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Family Involvement in Person-Centered Approaches for People with Intellectual Disabilities and Challenging Behaviors: A Scoping Review

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ABSTRACT

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

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-centered approaches.

Conclusion: More active family involvement in person-centered approaches for people with intellectual disabilities and challenging behaviors is recommended.

KEYWORDS

Person-centered approach; family involvement; scoping review

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 move to supported accommodation, as their intellectual disabilities causes significant

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limitations both in intellectual functioning and in adaptive behavior (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 families are unable to continue their support due to challenging behaviors (Brown et al., 2011; Llewellyn et al., 1999). Challenging behaviors include behaviors that challenges families, support staff and other professionals (NICE Guideline, 2015). Challenging behaviors are a social construction and can be defined as follows: 1) when the behavior breaks social norms, and 2) when the behavior 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 behaviors that challenges toward 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 behaviors, that positive family relationships could have a positive effect on the behaviors of people with intellectual disabilities. Challenging behaviors 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 behaviors.

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 behaviors, 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 judgment and insight into individuals' needs, thereby even contributing to challenging behaviors (Mooney & Lashewicz, 2014). Relationships between families and support staff often seem to be characterized 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-centered support framework. Every individual has their own specific needs and person-centered approaches attempt to personalize their support to meet these needs (Klatt et al., 2002; Sanderson, 2000). A person-centered 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 behaviors (Carr et al., 2002). Person-centered approaches also adopt an open-ended approach toward the individuals with intellectual disabilities. They are multi-element approaches, with the aim of improving the person's quality of life (i.e. not just on changing behaviors). 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 Behavioral 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-centered approaches can be implemented by professionals and/or family members. The current study focuses on person-centered approaches implemented by professionals, as little is known what, if any role, family members play in the delivery of person-centered 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-centered approach in the care for people with intellectual disabilities and challenging behaviors, 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-centered intervention? 3) what role did families play in the delivery of the person-centered 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 behavior" and "person-centered 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.

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)

Eligibility Criteria

Publications were included if the study concerned people with intellectual disabilities and challenging behaviors. When the study reported the delivery of a "person-centered" approach. That is, an approach that (1) adopts an open-ended approach toward the person with 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 behaviors); (3) requires delivery by multiple members of health and/or social care teams. Last, studies were included when an outcome measure concerned challenging behaviors 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-centered approaches emerged in the 1980s, an evidence base for person-centered approaches was established at a later date e.g., Robertson et al. (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).

Data Synthesis and Analysis

Two reviewers (INITIALS AUTHOR 1 and INITIALS AUTHOR 2) 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 (INITIALS AUTHOR 2) screened the remaining publications. Full text copies of all potentially relevant articles were then obtained. Again, two reviewers (INITIALS AUTHOR 1 and INITIALS AUTHOR 2) 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 (INITIALS AUTHOR 2). 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-centered 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 INITIALS AUTHOR 2. When in doubt about any detail, a second reviewer (INITIALS AUTHOR 1) was

Table 2. Study characteristics.

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
Beadle-Brown et al., (2012) UK	12 month trial	29 people, level of ID not reported Sex: NR Age: 44 (range 20–61) Challenging behavior 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-centered Active Support Training staff Staff received 1-day workshop on principles of person-centered 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 behaviors, no significant decrease in challenging behaviors
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 behavior 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 behaviors

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
De Wein and Miller (2009) USA	33 month multiple baseline case study	2 people with moderate or severe ID Sex: 2 males Age: 28–37 years Challenging behavior 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 behaviors decreased.

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
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 behavior 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 behavior 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 behavior 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 Behavioral Support. Including a functional assessment and personal behavioral support plan Training staff Not reported Personal plan A behavioral support plan including environmental accommodations, direct interventions, functional skills teaching and reactive strategies.	Family was interviewed by a board-certified behavior analyst to develop interim behavioral recommendations prior to a formal behavioral support plan.	No	Frequency of physical aggression was counted and monthly reported, challenging behaviors decreased when Positive behavioral Support was applied

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
Jones et al. (2013) UK	22 month trial	3 people with severe ID Sex: 2 males, 1 female Age: 48 (range 46–51) Challenging behavior 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 behavior' training'. Personal plan An individual Behavior Support Plan was created by a specialist behavior team, focusing on secondary prevention and reactive strategies.	Not reported	No	Frequency of challenging behaviors was counted, challenging behaviors decreased
		1 person with severe ID Sex: 1 female Age: mid-40s Challenging behavior present at baseline: aggression and/or self-injury and territorial behavior 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 behavior" training'. Personal plan Not reported	Not reported	No	Frequency of challenging behavior was counted, challenging behaviors decreased

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
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 behavior 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 Behavior Checklist for Adults, challenging behaviors 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 behavior 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 Behavioral Support; a functional assessment to determine causes of the challenging behavior and execution of the multi-element Behavioral 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 behavioral 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 behaviors were counted, all types of challenging behavior decreased

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
MacDonald et al. (2018) UK Aberrant Behavior Checklist, challenging behaviors decreased significantly	12 month	controlled trial	50 people, level of ID not reported Sex: 35 males, 15 females Age: 41 (range 18–63) Challenging behavior present at baseline: present in some, but not all participants Type of living situation: community group homes	Approach Positive Behavior 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

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
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 behavior 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 Behavioral Support; functional assessments (informant assessments, descriptive assessments, behavioral 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 nonviolent 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 behavioral 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 behavior was counted, challenging behaviors decreased

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
McGill et al. (2018) UK Aberrant Behavior Checklist-Community, challenging behavior decreased significantly	11 month cluster	randomized controlled trial	38 people, ID Sex: 13 males, 24 females Age: 48 (range 19–84) Challenging behavior present at baseline: 24 presented with challenging behavior Type of living situation: residential setting (1–8 residents)	Approach Setting-wide Positive Behavioral 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

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
Sandjojo et al. (2018) The Netherlands Developmental Behavior Checklist, no decrease in challenging behaviors	6 month	controlled trial	15 people with a borderline, mild, moderate or severe ID Sex: 8 males, 7 females Age: 31 (range) Challenging behavior 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
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 behavior present at baseline: some participants presented with challenging behavior 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 behavior decreased significantly

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
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 behavior 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 behaviors

(*Continued*)

Table 2. (Continued).

