is applied in practice. Therefore, the first aim of this thesis was to try to make the multicomponent Triple-C approach and its application in practice more explicit. In addition, the underlying mechanisms and theoretical foundation were examined.

The second pathway of this thesis was to obtain a better understanding of the family relationships of people with intellectual disabilities and challenging behaviour who reside in service facilities. Another significant aspect of the contextual and relational background of challenging behaviour is the context of a person's day-to-day relationships. People with intellectual disabilities and challenging behaviour who reside at service facilities consider their family as a significant part of their day-to-day relationships. Despite the significance of family, it was not clear if, and how family remain involved when people with intellectual disabilities and challenging behaviour move to residential services, where person-centred approaches such as Triple-C are applied. Hence, the second pathway investigated family involvement in the lives of people with intellectual disabilities and challenging behaviour who are living in residential services. This included how people with intellectual disabilities themselves perceive their family based social capital, and how challenging behaviour is associated with this capital.

Chapter 1

The Triple-C Model

In the early 1990s Hans van Wouwe and Dick van de Weerd developed the values-driven Triple-C approach in the Netherlands. The three C's represent Client, (i.e., the person with an intellectual disability), Coach (i.e., the support worker), Competence (i.e., the activity which the client and coach perform together). Stimulated by the normalization principle, and informed by attachment and social learning theories, the developers wanted to enable people with intellectual disabilities and challenging behaviour to experience a life as close as possible to an ordinary life enjoyed by people without intellectual disabilities. It is assumed within the vision of Triple-C that by meeting the human needs (physical, emotional, mental and meaningful needs) of people with intellectual disabilities and challenging behaviour, an ordinary life can be experienced as much as possible. Furthermore, instead of trying to control the challenging behaviour, Triple-C professionals are trained to have an emphatic, understanding and compassionate response to challenging behaviour. This is because an underlying assumption of Triple-C is that human behaviour is determined by the interaction between an individual and their environment, and that challenging behaviour could be seen as a response to a challenging environment. To promote a positive response towards people with intellectual disabilities and challenging behaviour an attempt is made to promote a meaningful lifestyle by filling people's daily programmes with meaningful activities, and providing them with unconditional support from their support staff.

The Relational Context

There are various causes that contribute to the development and/or reinforcement of challenging behaviour of people with intellectual disabilities, such as biological factors (e.g. syndromes), mental health issues or other people's behaviour. Therefore, it is important to consider the wider life context in order to understand the challenging behaviour in all its aspects, when supporting people with intellectual disabilities and challenging behaviour. The current thesis focussed on the context of people with intellectual disabilities' day-to-day relationships, as other people's behaviour, such as family members and support staff, can help to maintain challenging behaviour.

The social networks of people with intellectual disabilities are small compared to those without intellectual disabilities. Two groups of people can be distinguished in their social networks: the informal network members (e.g. family, friends) and the formal network members (e.g. support staff, psychologist). Professionals from the formal networks of people with intellectual disabilities often have a significant role in their lives because they provide instrumental support (e.g. running a household) as well as emotional support (e.g. listening to their problems). Family members mainly represent the informal networks of people with intellectual disabilities; their relationships are characterised by unconditional love, emotional closeness and a long-term perspective. The non-transitory and ubiquitous nature of these relationships make them a potent source of meaning in their lives and contribute to a sense of belonging.

People with intellectual disabilities have a higher chance of move away from their family home when they display challenging behaviour. Despite this move, family usually remains a central part of their lives. However, it may not always be self-evident that families are involved in the application or development of person-centred approaches which are used in the service facilities where their family member lives. This lack of involvement can be considered as a drawback, as the lifelong bonds that family have with their relative with an intellectual disability and challenging behaviour can provide an in-depth understanding of a person's needs. Moreover, earlier research has shown that person-centred approaches are more effective when family is more involved. Although people with intellectual disabilities and challenging behaviour highly value their family relationships, due to their challenging behaviour it is assumed that they will experience higher levels of social exclusion and less family involvement in their life. However, little is known about the specific characteristics of family networks of people with intellectual disabilities and challenging behaviour. Therefore, the second pathway of this thesis was to get a better understanding of the dimensions of these family relationships. Answers to these questions might be valuable for the support of people with intellectual disabilities and challenging behaviour, because it is known that sustainable, reciprocal relationships have a positive effect on their self-esteem and when they have a more central place within their family network, this can provide them with a sense of belonging.

Aims of the Thesis

The practice-based nature of Triple-C means that many of Triple-C professionals' (support staff, psychologists and managers) actions or activities are often underpinned by their implicit knowledge about the approach. An explicit description of the elements and an understanding of the mechanisms of change are missing. In addition, the application of Triple-C by professionals is not clear. For example, how can a support worker provide unconditional support when performing meaningful activities together, in situations where challenging behaviour could occur? In the first pathway of this thesis, the implicit knowledge of experienced Triple-C support staff and psychologists was systematically examined, to make the description and application of the approach more explicit.

In addition to the relationships with support staff, family relationships are also of great value to people with intellectual disabilities and challenging behaviour. However, little is known about the involvement of family in their lives and whom they consider to be (emotionally supportive) family. In the second pathway of this thesis, the involvement of family in person-centred approaches is examined. Whom people with mild intellectual disabilities and challenging behaviour consider as their family will also be investigated, and the characteristics of their family networks in terms of emotional support.

Chapter 2

Scientific evidence can be generated by systematically monitoring interventions that are considered to be "good practice". This systematic process has been executed for the practice-derived Triple-C approach. The practice-based nature of Triple-C means that many of the professionals' actions or activities are often underpinned by their implicit knowledge about the approach they are delivering. Through an iterative process, the practical knowledge of Triple-C professionals (founders, psychologists, team captains, managers, and members of the board of a service provider) and published accounts were assessed. Based on the results a logic model was developed to describe the approach and its underlying assumptions. The Triple-C logic model improves understanding of the different elements of the approach: the assumptions, preconditions, mechanisms of impact and the outcomes. In addition, the logic model of Triple-C provides insight into the key elements of the approach, such as the need for unconditional supportive relationship and carrying out meaningful activities together. Finally, defining the underlying logic of a practice-based approach like Triple-C is an important first step toward producing an evidence base for approaches developed from clinical practice.

Chapter 3

Chapter 3 describes how the tacit practical knowledge of Triple-C psychologists and support staff was examined in terms of what they viewed as a real connection between support staff and people with intellectual disabilities and challenging behaviour. This real connection is considered to be an integral part of a positive relationship between an individual with an intellectual disability and a support worker, which is a significant element of the Triple-C approach. To gain insight into the perceived nature of a real connection, six dyads comprising individuals with intellectual disabilities and challenging behaviour and their Triple-C support staff were video recorded during joint engagement in an activity. A video compilation was made and ten Triple-C psychologists and ten Triple-C support staff marked moments of real connection in this video compilation. Moreover, they shared their interpretations about what they considered to be indicative of a real connection between people with intellectual disabilities and challenging behaviour and their support staff. The results showed that psychologists and support staff designated real connections as occurring when they noticed concrete interactions, such as verbal or physical contact. Furthermore, based on a thematic analysis of the data, four themes were identified that encapsulated what professionals deemed to be signs of a real connection. That is, 1) the way in which connections between support staff and people with intellectual disabilities become visible such as joint engagement in an activity; 2) the importance of support staff creating a safe atmosphere such as displaying an approachable attitude; 3) support staff attuning to the needs of people with intellectual disabilities in a sensitive way such as adjusting their proximity to establish a connection; and 4) people with intellectual disabilities attempting to connect with their support staff. Based on the results of this study, it seems that the joint engagement in an activity appears to be a context that fosters opportunities for real connection. In addition, the results indicate that support staff should adopt a sensitive attitude and strive to create a safe atmosphere, in order to establish real connections with people with intellectual disabilities and challenging behaviour.

Chapter 4

The study in chapter 4 describes the results of a scoping review, which examined the type and frequency of family involvement in the application of person-centred approaches in the care for people with intellectual disabilities and challenging behaviour who live in residential services. Six databases (Embase, Medline, Web of Science, PsycINFO, Cochrane Central, and Google Scholar) were used. Studies that met the following inclusion criteria were selected: 1) focussing on person-centred approaches for people with intellectual disabilities and challenging behaviour, 2) containing an outcome measure regarding challenging behaviour, 3) studies were published between 2005 and 2019. Fifteen publications met the inclusion criteria, only five of which reported family involvement. Within these five publications, the frequency of contact and how family were involved appeared to differ depending on the type of person-centred approach used (from family being informed about the person-centred approach, to family monthly attending progress evaluations). As the treatment of a person with an intellectual disability and challenging behaviour is likely to benefit from good collaboration between support staff and family, it is recommended that service facilities reflect on ways of improving collaboration with family in relation to the care of individuals with challenging behaviour.

