

# Exploring individual parent-to-parent support interventions for parents caring for children with brain-based developmental disabilities: A scoping review

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## Abstract

**Background:** Brain-based developmental disabilities (BBDDs) comprise a large and heterogeneous group of disorders including autism, intellectual disability, cerebral palsy or genetic and neurodevelopmental disorders. Parents caring for a child with BBDD face multiple challenges that cause increased stress and high risk of mental health problems. Peer-based support by fellow parents for a various range of patient groups has shown potential to provide emotional, psychological and practical support. Here, we aim to explore existing literature on individual peer-to-peer support (iP2PS) interventions for parents caring for children with BBDD with a view to (1) explore the impact of iP2PS interventions on parents and (2) identify challenges and facilitators of iP2PS.

**Method:** An extensive literature search (January 2023) was performed, and a thematic analysis was conducted to synthesize findings.

**Results:** Fourteen relevant articles revealed three major themes regarding the impact of iP2PS on parents: (1) emotional and psychological well-being, (2) quality of life and (3) practical issues. Four themes were identified describing challenges and facilitators of iP2PS: (1) benefits and burden of giving support, (2) matching parent-pairs, (3) logistic challenges and solutions and (4) training and supervision of parents providing peer support.

**Conclusions:** This review revealed that iP2PS has a positive impact on the emotional and psychological well-being of parents, as well as the overall quality of life for families caring for a child with a BBDD. Individual P2PS offers peer-parents an

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opportunity to support others who are facing challenges similar to those they have experienced themselves. However, many questions still need to be addressed regarding benefits of different iP2PS styles, methods of tailoring support to individual needs and necessity of training and supervision for peer support providers. Future research should focus on defining these components and evaluating benefits to establish effective iP2PS that can be provided as standard care practice for parents.

#### KEYWORDS

brain-based developmental disabilities, child, parent-to-parent support, peer support, quality of life, well-being

## 1 | INTRODUCTION

Brain-based developmental disabilities (BBDDs) comprise a large and heterogeneous group of disorders including autism, intellectual disability, cerebral palsy or genetic and neurodevelopmental disorders, with an estimated prevalence ranging from 4.7% to 55.5% depending on definition (Francés et al., 2022). Parents caring for a child with BBDD face multiple challenges such as organizing their child's complex care needs and experiencing grief and loss due to their child's disability. This causes increased stress in parents (Marquis et al., 2020; Sloan et al., 2020). In order to meet their child's needs, many parents feel that they have several roles besides their 'normal' role as parents, including the role of case manager, safety guard and health care provider (Woodgate et al., 2015). In addition, parent carers often feel unsupported by their social network, as people outside the family may not be fully aware of the 'intense parenting' these parents face (Elangkovan & Shorey, 2020). It has also been reported that parents caring for a child with BBDD may experience stigma and feel judged, as their situations diverge from social expectations surrounding (neurotypical) children, family and parenting (Cantwell et al., 2015; Elangkovan & Shorey, 2020; Niedbalski, 2022).

The high demands faced by parent carers result in overall increased stress and risk of mental health problems (Cantwell et al., 2015; Gerstein et al., 2009; Marquis et al., 2020; Sloan et al., 2020). Parents of a child with BBDD are more likely to report financial difficulties and stopping or reducing work in order to care for their child (Jandrić & Kurtosis, 2021; Ouyang et al., 2014; Saunders et al., 2015). This serves to contribute to caregiver burden as parental employment can play a role in parental satisfaction (Jandrić & Kurtović, 2021). Thus far, treatment and management for BBDD mainly focus on the child, whereas there is growing evidence that increased parental resilience, empowerment and well-being are associated with better outcomes in, for example, children with autism spectrum disorder (ASD) (Crowell et al., 2019; Tarver et al., 2019). Thus, interventions aimed at increasing parental resilience, empowerment and well-being may also result in better outcomes in children with other BBDD.