Author(s), year, country and quality	Study design	Study population	Person-centered approach	Family involvement	Outcome on family contact	Outcome on challenging behaviors
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 behavior present at baseline: at least 1 participant of each home presented with challenging behavior 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 Behavior Check List,		Quantification of Aggression Scale, no decrease in challenging behaviors				

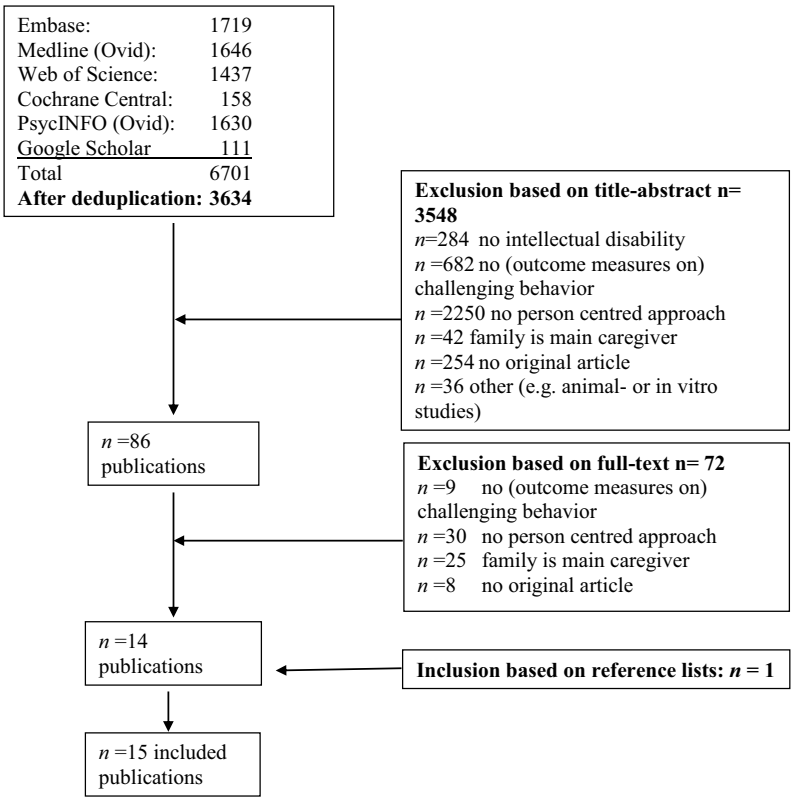

Figure 1. Selection of included publications.

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-centered approaches (e.g., pharmacotherapy, specific training such as social problem solving skills) or did not describe an outcome measure on challenging behaviors 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-centered approaches applied to people with intellectual

disabilities and challenging behaviors and included an outcome measure about challenging behaviors.

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 disability, in one study the Adaptive Behavior 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-Centered Approaches

The fifteen studies reported on six different person-centered approaches; five studies reported on PBS (Grey et al., 2018; MacDonald et al., 2010, 2018; McClean 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; Stancliffeet 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 behaviors 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-centered 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 behavior 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-centered 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 intellectual disabilities 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 (Grey et al., 2018; McClean et al., 2007; De Wein & Miller, 2009). Grey et al. (2018) and McClean et al. (2007) applied a Positive Behavioral 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 (Galli Carminati et al., 2007). They stated that this opportunity

was created through new programs and a reorganization 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 Behaviors

Ten of the included studies reported a decrease of challenging behaviors when the person-centered approach was applied (Galli Carminati et al., 2007; Grey et al., 2018; Jones et al., 2013; MacDonald et al., 2010; McClean et al., 2007; De Wein & Miller, 2009), 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 standardized measures (Aberrant Behavior Checklist (Community), ICAP General Maladaptive Index, and Developmental Behavior Checklist for Adults), whereas the studies that reported a general decrease, based their results on the recorded frequency of challenging behaviors (Grey et al., 2018; Jones et al., 2013; MacDonald et al., 2010; McClean et al., 2007; De Wein & Miller, 2009).

Five studies did not find a decrease of challenging behaviors (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 behaviors were found. For example, some participants entered the studies with low levels of challenging behaviors, making it harder to find significant decreases in challenging behaviors 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-centered approach was regarded as questionable (Sandjojo et al., 2018; Totsika et al., 2010).

DISCUSSION

This review concerned the frequency and type of family involvement in the application of person-centered approaches for people with intellectual disabilities and challenging behaviors 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-centered approach but never in implementing it. Person-centered 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 intellectual disabilities (Carr et al., 2002). The family can also help to put into place the person-centered approach when the individual is at the family home. By applying a similar approach in different places, the person with intellectual disabilities 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-centered 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-centered 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-centered 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-centered 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 behaviors, further research examining current practices in services for people with challenging behaviors, 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 behaviors (Clarke et al., 2019; Giesbers et al., 2020), and preliminary results show that the involvement of family in person-centered

approaches has positive effects (Dunlap & Fox, 2007). Consequently, researchers should incorporate a measure of family participation in studies investigating the effectiveness of person-centered 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 behaviors. 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 behaviors (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, nonhierarchical relationships, or joint venture), while on the other hand, acknowledging and recognizing 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-centered 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 intellectual disabilities and challenging behaviors.

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