Chapter 5

The study in chapter 5 describes the process to adapt the Family Network Method, an instrument that maps the multi-dimensional nature of family networks, into an instrument which is suitable for people with mild intellectual disabilities (Family Network Method – Intellectual Disability; FNM-ID). Nineteen individuals with mild intellectual disabilities participated in a pilot. Based on their suggestions and the experiences of the researchers, the FNM-ID was structured, standardised, and auditory and visual supportive techniques were added to the interview protocol.

The FNM-ID has three steps. First, participants are asked whom they consider to be their (significant) family. Second, the participants' perceptions of the emotional support received and given, between themselves and their family members, is measured. Finally, the participant's perceptions about the emotionally supportive relationships between all the family members is measured. To allow participants to decide whom they consider as family, the term 'family member' is deliberately left undefined. Results of the FNM-ID provide insights about whom they consider to be their family, and the participants' perceptions of relationships between all family members. This information provides a more detailed understanding of the family context of structural interdependencies in which people with mild intellectual disabilities and their close family relationships are embedded. The chapter displays two cases to illustrate the utility of the FNM-ID and to demonstrate which social network measures can be calculated based on the obtained data (e.g. density, centrality and reciprocity). Subsequently, data obtained with the FNM-ID was used for three studies that are described in the Chapters 6, 7, and 8.

Chapter 6

This chapter compares the perspectives of people with mild intellectual disabilities and their key support staff on family networks. The FNM-ID was used to map the perspectives of both groups on the family network of the participant with a mild intellectual disability. In addition, key support staff filled out the Behaviour Problems Inventory-01 and the Adult Behaviour Checklist, to measure the degree of emotional and behavioural problems displayed by the participants with mild intellectual disabilities. In total, 138 participants with mild intellectual disabilities (18 – 40 years) and their key support staff (*n* = 138) participated in the study.

Results showed that people with mild intellectual disabilities perceived their family networks to be larger and to provide more support than their key support staff did. Extended family members (e.g., uncles, aunts, nieces) and family in-law (typically partners of the sisters and brothers of the person with a mild intellectual disability) were listed more by people with mild intellectual disabilities. When participants were living in a residential facility, the differences in perspectives with their support staff became even larger. This might have been because the participants with mild intellectual disabilities met their family members outside the service facility. Differences in perspectives were also associated with the externalising behaviour of participants with mild intellectual disabilities. Higher levels of externalising behaviour were associated with larger differences in perspectives. In contrast, when participants with intellectual disabilities displayed higher levels of internalising behaviour, their perspectives were closer to those of their support staff. Based on these results, it can be concluded that people with mild intellectual disabilities and their key staff are unlikely to provide the same information about family networks.

Chapter 7

The study in chapter 7 examined whether challenging behaviour might be related with family relationships. Again, the FNM-ID was used to map the family networks of people with mild intellectual disabilities with and without challenging behaviour. Seven different family network measures of participants with mild intellectual disabilities with and without challenging behaviour were then compared. The Behaviour Problems Inventory – 01 was used to determine whether a participant displayed challenging behaviour or not. Based on the working definition of this questionnaire, 36 participants out of 138 met the definition for having challenging behaviour. The seven network measures that were compared included: the size of the family network, the size of the significant family network, the density of the family network, the amount of reciprocal supportive relationships within the family network, the amount of reciprocal supportive relationships of the participant with a mild intellectual disability, the amount of received and given emotional support of the participant and how many family members the participant could reach in one step (i.e. directly, without an intermediate family member). The challenging behaviour scores were not associated with family network characteristics and perceived emotional support. There were only a few, and generally small, differences found between the family networks of people with or without challenging behaviour. A moderate sized group difference was found for the mutual support in the whole family network. People with challenging behaviour perceived less mutual support in their whole family network compared to participants without challenging behaviour. The results suggest that people with mild intellectual disabilities and challenging behaviour perceive the quality of their family relationships in a similar to those without challenging behaviour. Nevertheless, caution is needed in interpreting these findings due to the small sample size of participants with challenging behaviour.

Chapter 8

The last study about the family networks of people with mild intellectual disabilities, presented in Chapter 8, displays the results of an exploratory study of perceived family networks. Based on the perspectives of people with mild intellectual disabilities on their own family networks, it was examined if different family network typologies could be distinguished in terms of emotional support. The family networks, measured by the FNM-ID, of 137 participants with mild intellectual disabilities were analysed.

A latent class analysis was used to identify the different family typologies, based on seven social network measures. The analysis resulted in four distinguishable family network typologies. Two of the typologies could be characterised as supportive and two of them could be characterised as less supportive family networks. In the supportive family network typologies, the person with a mild intellectual disability is part of a close (reciprocally supportive) family group. In the less supportive family network typologies, people with mild intellectual disabilities experience less family-based social capital. That is, they have smaller family networks in terms of both size and support, or, when the size of the family networks is larger, people with mild intellectual disabilities do not view themselves as being close to their family members.

In addition, associations between the family network types and personal characteristics of the participants with mild intellectual disabilities, their emotional and behavioural problems, and well-being were examined. Data on behavioural and emotional problems were obtained using the Adult Behaviour Checklist (filled out by their key support workers), and wellbeing was measured with the Personal Wellbeing-Index (filled out by participants with mild intellectual disability themselves). A small association was found with emotional and behavioural problems and one of the supportive typologies. Participants in one of the supportive family network typologies scored higher on the subscales rule-breaking and intrusive behaviour of the Adult Behaviour Checklist. These outcomes seem at odds with earlier research. Two potential hypothesis could explain this result. First, an illusory positive bias of people with behavioural problems could have inflated their self-perceptions. Second, people who are more aggressive are less passive and more demanding, and might be better at maintaining relationships with family members. In conclusion, the results show that while the social capital of people with mild intellectual disabilities tends to be low, there is some variability. This suggests that people with mild intellectual disabilities have different support needs, in terms of strengthening or extending their social network.

Chapter 9

Finally, in the general discussion in Chapter 9, the main findings of the thesis are summarized and integrated, and the implications for policy and practice are discussed.

The Triple-C logic model shows the assumptions, preconditions, mechanisms of impact and the outcomes from the approach. Findings of the first pathway for the Triple-C logic model may contribute to clearer communication among professionals which, in turn, will result in a more optimal transfer, a shared understanding of the approach and better delivery of the approach. In addition, the results add to an important first step toward producing an evidence base for Triple-C. The results emphasise that the elements in the logic model do not represent a 'menu' of options. Instead, to implement Triple-C effectively, the combined use of all of the elements of the logic model is strongly recommended, involving all levels of an organisation. Additionally, when looking in more detail into the application of a significant element of Triple-C (the relationship between people with intellectual disabilities and challenging behaviour and support staff), results indicate that joint engagement in a meaningful activity appears to be a context that fosters opportunities for real connection. Support staff should have a sensitive and approachable attitude and create a safe atmosphere in order to become connected with people with intellectual disabilities and challenging behaviour. Moreover, specific actions were mentioned by support staff and psychologists that were considered useful for support staff to establish or maintain a connection with people with intellectual disabilities and challenging behaviour (e.g. giving instructions, using gestures).

The results of the second pathway of this thesis suggest that the support of people with intellectual disabilities and challenging behaviour can be more effective and sustainable when the support is designed and implemented by a collaboration between formal (e.g. family) and informal (e.g. support staff) members of people's social networks. The Triple-C approach does not mention family involvement. It would be a valuable addition to include the involvement of family in the approach. When people with challenging behaviour reside partly at a service facility, and partly at their family home, applying Triple-C in both settings could lead to more consistent support, for example by using the same daily program or the way others respond to the person's challenging behaviour. Therefore, in these circumstances it would be beneficial to train family members to use Triple-C.