### 1.1 | Peer support

In the past decades, peer-based support by fellow parents for a various range of patient groups has shown potential to provide social sameness, acquisition of practical information and emotional support (DeHoff et al., 2016; Henderson et al., 2014; Mirza et al., 2018; Shilling et al., 2013). Peer-based support can be briefly defined as 'social and/or emotional support between people with similar lived experiences of mental-health, social, psychological and/or medical challenges' (Fortuna et al., 2022). Over time, the definition has evolved. In the original definition by Solomon (2004), the person was required to have a mental condition, but this was later revised to 'mental health challenges'. This adjustment reflects the understanding in the current study that parents may not necessarily have a mental health condition themselves but can still encounter social, psychological or medical challenges when providing care for their child with BBDD. In this review, parental peer-based support is referred to as parent-to-parent support (P2PS).

### 1.2 | Previous reviews on P2PS

Over the years, several studies have explored the feasibility and efficacy of P2PS. Recently, two reviews have summarized these results: Chakraborti et al. (2021) reported on peer support networks among families of children with neurodevelopmental and intellectual disabilities, and Wong and Shorey (2022) reviewed qualitative studies exploring experiences of parents caring for children with neurodevelopmental disorders with P2PS intervention programs. Both reviews reported that parents experienced P2PS as a positive and supportive intervention and identified the shared 'lived' experiences as a key element of successful P2PS. The reviews included a wide range of interventions, such as group sessions, individual support, training and education, digital platforms and play dates. Although these reviews reported that P2PS has positive effects on the well-being of parents caring for children with additional needs, it remains challenging to identify which type, mode of delivery and/or key elements are driving the effects. Because the 'shared and lived experience' was identified

as a key element in both reviews, we decided to focus on *individual P2PS* (iP2PS) to further examine facilitators and barriers of successful P2PS. iP2PS is defined as individualized support provided in a one-on-one setting, as opposed to peer-based support offered in group settings. It is delivered by a parent with similar experiences caring for a child with BBDD (Dodds & Walch, 2022). During these sessions, parents of a child with BBDD have conversations and share experiences in order to support each other (Wong & Shorey, 2022). The type of support (e.g., emotional, social and practical) can be tailored to the needs of the parent requesting support. The support can be provided in-person, by telephone or online and functions on a voluntary basis.

In this review, we aimed to explore existing literature on individual peer-to-peer support (iP2PS) interventions for parents caring for children with BBDD with a view to (1) explore the impact of iP2PS interventions on parents and (2) identify challenges and facilitators of iP2PS.

## 2 | METHODS

This scoping review was performed according to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) extension for Scoping reviews (Tricco et al., 2018) (see Table A1 for PRISMA ScR Checklist). Typically, in scoping reviews, the appraisal and inclusion of evidence are not limited by the methodological quality of that evidence; therefore, a quality assessment of the studies was not carried out.

### 2.1 | Search terms and strategy

A PubMed search was conducted in July 2021 and repeated in January 2023 to update the results (see Appendix B for the search string). The records were imported in the web application Rayyan (<https://rayyan.qcri.org>), and duplicates were removed. For the initial search, we used a novel tool called ASReview (van de Schoot et al., 2021) assisting systematic reviews, to screen titles and abstracts, which resulted in an artificial intelligence sequential assisted list of publications from most to least relevant. ASReview is an open-source machine learning-aided pipeline developed to facilitate systematic reviews. Previous studies indicated that the tool's algorithm could accurately identify 95% of relevant publication after screening approximately 20% (Ferdinands, 2020). Consequently, this was treated as the stopping criterium. The relevant publications were then screened for eligibility. If title and abstract did not provide sufficient information, full-text articles were assessed for eligibility. Relevant records (i.e., full text of manuscripts) were read by independent reviewers (JN, AP, ZD). In addition, reference lists were studied for cross-references and studies were included if they met inclusion criteria. Discrepancies between the independent reviewers were discussed in a consensus meeting with multiple authors (AP, ZD, JZ, MK). See Figure 1 for a flow chart of study procedures.