Finally, the results of this thesis indicate that professionals (e.g. support staff or psychologists) should be more aware of whom people with mild intellectual disabilities and challenging behaviour consider as (significant) family. This knowledge is considered vital for professionals to help sustain family involvement in the lives of people with mild intellectual disabilities and challenging behaviour. The perceived emotional support within the family networks of people with mild intellectual disabilities and challenging behaviour living in service facilities do not differ from those of people with mild intellectual disabilities without challenging behaviour, although the type of challenging behaviour that is displayed does seem to effect how well support staff know the individual's family network. This lack of knowledge might be harmful for the relationships between people with intellectual disabilities and challenging behaviour and their family members. That is, better informed support staff might be more able to support people with mild intellectual disabilities and challenging behaviour to maintain, strengthen, or expand contact with their family members. Furthermore, results of the thesis showed that there are a variety of family contexts in terms of emotional support. Therefore, it is recommended that support staff should have sufficient time to immerse themselves in the family networks of people with mild intellectual disabilities and challenging behaviour, to help them foster meaningful social contacts with significant others and to experience a sense of belonging and the opportunity to participate in valued, equal relationships.

In sum, based on the results of this thesis, it can be concluded that the development of the Triple-C logic model is a significant start to applying the Triple-C approach more systematically in practice and to underpin the approach with scientific evidence. Furthermore, it would be a valuable addition to involve family in the delivery of Triple-C, because family members have a significant role in providing emotional support to people with mild intellectual disabilities and challenging behaviour.

Samenvatting

In dit proefschrift staan de contextuele en relationele aard van probleemgedrag centraal, waarbij allereerst nader onderzoek is gedaan naar het op praktijkervaringen gebaseerde Triple-C model (eerste onderzoekslijn). Dit is een persoonsgerichte benadering die nadruk legt op de context en relaties van mensen met een verstandelijke beperking en probleemgedrag. Hoewel Triple-C vaak wordt toegepast in zorgorganisaties in Nederland om mensen met een verstandelijke beperking en probleemgedrag te ondersteunen, wordt het model inconsistent toegepast in de praktijk en ontbreekt er nog een wetenschappelijk onderbouwing. Daarom zijn de onderliggende mechanismen en theoretische onderbouwing van het Triple-C model onderzocht, resulterend in een Triple-C logic model. Om meer zicht te krijgen op de context van de dagelijkse relaties van een persoon met een verstandelijke beperking en probleemgedrag is tevens onderzoek gedaan naar de familierelaties (tweede onderzoekslijn). Voor mensen met een verstandelijke beperking en probleemgedrag die in een zorgorganisatie verblijven maken familieleden een belangrijk onderdeel uit van hun dagelijkse relaties. Nagegaan is hoe familie betrokken blijft wanneer mensen met een verstandelijke beperking en probleemgedrag verhuizen naar een zorgorganisatie waar persoonsgerichte benaderingen zoals Triple-C worden toegepast. Daarnaast is er gekeken naar wie mensen met een verstandelijke beperking tot hun familienetwerken rekenen, de emotionele ondersteuning die ze binnen deze netwerken ervaren, en hoe hun probleemgedrag met deze familienetwerken samenhangt.

Hoofdstuk 1

Het Triple-C Model

Begin jaren negentig ontwikkelden Hans van Wouwe en Dick van de Weerd in de Nederlandse zorg voor mensen met een verstandelijke beperking en probleemgedrag het waarden gedreven Triple-C model. De drie C's vertegenwoordigen de Cliënt (d.w.z. de persoon met een verstandelijke beperking), de Coach (d.w.z. de begeleider) en Competentie (d.w.z. de activiteit die de cliënt en coach samen uitvoeren). Gestimuleerd door het normalisatieprincipe, gehechtheid en sociale leertheorieën, beoogden de ontwikkelaars van Triple-C mensen met een verstandelijke beperking en probleemgedrag een leven te laten ervaren dat zo dicht mogelijk ligt bij het leven van mensen zonder verstandelijke beperking. Binnen de visie van Triple-C wordt aangenomen dat een gewoon leven zoveel mogelijk kan worden ervaren door te voorzien in de menselijke behoeften (zowel de fysieke, emotionele, mentale als zingevende behoeften) van mensen met een verstandelijke beperking en probleemgedrag. Daarnaast wordt binnen de visie van Triple-C aangenomen dat menselijk gedrag wordt bepaald door de interactie tussen een individu en zijn omgeving, en dat probleemgedrag kan worden gezien als een reactie op een omgeving die als uitdagend wordt ervaren. Vanuit deze visie worden

Triple-C professionals (begeleiders, orthopedagogen en managers) opgeleid om op een empathische, begripvolle en compassievolle manier te reageren op probleemgedrag, in plaats van te proberen het probleemgedrag te beheersen. Tevens worden dagprogramma's aangeboden die bestaan uit betekenisvolle activiteiten, waarbij in de uitvoering onvoorwaardelijke steun wordt geboden door begeleiders.

De Relationele Context

Verschillende factoren kunnen bijdragen aan het ontstaan en/of het versterken van probleemgedrag van mensen met een verstandelijke beperking, zoals biologische factoren (bijv. een syndroom), psychische problemen, of het gedrag van anderen. Om het probleemgedrag van mensen met een verstandelijke beperking in al zijn facetten te begrijpen is het daarom belangrijk om deze bredere context in ogenschouw te nemen. Aangezien het gedrag van belangrijke anderen, zoals begeleiders en familieleden, een versterkend effect kan hebben op probleemgedrag richt dit proefschrift zich op de context van de dagelijkse sociale relaties en sociale netwerken van mensen met een verstandelijke beperking.

De sociale netwerken van mensen met een verstandelijke beperking zijn in vergelijking met de sociale netwerken van mensen zonder verstandelijke beperking klein. Binnen de sociale netwerken van mensen met een verstandelijke beperking kunnen twee groepen mensen onderscheiden worden: de informele netwerkleden (bijv. familie, vrienden) en de formele netwerkleden (bijv. begeleiders, orthopedagoog). In het leven van mensen met een verstandelijke beperking spelen begeleiders vaak een belangrijke rol omdat zij zowel instrumentele ondersteuning bieden (bijvoorbeeld ondersteuning bij het runnen van een huishouden) als emotionele steun (bijvoorbeeld luisteren naar hun problemen). Het informele netwerk van mensen met een verstandelijke beperking bestaat voornamelijk uit familie; deze familierelaties worden gekenmerkt door onvoorwaardelijke liefde, emotionele verbondenheid en een lange termijnperspectief. De niet-voorbijgaande en alomtegenwoordige aard van deze relaties maakt hen van grote betekenis in het leven van mensen met een verstandelijke beperking. Daarnaast dragen deze familierelaties bij aan het gevoel erbij te horen.

Wanneer mensen met een verstandelijke beperking probleemgedrag vertonen, hebben ze een grotere kans om bij een zorgorganisatie te wonen. Ondanks deze woonsituatie blijft familie evenwel een belangrijk onderdeel van hun leven. Het is echter niet altijd vanzelfsprekend dat familieleden worden betrokken bij de toepassing of inzet van persoonsgerichte benaderingen zoals Triple-C. Gelet op de levenslange band en het diepgaande begrip van de behoeften van hun familielid met een verstandelijke beperking en probleemgedrag, kan het ontbreken van betrokkenheid van familieleden als een nadeel worden beschouwd. Bovendien heeft eerder onderzoek aangetoond dat persoonsgerichte benaderingen effectiever zijn wanneer de familie ook daadwerkelijk meer betrokken is. Hoewel mensen met een verstandelijke beperking en probleemgedrag veel waarde hechten aan hun familierelaties, wordt over het algemeen aangenomen dat ze vanwege hun probleemgedrag een mindere mate van familie betrokkenheid in hun leven ervaren. Er is echter weinig bekend over de specifieke kenmerken van familienetwerken van mensen met een verstandelijke beperking en probleemgedrag. Daarom is in de tweede onderzoekslijn van dit proefschrift getracht om een beter begrip te krijgen van de kenmerken van familierelaties van mensen met een verstandelijke beperking en probleemgedrag. Inzicht in deze relaties kan waardevol zijn voor de ondersteuning van deze mensen, omdat bekend is dat duurzame, wederkerige relaties een positief effect hebben op zelfwaardering. Wanneer mensen met probleemgedrag een meer centrale plaats innemen binnen hun familienetwerk kan hen dit bovendien het gevoel geven erbij te horen.

Doelen van dit Proefschrift

Het praktijkgerichte karakter van Triple-C maakt dat veel van de handelingen of activiteiten van Triple-C professionals (begeleiders, orthopedagogen en managers) vaak voortkomen uit hun impliciete kennis over de benadering. Een expliciete beschrijving van de Triple-C elementen en begrip van de werkende en onderliggende mechanismen ontbreken echter. Daarnaast is het niet duidelijk hoe Triple-C in de praktijk door Triple-C professionals dient te worden toegepast. Bijvoorbeeld, hoe geef je als begeleider onvoorwaardelijke ondersteuning bij het samen uitvoeren van betekenisvolle activiteiten, in situaties waarin probleemgedrag kan voorkomen? In de eerste onderzoekslijn van dit proefschrift is daarom de impliciete kennis van ervaren Triple-C begeleiders en orthopedagogen systematisch onderzocht om de beschrijving en de toepassing van het model explicieter te maken.

Naast de relaties van mensen met een verstandelijke beperking en probleemgedrag met begeleiders, zijn ook familierelaties van grote waarde. Er is echter weinig bekend over de betrokkenheid van familie in hun dagelijkse leven en in wie mensen met een verstandelijke beperking beschouwen als (emotioneel ondersteunende) familie. In de tweede onderzoekslijn van dit proefschrift wordt daarom de betrokkenheid van de familie bij persoonsgerichte benaderingen onderzocht. Er zal worden gekeken wie mensen met een licht verstandelijke beperking en probleemgedrag als hun familie beschouwen, en wat de kenmerken van hun familienetwerken zijn in termen van emotionele steun.

Hoofdstuk 2

Wetenschappelijk bewijs kan worden gegenereerd door systematisch interventies die als “good practice” worden beschouwd, te evalueren. Dit systematische proces is uitgevoerd en beschreven in hoofdstuk 2 voor de op praktijkervaringen gebaseerde Triple-C benadering. Het praktijkgerichte karakter van Triple-C betekent dat veel van de handelingen van professionals vaak worden ondersteund door hun impliciete kennis over de methodiek. Via een iteratief proces is de praktische kennis van Triple-C professionals (ontwikkelaars, orthopedagogen, teamleiders, managers en leden van de Raad van Bestuur) onderzocht en heeft documentenanalyse plaatsgevonden. Op basis van deze resultaten is een Triple-C logic model ontwikkeld om het model en de onderliggende aannames inzichtelijk te beschrijven. Het Triple-C logic model draagt bij aan een beter begrip van de verschillende onderdelen van de methodiek, door inzicht te geven in de onderliggende aannames, randvoorwaarden, werkende mechanismen en de verwachte uitkomsten. Daarnaast geeft het Triple-C logic model inzicht in de belangrijkste elementen van het model, zoals de behoefte aan een onvoorwaardelijke ondersteuningsrelatie tussen een begeleider en een persoon met een verstandelijke beperking en probleemgedrag, en het gezamenlijk uitvoeren van betekenisvolle activiteiten. Tot slot is gebleken dat het definiëren van de onderliggende aannames van benaderingen die zijn ontwikkeld vanuit de klinische praktijk, zoals het Triple-C model, een belangrijke eerste stap is in de richting van het leggen van een wetenschappelijke basis.

Hoofdstuk 3

Oprechte verbinding wordt beschouwd als een integraal onderdeel van een positieve relatie tussen een persoon met een verstandelijke beperking en een begeleider, wat een belangrijk onderdeel is van het Triple-C model. In hoofdstuk 3 wordt beschreven hoe de impliciete kennis van Triple-C orthopedagogen en begeleiders met betrekking tot de oprechte verbinding tussen begeleiders en mensen met een verstandelijke beperking en probleemgedrag werd onderzocht. Om inzicht te krijgen in wat Triple-C begeleiders en orthopedagogen beschouwen als een oprechte verbinding, zijn zes tweetallen, bestaande uit een persoon met een verstandelijke beperking en probleemgedrag en hun Triple-C begeleider, gefilmd tijdens het gezamenlijk uitvoeren van een activiteit. Van deze opnames werd een videocompilatie gemaakt. Tien Triple-C orthopedagogen en tien Triple-C begeleiders markeerden hierin de momenten die zij beschouwden als momenten van oprechte verbinding. De resultaten lieten zien dat dit voornamelijk aan de orde was wanneer de participanten concrete interacties zagen, zoals verbaal of fysiek contact. Daarnaast gaven ze hun interpretaties over wat zij beschouwden als indicatief voor deze oprechte verbinding tussen mensen met een verstandelijke beperking en probleemgedrag en hun begeleiders. Op basis van een thematische analyse werden vier thema's geïdentificeerd, namelijk: 1) de manier waarop verbindingen tussen begeleiders en mensen met een verstandelijke beperking zichtbaar worden, zoals gezamenlijke betrokkenheid bij een activiteit; 2) het belang van een door de begeleider gecreëerde veilige sfeer, bijvoorbeeld middels een toegankelijke houding; 3) het belang af te stemmen op de behoeften van mensen met een verstandelijke beperking, bijvoorbeeld door het aanpassen van hun nabijheid om een verbinding tot stand te brengen; en 4) het initiatief van mensen met een verstandelijke beperking zelf om in contact te komen met hun begeleiders. De resultaten van dit onderzoek laten zien dat de gezamenlijke betrokkenheid bij een activiteit een context creëert van kansen voor een oprechte verbinding. Een sensitieve houding en een veilige sfeer kunnen hierbij volgens de resultaten ondersteunend zijn.

Hoofdstuk 4

Het onderzoek in hoofdstuk 4 beschrijft de resultaten van een scoping review, waarin het type en de frequentie van familie betrokkenheid bij de toepassing van persoonsgerichte benaderingen in de ondersteuning voor mensen met een verstandelijke beperking en probleemgedrag wonend bij een zorgorganisatie is onderzocht. Zes databases (Embase, Medline, Web of Science, PsycINFO, Cochrane Central en Google Scholar) werden geraadpleegd. Publicaties die voldeden aan de volgende inclusiecriteria werden geïncludeerd: 1) gericht zijn op persoonsgerichte benaderingen voor mensen met een verstandelijke beperking en probleemgedrag, 2) die een uitkomstmaat bevatten met betrekking tot het probleemgedrag en 3) die gepubliceerd zijn tussen 2005 en 2019. Vijftien publicaties voldeden aan de inclusiecriteria, waarvan vijf publicaties over familiebetrokkenheid rapporteerden. De analyse laat zien dat frequentie van contact en betrokkenheid van familie verschillen afhankelijk van het type persoonsgerichte benadering dat werd toegepast (van het informeren van de familie over de persoonsgerichte aanpak tot het maandelijks bijwonen van voortgangsevaluaties). Omdat verondersteld wordt dat de ondersteuning van mensen met een verstandelijke beperking en probleemgedrag baat zal hebben bij een goede samenwerking tussen begeleiders en familie, wordt op basis van de resultaten van deze scoping review aanbevolen dat zorgorganisaties nadenken over manieren om de samenwerking met familie te verbeteren in relatie tot de zorg voor individuen met probleemgedrag.

Hoofdstuk 5

Om meer zicht te krijgen op wie mensen met een licht verstandelijke beperking tot hun familienetwerk rekenen en welke emotionele steun ze binnen deze netwerken ervaren, is de Family Network Method aangepast tot een instrument dat geschikt is voor mensen met een licht verstandelijke beperking (Family Network Method - Intellectual Disability; FNM-ID) Met behulp van de FNM-ID kan de multidimensionale aard van familienetwerken in kaart worden gebracht. In Hoofdstuk 5 wordt het proces beschreven hoe dit instrument is aangepast. Negentien mensen met een licht verstandelijke beperking namen deel aan een pilot. Op basis van hun suggesties en de ervaringen van de onderzoekers werd de FNM-ID gestructureerd, gestandaardiseerd en werden auditieve en visuele ondersteunende technieken aan het interviewprotocol toegevoegd.