### 2.2 | Article selection

To be included, papers needed (i) to report on parents caring for children with BBDD; (ii) to report results of an intervention involving parent-to-parent support, defined as emotional and/or social support; (iii) to explicitly report results of individualized support in a one-on-one setting; (iv) to include original data; and (v) to be a publication of a full article (not a conference abstract) published in a peer-reviewed journal and written in English. Studies were excluded if (i) the intervention had a primary educational purpose (e.g., parenting/communication skills aimed at reducing problem behaviour, and/or psycho-education), or if (ii) the intervention included a variation of P2P support and did not present exclusive iP2PS results.

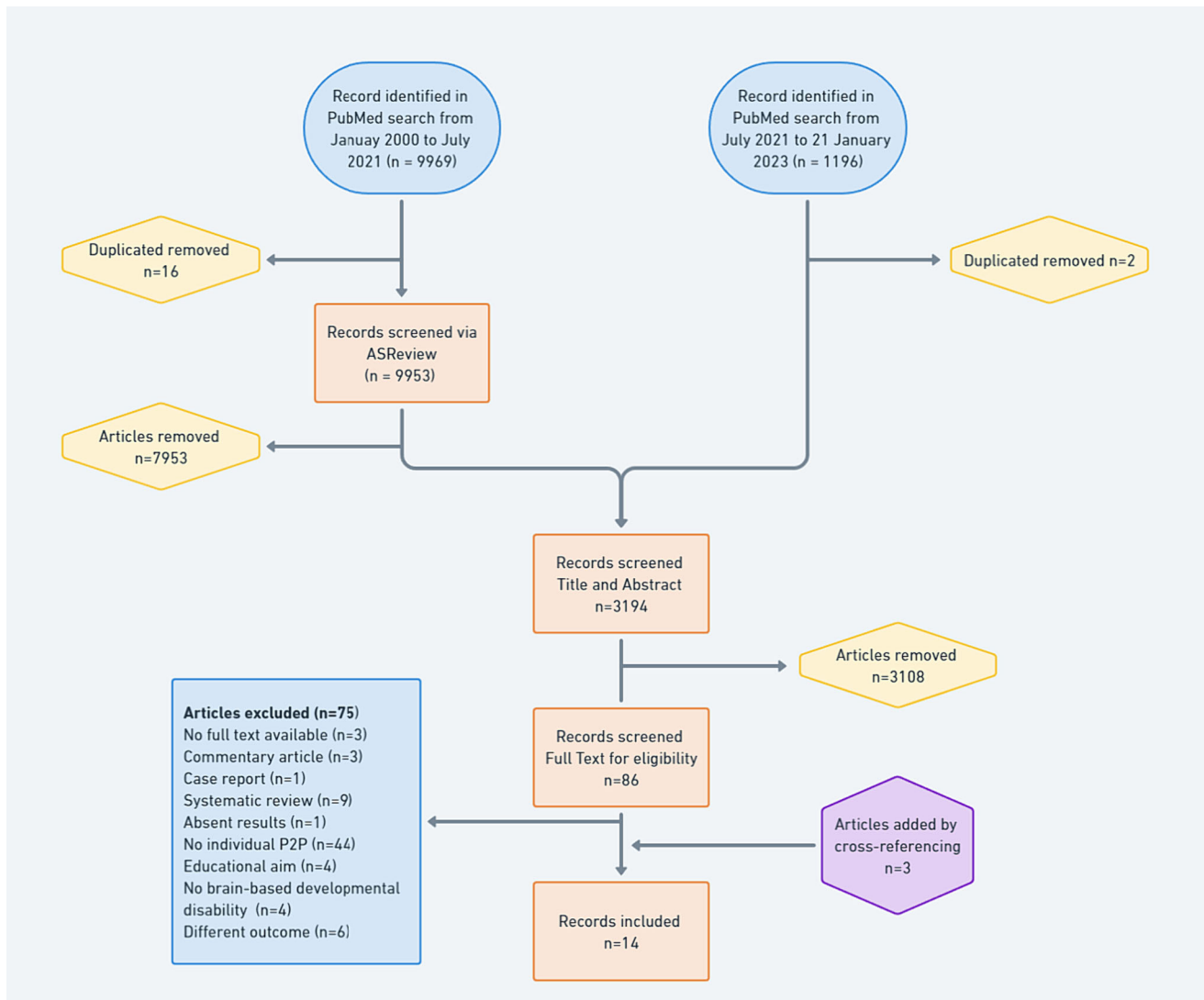
### 2.3 | Data extraction and synthesis

Data were extracted from included studies by two authors (AP, ZD), comprising general information (first author, year of publication, study design, number of participants), participants' characteristics (including type of BBDD), characteristics of the iP2PS intervention (including delivery, e.g., in person or via telephone/internet), key components (i.e., the components of that particular P2PS intervention that were identified by authors as most important or helpful), impact of iP2PS on the parents and challenges and facilitators (e.g., logistics and matching). A thematic analysis was conducted according to Braun and Clarke (2006), during which the findings of each article were labelled and categorized. Five reviewers (AP, ZD, JZ, MK, MJ) discussed and analysed the extracted data and labels to identify major themes. Disagreements were resolved by discussion until consensus was reached.

## 3 | RESULTS

After removal of duplicates, a total of 9953 records were identified with the first search (Figure 1). These entries were loaded into ASReview, assessing articles. This resulted in an artificial intelligence-assisted list of 2000 publications, in hierarchical order with 'most relevant' on top of the list. The 2000 entries assessed as 'most relevant' by ASReview were manually screened for title and abstract. The updated search yielded 1194 non-duplicate newly published articles. Following screening of title and abstract, 3108 articles were excluded because of various reasons such as the absence of an intervention, researching a different disease other than BBDD or researching subjects other than parents.