De FNM-ID bestaat uit drie stappen. Allereerst wordt aan de participanten gevraagd wie zij beschouwen als hun (belangrijke) familie. Ten tweede wordt het perspectief van de participanten op de ontvangen en gegeven emotionele steun, tussen henzelf en hun familieleden, gemeten. Ten slotte wordt het perspectief van de participanten op de emotionele ondersteuningsrelaties tussen alle familieleden uitgevraagd. Om participanten te laten bepalen wie zij als familie beschouwen, is de term ‘familie’ bewust ongedefinieerd gelaten. De resultaten van de FNM-ID geven inzicht in wie mensen met een licht verstandelijke beperking als hun familie beschouwen, en hun perspectief op de emotionele ondersteuningsrelaties tussen al hun opgenoemde familieleden. Deze informatie geeft een meer gedetailleerd beeld van de opbouw en structuur van de bredere familiecontext, inclusief alle onderlinge verbindingen en afhankelijkheden. Het hoofdstuk bevat twee casussen om de toepasbaarheid van de FNM-ID te illustreren en om te laten zien welke sociale netwerkmaten er berekend kunnen worden op basis van de verkregen data (bijv. dichtheid, centraliteit en wederkerigheid). De in dit hoofdstuk beschreven FNM-ID werd vervolgens gebruikt om data te verzamelen voor de onderzoeken die worden beschreven in de hoofdstukken 6, 7 en 8.

Hoofdstuk 6

In dit hoofdstuk worden de perspectieven van mensen met een licht verstandelijke beperking en hun persoonlijk begeleiders op familienetwerken vergeleken. Om de perspectieven van beide groepen op het familienetwerk van de participant met een licht verstandelijke beperking in kaart te brengen werd gebruik gemaakt van de FNM-ID. Daarnaast vulden de persoonlijk begeleiders de Behaviour Problems Inventory-01 en de Adult Behaviour Checklist in om de mate van emotionele en gedragsproblemen te meten die participanten met een licht verstandelijke beperking vertoonden. In totaal namen 138 mensen met een licht verstandelijke beperkingen (18-40 jaar) en hun persoonlijk begeleiders (*n* = 138) deel aan het onderzoek.

De resultaten van dit onderzoek laten zien dat mensen met een licht verstandelijke beperking zelf hun familienetwerken als groter beschouwden. Tevens vonden ze dat ze meer emotionele steun gaven dan hun persoonlijk begeleiders dat vonden. Familieleden buiten het kerngezin (bijv. ooms, tantes, nichten) en schoonfamilie (meestal partners van de zussen en broers van de persoon met een licht verstandelijke beperking) werden vaker genoemd door mensen met een licht verstandelijke beperking als leden van het familienetwerk. De perspectieven op het familienetwerk verschilden nog sterker wanneer mensen met een licht verstandelijke beperking in een residentiele woonvoorziening wonen. Dit verschil kan mogelijk worden verklaard doordat participanten met een licht verstandelijke beperking hun familieleden buiten de zorgorganisatie ontmoetten. Eveneens werd er een verband gevonden tussen de mate van verschil in perspectief en de mate van externaliserend gedrag van de participanten met een licht verstandelijke beperking. Naarmate de participant meer externaliserend gedrag liet zien, waren de verschillen in perspectieven tussen beide groepen participanten groter. Wanneer participanten met een licht verstandelijke beperking daarentegen meer internaliserend gedrag vertoonden, kwamen hun perspectieven dichter bij die van hun persoonlijk begeleiders. Op basis van deze resultaten kan worden geconcludeerd dat het onwaarschijnlijk is dat mensen met een licht verstandelijke beperking en hun persoonlijk begeleiders dezelfde kijk hebben op de familienetwerken van mensen met een licht verstandelijke beperking. Factoren die invloed hebben op dit verschil in perspectief tussen beide groepen zijn de woonsituatie en de emotionele en gedragsproblemen van de persoon met een verstandelijke beperking.

Hoofdstuk 7

In de studie in hoofdstuk 7 werd onderzocht of probleemgedrag van mensen met een licht verstandelijke beperking invloed heeft op de familierelaties. Ook voor dit onderzoek werd de FNM-ID gebruikt om de familienetwerken van mensen met een licht verstandelijke beperking met en zonder probleemgedrag in kaart te brengen. Vervolgens werd gekeken of participanten met en zonder probleemgedrag van elkaar verschilden op zeven verschillende familienetwerkmaten. De Behaviour Problems Inventory-01 werd gebruikt om te bepalen of een participant probleemgedrag vertoonden. Op basis van de werkdefinitie van deze vragenlijst vertoonden 36 van de 138 deelnemers probleemgedrag. De zeven netwerkmaten die werden vergeleken waren: de grootte van het familienetwerk, de grootte van het belangrijke familienetwerk, de dichtheid van het familienetwerk, het aantal wederzijdse ondersteunende relaties binnen het familienetwerk, het aantal wederzijdse ondersteunende relaties die de participant met een licht verstandelijke beperking heeft met zijn familieleden, de hoeveelheid ontvangen en gegeven emotionele steun van de participant en de hoeveelheid familieleden die de participant in één stap binnen zijn familienetwerk kan bereiken (d.w.z. direct, zonder tussenliggend familielid). De resultaten lieten zien dat de mate van probleemgedrag niet samenhing met familienetwerk kenmerken en de ervaren emotionele steun. Er werden slechts enkele, en over het algemeen kleine, verschillen gevonden tussen de familienetwerken van mensen met of zonder probleemgedrag. Zo werd er een matig groepsverschil gevonden voor de onderlinge ondersteuning in het gehele familienetwerk. In vergelijking met participanten zonder probleemgedrag ervaarden mensen met probleemgedrag minder wederzijdse steun in hun gehele familienetwerk. De resultaten van dit onderzoek suggereren dat mensen met een licht verstandelijke beperking en probleemgedrag de kwaliteit van hun familierelaties op een vergelijkbare manier ervaren als mensen zonder probleemgedrag. Echter, vanwege de kleine steekproef van participanten met probleemgedrag is voorzichtigheid geboden bij het interpreteren van deze bevindingen.

Hoofdstuk 8

In de laatste studie is op basis van perspectieven van mensen met een licht verstandelijke beperking een verkennend onderzoek uitgevoerd naar verschillende familienetwerktypologieën met betrekking tot emotionele ondersteuning binnen het familienetwerk. Hiertoe werden de familienetwerken, gemeten met de FNM-ID, van 137 deelnemers met een licht verstandelijke beperking geanalyseerd.

Om verschillende familietypologieën te identificeren werd een latente klassenanalyse op basis van zeven sociale netwerkmaten uitgevoerd. Op basis van de latente klassenanalyse kwamen vier te onderscheiden familienetwerktypologieën voort. Twee van de typologieën kunnen worden gekarakteriseerd als ondersteunend en twee als minder ondersteunende familienetwerken. In de ondersteunende familienetwerktypologieën maakt de persoon met een licht verstandelijke beperking deel uit van een hechte (wederzijds ondersteunende) groep familieleden. Het verschil in deze twee ondersteunende netwerktypen is dat het tweede typen gemiddeld kleiner is, en dat er in deze familienetwerken gemiddeld net iets meer emotionele ondersteuning wordt gegeven en ontvangen dan in het eerste ondersteunende netwerktype. In de minder ondersteunende familienetwerktypologieën ervaren mensen met een licht verstandelijke beperking minder familiegericht sociaal kapitaal. Dit wil zeggen dat de mensen met een verstandelijke beperking een kleiner familienetwerk hebben met betrekking tot zowel de omvang als de emotionele ondersteuning, of, wanneer de omvang van het familienetwerk groter is, dat deze mensen met een licht verstandelijke beperking meer afstand tot hun familieleden ervaren.

Daarnaast werd gekeken naar mogelijke verbanden tussen de familienetwerktypologieën en persoonlijke kenmerken van de participanten met een licht verstandelijke beperking, hun emotionele en gedragsproblemen, en hun welzijn. Data over gedrags- en emotionele problemen werden verkregen met behulp van de Adult Behaviour Checklist (ingevuld door persoonlijk begeleiders), en het welzijn werd gemeten met de Personal Wellbeing-Index (ingevuld door participanten met een licht verstandelijke beperking zelf). Er werd een kleine samenhang gevonden tussen emotionele en gedragsproblemen en een van de ondersteunende typologieën. Participanten van een van de ondersteunende familienetwerktypologieën scoorden hoger op de sub schalen “regel overtredend gedrag” en “intrusief gedrag” van de Adult Behaviour Checklist. Deze uitkomsten lijken in strijd met eerder onderzoek dat aantoonde dat probleemgedrag een negatief effect heeft op het krijgen en geven van steun. Twee mogelijke hypothesen zouden dit resultaat kunnen verklaren. Ten eerste zouden participanten met gedragsproblemen een positiever denkbeeld van zichzelf kunnen hebben wat hun zelfperceptie vergroot en waardoor ze positievere antwoorden geven. Ten tweede zijn agressievere mensen minder passief en veeleisender, en zijn ze hierdoor wellicht beter in het onderhouden van relaties met familieleden. Concluderend laten de resultaten zien dat hoewel het sociaal kapitaal van mensen met een licht verstandelijke beperking doorgaans laag is, er enige variatie is in de grootte van het netwerk en de emotionele ondersteuning in het familienetwerk. Dit suggereert dat mensen met een licht verstandelijke beperking verschillende ondersteuningsbehoeften hebben, in termen van het versterken of uitbreiden van hun familienetwerk.

Hoofdstuk 9

In de algehele discussie in hoofdstuk 9, worden tot slot de bevindingen van dit proefschrift samengevat en geïntegreerd, en de implicaties voor beleid en praktijk besproken.

Het Triple-C logic model beschrijft de aannames, randvoorwaarden, werkende mechanisme en de verwachte uitkomsten van Triple-C. Bevindingen van de eerste onderzoekslijn naar het Triple-C model kunnen bijdragen aan duidelijkere communicatie tussen professionals, wat uiteindelijk zal resulteren in een meer optimale uitvoering, en een beter gedeeld begrip van Triple-C. Tevens dragen de resultaten bij aan een belangrijke eerste stap in de richting van het leggen van een wetenschappelijke basis voor Triple-C. De resultaten uit het onderzoek benadrukken dat de elementen in het logic model geen 'menu' van opties zijn waar men uit kan kiezen. Om Triple-C effectief te implementeren, wordt het gecombineerd gebruik van alle elementen van het logic model sterk aanbevolen, waarbij alle niveaus van een organisatie betrokken zijn. Wanneer er specifieker naar de toepassing van een belangrijk element van Triple-C wordt gekeken (de relatie tussen mensen met een verstandelijke beperking en probleemgedrag en begeleiders), laten de resultaten zien dat gezamenlijke betrokkenheid bij een betekenisvolle activiteit de context creëert om tot een oprechte verbinding te komen. Een sensitieve en toegankelijke houding van begeleiders ten opzichte van mensen met een verstandelijke beperking en een veilige sfeer zijn daarbij ondersteunend. Bovendien werden door de begeleiders en orthopedagogen specifieke aandachtspunten genoemd, zoals het geven van instructies en het gebruik van gebaren, die waardevol werden geacht voor begeleiders om een oprechte verbinding te maken of te behouden met mensen met een verstandelijke beperking en probleemgedrag.

De resultaten van de tweede onderzoekslijn (onderzoeken naar familienetwerken) van dit proefschrift suggereren dat de ondersteuning van mensen met een verstandelijke beperking en probleemgedrag effectiever en duurzamer is wanneer deze ondersteuning tot stand is gekomen en wordt geïmplementeerd in samenwerking tussen familie en begeleiders. Het Triple-C model heeft nog geen concrete beschrijving van het betrekken van familie in de begeleiding en behandeling van mensen met probleemgedrag. Het betrekken van familieleden bij de toepassing van Triple-C kan evenwel een waardevolle aanvulling zijn. Wanneer mensen met probleemgedrag deels in een zorgorganisatie en deels bij hun familie verblijven, kan het toepassen van Triple-C in beide situaties leiden tot meer consistente ondersteuning, bijvoorbeeld door hetzelfde dagelijkse programma te gebruiken of door op eenzelfde manier te reageren op het probleemgedrag van de betreffende persoon. In dit soort situaties kan het nuttig zijn om betrokken familieleden te trainen in het gebruik van Triple-C.

De resultaten van dit proefschrift laten verder zien dat professionals (bijv. begeleiders of orthopedagogen) zich meer bewust kunnen zijn van wie mensen met een licht verstandelijke beperking en probleemgedrag beschouwen als (belangrijke) familie. Op basis van de resultaten van dit proefschrift wordt deze kennis van groot belang geacht voor professionals om familie bij het leven van mensen met een licht verstandelijke beperking en probleemgedrag te kunnen betrekken. De ervaren emotionele steun binnen het familienetwerk van mensen met een licht verstandelijke beperking en probleemgedrag die bij een zorgorganisatie wonen, verschilt niet van die van mensen met een licht verstandelijke beperking zonder probleemgedrag, hoewel het soort probleemgedrag dat men laat zien wel degelijk invloed lijkt te hebben op hoe goed begeleiders het familienetwerk van het individu kennen. Dit gebrek aan kennis kan impact hebben op de relaties tussen mensen met een verstandelijke beperking en probleemgedrag en hun familie. Dat wil zeggen, wanneer begeleiders beter geïnformeerd zijn, zijn ze wellicht beter in staat om mensen met een licht verstandelijke beperking en probleemgedrag te ondersteunen om het contact met hun familieleden te behouden, te versterken of uit te breiden. Tevens laten de resultaten in dit proefschrift zien dat er verschillende gezinscontexten zijn wat emotionele steun betreft. Daarom wordt aanbevolen dat begeleiders voldoende tijd krijgen om zich te verdiepen in de familienetwerken van mensen met een licht verstandelijke beperking en probleemgedrag. Dit inzicht in het familienetwerk kan mensen met probleemgedrag helpen om betekenisvolle sociale contacten te onderhouden met belangrijke anderen, om een gevoel van verbondenheid te ervaren, en om de mogelijkheid te hebben om deel te nemen aan gewaardeerde, gelijkwaardige relaties.

Samenvattend kan op basis van de resultaten van dit proefschrift worden geconcludeerd dat de ontwikkeling van het Triple-C logic model een belangrijke stap is in het systematischer in de praktijk toepassen en wetenschappelijk onderbouwen van het Triple-C model. Daarnaast blijkt dat het betrekken van familie bij Triple-C een waardevolle toevoeging kan zijn, omdat familieleden een belangrijke rol spelen bij het bieden van emotionele steun aan mensen met een verstandelijke beperking en probleemgedrag.

Dankwoord (Acknowledgements)
Curriculum Vitae
Publications

Dankwoord

Toen ik in 2012 mijn master Orthopedagogiek afrondde aan de Universiteit Leiden, was ik klaar voor een baan in de praktijk. Ik kreeg de kans om als orthopedagoog bij ASVZ aan de slag te gaan, in combinatie met enkele onderzoekstaken. Uiteindelijk groeide deze onderzoekstaken uit tot een promotieonderzoek naar Triple-C. Ondanks de uitdagingen die een promotieonderzoek met zich meebrengt, ben ik erg blij dat ik toen voor het wetenschappelijke pad heb gekozen. Door deze uitdagingen, heb ik namelijk veel geleerd gedurende het proces. Hiervoor ben ik een aantal mensen dankbaar die ik op deze plek graag wil benoemen.

Allereerst, zonder de deelname van mensen met een verstandelijke beperking, hun familieleden, begeleiders en andere zorgprofessionals was dit proefschrift nooit tot stand gekomen. Ik ben jullie bijzonder dankbaar voor jullie deelname en openheid om jullie ervaringen en kennis met mij te delen. Daarnaast wil ik de medewerkers van Amarant, ASVZ, Dichterbij, Prisma en Zuidwester bedanken die een rol hebben gespeeld in de werving van alle deelnemers.

Zonder mijn begeleidingsteam was het nooit gelukt om deze promotiestudie te voltooien. Petri, jouw inzet voor mensen met een verstandelijke beperking vind ik bewonderingswaardig. Je arbeidsethos is onevenaarbaar, en ondanks alle drukte blijf je beschikbaar en betrokken. Je hebt me veel geleerd op het gebied van onderzoek doen, en je hebt mij af en toe morele ondersteuning moeten bieden op de momenten dat ik twijfelde aan mijn onderzoeksvaardigheden. Naast het begeleiden van dit project heb je me ook veel geleerd over het werkveld en hoe je je hierin kunt bewegen. We hebben fijne gesprekken gehad tijdens onze werkoverleggen, congressen en telefoontjes tussendoor. In deze gesprekken vroeg je door, zodat ik plekken kwam waar ik nog nooit was geweest. Hierdoor werden deze reflectieve gesprekken een avontuur met mijzelf en hebben ze mij als professional en als mens doen ontwikkelen. Dank hiervoor. Lex, het is een gave wanneer mensen ingewikkelde methodieken en statistieken helder kunnen verwoorden. Als ik in de kramp schoot wanneer ik bepaalde analyses moest uitvoeren was jij hierin de redelijkheid. Als we samen in je knusse kantoor aan de grenen tafel de onderzoeksresultaten aan het interpreteren waren (inclusief gevulde snoep pot en/of koektrommel) vond ik statistiek zelfs leuk worden! Je wist met je kritische vragen en suggesties de onderzoeksopzet kwalitatief altijd weer een stapje verder te krijgen. Ik vond het heel erg prettig om met jou samen te werken. Andrew, I admire the commitment you have for people with intellectual disabilities and how you give them a voice through research. I thank you for all your helpful and motivating support during this project. You taught me how to interpret research results carefully and in the context of the target population.