In total, 86 full-text articles were read of which 11 articles met inclusion criteria and were available for synthesis. Cross-referencing yielded three additional articles meeting inclusion criteria, increasing the total number of included articles to 14. Among these, two articles reported on different objectives of the same study. Consequently, the final count remained at 14 articles, which collectively reported on 13 studies. Of these 13 studies, five had a qualitative, two a



**FIGURE 1** PRISMA flowchart of study selection.

quantitative and six a mixed-methods design. Four studies used a control group. Three studies were designed as randomized or blinded trials. The remaining studies were observational, including one case study. In Table 1, study characteristics are summarized, including study population, sample size, iP2PS interventions and measurements.

### 3.1 | Characteristics

The included studies ( $n = 13$ ) described iP2PS interventions within a variety of BBDD: parents of a Neonatal Intensive Care Unit (NICU) child ( $n = 2$ ); parents of a child with unspecified needs or disabilities ( $n = 3$ ); parents of children with various BBDD (including cerebral palsy, attention deficit hyperactivity disorder [ADHD] and auditory processing disorder) ( $n = 3$ ); and parents of children with various mental health problems ( $n = 5$ ), including two studies specifically targeted at ASD, one study on substances use disorders, one targeting a combination of intellectual disability and behavioural difficulties and one on

emotional disturbances. In this latter study, parents were included from public schools that served only youth identified as emotionally disturbed and in need of a special education setting. Delivery of the iP2PS intervention was in-person ( $n = 3$ ), a combination of in-person and phone-based iP2PS ( $n = 5$ ), a phone-based iP2PS ( $n = 2$ ) or a combination of in-person, phone-based and Facebook-based iP2PS ( $n = 1$ ). Two studies did not describe the mode of delivery. The P2PS program was brought to the attention of parents in various settings, including community-based settings, hospitals and schools, and was entirely voluntary. Some programs offered parents the option to sign up themselves, whereas some programs approached parents to participate in the program (and some programs used a combination of both). All studies were conducted in Western countries, specifically the United Kingdom ( $n = 3$ ), United States ( $n = 6$ ), Canada ( $n = 3$ ) and Australia ( $n = 1$ ). Across six studies, minimal to no information was provided concerning the ethnic or cultural backgrounds of the participants (Blake et al., 2019; Bray et al., 2017; Carpenter et al., 2020; McCrossin et al., 2022; McCrossin & Lach, 2022; Moody et al., 2019).