I would also like to thank prof. dr. Richard Hastings for his valuable supervision. Richard, your knowledge and expertise in the research on people with intellectual disabilities and challenging behaviour, and complex interventions were very valuable for this project. I have learned a lot from your strong theoretical, methodological and analytical expertise.

Op deze plek wil ik ook graag de Raad van Bestuur van ASVZ bedanken. De kans die jullie mij hebben geboden om mij te mogen ontwikkelen als wetenschapper, professional en als mens heb ik als zeer waardevol ervaren. Hanneke, ik kan mij nog als de dag van gister herinneren dat je mij deze kans aanbood. Ik ben je nog steeds dankbaar dat je mij het zetje in de juiste richting hebt gegeven en het onderzoek in al die jaren met interesse en vertrouwen hebt gevolgd.

Hans en Dick, ik heb veel bewondering voor de moed die jullie hebben getoond om jullie model tegen het wetenschappelijke licht te laten houden. Ik dank jullie voor het vertrouwen wat jullie in mij hebben gesteld om deze taak uit te voeren. Jullie waren altijd bereid om mijn ontelbare vragen te beantwoorden en mee te lezen met mijn stukken om te controleren of ik jullie gedachtengoed juist had geïnterpreteerd. Ik heb onze samenwerking als zeer prettig ervaren met als hoogtepunt onze gezamenlijke presentatie op het European Association for Mental Health in Intellectual Disability congres in Luxemburg.

Daarnaast wil ik hier ook graag de overige leden van de ASVZ klankbordgroep bedanken voor het volgen, meedenken en het stellen van (kritische) vragen aangaande het onderzoek. Cees, ik heb het als erg waardevol ervaren om een onderzoeker van 'buiten' mee te laten denken in de onderzoeksvragen en -opzetten. Je hebt hiermee aanscherpingen aangebracht in het project. Lucy, het is fijn om een collega te hebben zoals jij; iemand met wie je kunt lachen, persoonlijk betrokken is, maar ook iemand die kritisch blijft. Ik ben blij dat we elkaar straks weer vaker gaan treffen in onze dagelijkse werkzaamheden. Maarteke, we kenden elkaar al vanuit de volleybal wereld voordat we wisten dat we allebei bij ASVZ werkten. Je bent later in dit project aangehaakt, toen je als manager Zorgondersteuning en Zorgontwikkeling aan de slag ging. Het is fijn om een manager te hebben die je vertrouwen geeft, goed kan luisteren en de juiste reflectieve vragen weet te stellen.

De leden van de promotiecommissie prof. dr. Kees Ahaus, prof. dr. Dike van der Mheen, prof. dr. Xavier Moonen, prof. dr. Carlo Schuengel en dr. Nienke Peters-Scheffers wil ik graag bedanken voor de bereidheid om dit proefschrift kritisch te beoordelen en deel te nemen aan de oppositie.

Het promotieonderzoek heb ik uitgevoerd bij Tranzo, een onderzoeksdepartement van Tilburg School of Social and Behavioral Sciences. Hier heb ik mij altijd zeer welkom gevoeld, dank daarvoor Henk en Dike. Ook wil ik graag alle Tranzo collega's bedanken voor de fijne werkomgeving, gezellige lunchbijeenkomsten, team- en heidagen. Speciale dank gaat ook uit aan alle kamergenoten in de afgelopen jaren. Hannah en Bianca, toen ik begon met dit onderzoek deelden we een kamer in het Tias gebouw. We hebben fijne gesprekken gehad over het doen van onderzoek, promoveren, maar ook allerlei persoonlijke thema's passeerde de revue. Kim, je harde werken en doorzettingsvermogen waren een voorbeeld voor mij. We hebben veel gelachen, maar ook serieuze gesprekken kunnen voeren over zowel werk als thuis. Marion, met jouw werkervaring bij de VGN leerde je mij ook een andere kant van de zorg kennen. Je reflecties op ons werk en de grondigheid waarmee jij je werk uitvoert, hebben mij veel geleerd. Suzanne, Leonieke en Ylva, met jullie heb ik mijn laatste jaren in de Reitse Poort een kamer gedeeld. Leonieke en Ylva, ik heb het als erg waardevol ervaren om met onderzoekers uit andere werkvelden te kunnen sparren en om ervaringen te kunnen delen. Suzanne, we hebben veel met elkaar gesproken over de zorg aan mensen met een verstandelijke beperking en probleemgedrag. Ik vond het erg interessant om de ontwikkelingen van jouw project van dichtbij te kunnen volgen. We zullen elkaar vast nog tegenkomen!

Daarnaast wil ik ook graag alle (oud)collega's van de Academische Werkplaats Leven met een verstandelijke beperking bedanken voor de fijne samenwerking. Luciënne, dank voor je inzet tijdens onze werving, en voor het coördineren van de factsheet en het praktijkproduct. Ik waardeer het dat ik altijd even bij je binnen kon lopen voor een vraag of gewoon een gezellig praatje. Elsbeth, ik zal onze dagen in het Tias kantoor niet gauw vergeten, waar we omgeven door honderden strookjes, grip probeerde te krijgen op alle Triple-C thema's. Ik wil je graag bedanken voor de fijne samenwerking, ik kon altijd bij je terecht voor een luisterend oor of met de vraag om weer eens 'mee te lezen'. Noud, als ik een vraag had was jij zo ongeveer altijd mijn eerste hulplijn. Maar daarnaast kan ik ook ongelofelijk met je lachen. Dank voor de fijne samenwerking. Marloes, ik herinner me nog goed hoe zenuwachtig we waren voor onze allereerste presentatie tijdens ons eerste bezoek aan het internationale congres van de International Association for the Scientific Study of Intellectual and Developmental Disabilities in Melbourne. Ik zal deze gezamenlijke ervaring nooit vergeten, het was een leerzame reis die we hebben gedeeld. Cathelijn, mijn mede ASVZ-collega onderzoeker, ik heb enorm veel bewondering voor de theoretische en praktijk kennis die je altijd paraat hebt. Maar ook je motiverende woorden heb ik erg gewaardeerd in de afgelopen jaren. Marieke en Kayleigh, 'nieuwe' collega's die ik alleen nog maar heb ontmoet via het beeldscherm dankzij de Covid-19 maatregelen, ik wil jullie bedanken voor het nalezen van het gehele manuscript. Als laatst wil ik graag Ad, Angélique en Ria bedanken die mij tijdens het promotieonderzoek hebben ondersteund met het verzamelen en analyseren van data.

Een speciaal woord van dank gaat ook uit naar mijn paranimfen: Sanne en Sascha. Sanne, we zijn ongeveer tegelijk begonnen aan onze projecten. Ik vond het heel erg fijn dat ik gedurende het project samen met jou heb kunnen optrekken. Niet alleen om te kunnen leren van je wetenschappelijke expertise, zoals je scherpe analytische blik en schrijfvaardigheden, maar ook juist om de persoonlijke klik die we hebben. We hebben heel wat lief en leed gedeeld. Ik ben blij dat je vandaag achter mij staat. Sascha, we kennen elkaar al heel ons leven en zijn samen opgegroeid. Het voelt altijd vertrouwd als we samen zijn. We hebben beiden een passie voor lekker eten en drinken, waardoor we graag alle nieuwste horeca tentjes in Rotterdam afgaan. Daarnaast kan ik alles met je delen en hebben we vaak aan een half woord al genoeg. Dank dat je vandaag mijn paranimf wilt zijn.

Mijn lieve vriendinnen: Joja, Irene, Mirjam, Léonie, Sophie, en Michèlle. Joja, ook al zien we elkaar niet vaak door onze drukke levens, als we samen zijn voelt het vertrouwd. Ik waardeer onze gesprekken over werk, en inmiddels ook hoe we dit combineren met een gezin. Irene, onze vriendschap ontstond in het volleybalveld, maar inmiddels, nu we onze volleybalschoenen aan de wilgen hebben gehangen, zien we elkaar nog steeds (al dan niet met kids). Ik kan altijd enorm met je lachen en waardeer de manier waarop je vol overgave voor dingen kunt gaan. Mirjam, we kennen elkaar nog niet zo lang, maar als we met onze meisjes afspreken voelt het altijd heel ontspannen. Ik vind het fijn om met een gelijkgezinde de ervaringen over het moederschap te kunnen delen. Léonie en Sophie, onze vriendschap gaat al heel wat jaartjes terug. Ik vind het heel bijzonder dat we in al die jaren al zoveel mijlpalen met elkaar hebben kunnen delen. We zijn allen onze eigen weg gegaan, maar toch blijven we verbonden. Michèlle, ook onze geschiedenis gaat ver terug (samen op zondag spelen bij Opa en Oma, of bij jullie thuis in de kas). Inmiddels zijn we beiden moeder van twee meiden, en delen we onze ervaringen. Het voelt altijd vertrouwd als we samen zijn. Een groep mensen die ook al jaren meegaan zijn de vrienden en vriendinnen van 'BZ' alias 'Belangrijke Zaken'. Ook hier heb ik met veel van jullie een ontwikkeling doorgemaakt van tiener tot werkende ouder. Maar ondanks deze veranderingen zijn de borrels, feestjes en weekendjes weg nog steeds even gezellig!

Tot slot mijn eigen familie. Willem en Ria, bedankt voor al jullie interesse en dat jullie altijd voor ons klaar staan. Renzo en Carlijn, ondanks dat we elkaar niet vaak zien door de topografische afstand vind ik het altijd fijn om bij jullie te zijn. Door de gezamenlijke interesses die we delen (het jonge ouderschap, een huis bouwen/renoveren, volleybal en werk), maar ook de lol die we hebben!

Titi, mijn zorgzame en spontane zus. Ik heb bewondering voor je tomeloze energie, creativiteit en enthousiasme. Je ziet overal mogelijkheden, geeft nooit op, en bent een enorm harde werker. Ik vind het fijn om te merken dat onze relatie is meegegroeid van 'kleine en grote zus' naar gelijkwaardig. Hev, ik ben blij dat je bij ons in de familie bent gekomen. Met je grote praat en zelfspot pas je er goed tussen. Ik kan enorm om en met je lachen! Lieve, serieuze Luba, het is zo mooi om van dichtbij te zien hoe je je hebt ontwikkeld van meisje naar jonge vrouw. Je hebt zoveel in je mars, ik ben benieuwd waar het je gaat brengen! Germaine, ook al wonen we ver bij elkaar vandaan, de momenten dat we bij elkaar zijn voelen altijd vertrouwd. Ik herken mijzelf in jou in de manier waarop je de dingen in het leven wilt organiseren. Ik vind het altijd heel gezellig om te kletsen over alle ontwikkelingen in onze thuisstad Rotjeknor. Lieve Maya, je bent een slimme en creatieve meid, met een zacht karakter en een enorm gevoel voor humor! De door jou gemaakte stamboom hangt hier met trots aan onze muur.

Thomas, vroeger konden we elkaar letterlijk de tent uit vechten, maar naarmate de jaren vorderde werd onze relatie meer volwassen, en delen we een enorm goed gevoel voor humor ;-). Onder jouw ruwe bolster huist een blanke pit met een goed hart, die ook nog eens een echte family-man is. Ik vind het heel fijn dat we zo vaak bij elkaar over de vloer komen. Marit, je bent een intelligente, genuanceerde tegenhanger van Thomas. Ik ben blij dat je mijn schoonzusje bent, ik kan enorm met je lachen, we hebben zo ongeveer dezelfde inrichting, en samen op vakantie of wintersport gaan is altijd heel relaxed.

Lieve pap en mam, jullie zijn er altijd voor ons, geen vraag is te veel. Dank voor alle kansen die jullie mij hebben geboden. Ik vind het heel fijn dat jullie altijd dichtbij zijn en we regelmatig met elkaar op pad gaan, zoals vakanties en etentjes. Mam, je kent mij door en door, je hebt vaak al eerder dan ikzelf door als mij wat dwars zit. Ik waardeer het enorm dat ik mijn hart altijd bij je kan luchten. Pap, samen klussen is echt ons ding, ik hoop dit nog lang met je te kunnen doen! Je betrokkenheid bij Carice en Maxime vind ik heel mooi om te zien, ik hoop dat ze nog lang van je kunnen genieten.

Sander, in mijn hele leven ben ik inmiddels meer met, dan zonder jou. De manier waarop we elkaar aanvullen maar ook hetzelfde zijn, maakt dat ik zo gelukkig ben met jou. Als ik met jou ben weet ik dat alles altijd goed komt. Lieve Carice en Maxime, jullie hebt mij laten ervaren hoe onvoorwaardelijke moederliefde voelt. Iedere dag met jullie is een feestje. Jullie energie, vrolijkheid en zachtaardigheid hebben mij doen beseffen wat er echt toe doet in het leven.

Curriculum Vitae

Tess Tournier werd op 11 oktober 1986 geboren te Rotterdam. In 2005 behaalde zij aan het IJsselcollege te Capelle aan den IJssel haar vwo-diploma. Vervolgens ging zij Oefentherapie Cesar studeren aan de Hogeschool Utrecht, waar zij in 2009 haar diploma behaalde. Na het afronden van deze opleiding ging zij aan het werk als kinderoefentherapeut op een school voor kinderen met gedragsproblemen. Hier behandelde ze kinderen met motorische ontwikkelingsachterstanden. Daarnaast startte zij met de premaster orthopedagogiek, om in 2010 toegelaten te worden tot de master Orthopedagogiek aan de Universiteit Leiden. Tijdens deze master wisselde ze haar baan als kinderoefentherapeut in, om aan de Hogeschool Utrecht les te geven aan de opleiding Oefentherapie Cesar. In het laatste jaar van haar master Orthopedagogiek liep ze stage als orthopedagoog bij de zorginstelling ASVZ. Haar master ronde ze in 2012 af, waarna zij een open sollicitatie stuurde om te mogen werken als orthopedagoog bij ASVZ. In februari 2013 werd ze bij ASVZ aangesteld als orthopedagoog, gecombineerd met wetenschappelijk onderzoek naar Triple-C. In februari 2014 liep dit over in een aanstelling als promovenda bij ASVZ en was zij vanuit deze aanstelling verbonden aan de Academische Werkplaats Leven met een verstandelijke beperking (Tranzo, Tilburg University), waar zij onder begeleiding van prof. dr. Petri Embregts (Tilburg University), dr. Lex Hendriks (Radboud Universiteit) en prof. dr. Andrew Jahoda (University of Glasgow, Verenigd Koninkrijk) haar promotieonderzoek heeft uitgevoerd. Momenteel werkt zij als orthopedagoog bij ASVZ.

Tess Tournier was born on October 11, 1986 in Rotterdam, the Netherlands. In 2005, she graduated from pre-university education at IJsselcollege in Capelle aan den IJssel. Afterwards, she studied Kinetics Therapy at the University of Applied Sciences Utrecht. After completing this study in 2009, she started working as a kinetics therapist at a school for children with behavioural problems, treating children with motor developmental delay. In addition, she started a pre-master in Education and Child Studies, followed by the master program in Clinical Child and Adolescent Studies (Orthopedagogiek) at Leiden University in 2010. During this master, she exchanged her job as a kinetics therapist to become a teacher at Kinetics Therapy education at the University of Applied Sciences Utrecht. In the last year of her master's in Clinical Child and Adolescent Studies, she did an internship as a psychologist at ASVZ, a service facility for people with intellectual disabilities. After completing her master's degree she started to work at ASVZ as a psychologist in February 2013. As of February 2014, she started as a PhD candidate at ASVZ in collaboration with the Academic Collaborative Centre Living with an intellectual disability (Tranzo, Tilburg University), where she was supervised by prof. dr. Petri Embregts (Tilburg University), dr. Lex Hendriks (Radboud University) and prof. dr. Andrew Jahoda (University of Glasgow, United Kingdom). The results of this research are presented in this thesis. She currently works as a psychologist at ASVZ.

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