**TABLE 1** Study characteristics.

Author and year	Aim of the study	Design	Description of study population <sup>a,b</sup>	Ethnic or cultural background <sup>c</sup>	Sort of BBDD
Blake et al., 2019	To explore the influence of a group- and IP2PS on the emotional and psychological well-being of parents and peer-parents	Prospective study	Parents receiving support (N = 12); peer-parents (N = 33)	Parents from the United Kingdom	Disabilities and/or additional needs
Bray et al. (2017)	To examine the influence of the intervention on parents' and peer-parents' well-being and their ability to deal with the day-to-day circumstances experienced when parenting a disabled child	Prospective study	Parents receiving support (N = 26); peer-parents (N = 12)	Parents from the United Kingdom	Disabilities and/or additional needs (e.g., ASD, down syndrome, and cerebral palsy)
Carpenter et al., 2020	To assess the feasibility of implementing such a service in the community, assess the acceptability of the training and coaching service among those being trained as peer-parents, and assess the acceptability and potential helpfulness of remote P2PS among parents utilizing the program	Prospective study	Parents receiving support (N = 110); peer-parents (N = 228)	Parents from the United States	Substance use disorder
Dew et al. (2019)	To assess which aspects of the P2PS the parents identified as contributing to the effectiveness of the program to provide them with support	Retrospective study	Mothers receiving support (N = 13)	Mothers from Australia with the majority from an Anglo-Australian background (n = 10)	Intellectual disability and challenging behavior
Hurst (2006)	To evaluate the pattern of utilization of parents and other family members who attended the P2PS intervention over a 2-year period and examine the results of a parent satisfaction survey (PSS)	Retrospective study	Parents receiving support (N = 44)	Parents from the United States with the following background: Euro-American (n = 34), Hispanic (n = 7), African American (n = 2), Asian-Pacific Islander (n = 1), Native American (n = 1), other and/or not reported (n = 3)	Preterm hospitalized in the NICU
Jamison et al., (2017)	To evaluate the P2PS for parents of children with ASD in an ethnically and culturally diverse minority sample with the hypothesis that focused contact with a peer-parent will (1) improve family utilization of ASD services, (2) have a positive impact on parents' knowledge of ASD and treatment options, and (3) improve family stress and parent perceptions of family support and empowerment.	Randomized controlled trial	Parents receiving support (N = 19); control group (N = 20)	Parents from the United States with mainly black and/or Hispanic background	ASD

TABLE 1 (Continued)

Author and year	Aim of the study	Design	Description of study population <sup>a,b</sup>	Ethnic or cultural background <sup>c</sup>	Sort of BBDD
Kutash et al., (2011)	To evaluate the feasibility of implementing a school-based P2PS program for families of youth with ED who are served in special education programs	Randomized controlled trial	Parents receiving support (N = 60); control group (N = 50)	Parent from the United States with the following background: Black/non-Hispanic (n = 28), White/non-Hispanic (n = 17), Hispanic (n = 7), Native American (n = 1), and other (n = 7)	Emotionally disturbed (ED) and in need of a special education setting
McCrossin & Lach, (2022)	To describe the specific pathways by which peer support may contribute to resilience in families and how processes embedded in this type of support can enrich family resilience theory	Prospective study	Parents receiving support (N = 4); peer support parents (N = 8) and paid regional network coordinators/staff (N = 7)	Parents from Canada identifying as indigenous (n = 4), newcomer to Canada (n = 1), English as a second language (n = 2), other (n = 12)	Neurodisabilities
McCrossin et al., (2022)	To provide a rich description of the P2PS program	Prospective study	Parents receiving support (N = 1); peer-parent (N = 1) and paid regional network coordinators/staff (N = 1)	Mother from same rural region in Western Canada	Neurodisabilities
Moody et al., (2019)	To explore of the P2PS program would lead to improved family quality of life and functioning, an increase in service use, and high acceptability among recipients	Randomized controlled trial	Parents receiving support (N = 33); control group (N = 34)	Parents from the United States with the following ethnicity for parents receiving support: Hispanic (n = 2) and non-Hispanic (n = 28); and for control group Hispanic (n = 2) and non-Hispanic (n = 27)	ASD
Pollock et al., 2022	To describe the support provided and the population served through this P2PS program	Retrospective study	Peer-parents (N = 3) notes of 203 supportive contacts with 90 parents	Parents from the United States with the following background for the peer-parents: American Indian/Native American (n = 2), Asian (n = 2), Black or African American (n = 30), more than one race (n = 3), White/Caucasian (n = 51), Unknown/not reported (n = 2)	Special health care needs
Preyde and Ardal (2003)	To evaluate the effectiveness of an iP2PS program—a hospital-based intervention for parents of very preterm neonates—in alleviating stress, anxiety and depression and providing social support	Prospective study	Mothers receiving support (N = 32); control group (N = 28)	Parents from Canada with the following ethnic background for the mother receiving support visible minority (n = 17) and white (n = 15); and for the control group visible minority (n = 11) and white (n = 15)	Preterm
Shilling et al. (2015a, 2015b)	(Part 1) To understand perceived outcomes and identify influential components of the P2PS (Part 2) To explore organizational and process factors that were perceived	Retrospective study	Parents receiving support (N = 12), peer-parents (N = 23) and professionals (n = 10)	Participants from the United Kingdom with for all the participants a white background	Disabilities (e.g., ASD, ADHD, down syndrome, and cerebral palsy)

TABLE 1 (Continued)

Author and year	Aim of the study	Design	Description of study population <sup>a,b</sup>	Ethnic or cultural background <sup>c</sup>	Sort of BBDD
	necessary or influential in building that sense of shared experience between peer-parents and parents				
Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; BBDD, brain-based developmental disorder; NICU, Neonatal Intensive Care Unit.					
<sup>a</sup> Only the researched populations are described.					
<sup>b</sup> Only the participants are described who participated in the intervention and the study.					
<sup>c</sup> The ethnic and cultural background is described with, if reported, diversity aspects.					
<sup>d</sup> Only the surveys relevant to the scoping reviewer are described.					
<sup>e</sup> This study explored the Face2Face scheme program.					
<sup>f</sup> This study explored the Family Support Program coordinated by the Family Support Institute of British Columbia.					
<sup>g</sup> This study explored the Colorado Parent Mentoring Program (CPM).					
<sup>h</sup> This study explored the Family Partner Program.					

TABLE 1 (Continued)

Author and year	P2P support intervention, duration, provided by	Training peer-parents	Measurements and time point <sup>d</sup>	Conclusions
Blake et al., 2019	In-person, group- and iP2PS, duration: several months <sup>e</sup> ; offered by a charity in community-based settings where parents could reach out themselves on voluntary basis	Yes	Quantitative: Emotional and psychological well-being (measured by <i>Footsteps Tool and Resilience Scale (RS-14)</i> ) Qualitative: Semi-structured telephone interviews All measurements were administered at the start and 6 to 9 months after the start	P2PS had a positive effect with the main benefit that the P2PS helped parents to build social connections and feel safe and supported within a community of other parents who understood their lives.
Bray et al. (2017)	In-person, group- and iP2PS, duration: 3–5 months <sup>e</sup> ; offered by a charity in community-based settings where parents could reach out themselves on voluntary basis	Yes	Quantitative: Wellbeing (measured by the <i>Pediatric Inventory for Parents (PIP) and General Health Questionnaire-12 (GHQ-12)</i> ); the ability to deal with the day-to-day circumstances (measured by the <i>PedsQL Family Impact Module</i> ) Qualitative: Interviews All measurements were administered at the start and at the end of the intervention (unknown time point)	P2PS helped create supportive meaningful relationships for parents receiving support to embrace opportunities to flourish, grow and thrive. Parents providing support also flourished and thrived as a result of their engagement in the program; through training, connecting to others and seeing possibilities for the future.
Carpenter et al., 2020	Phone-based, iP2PS, duration: 5, approximately 60-min weekly phone calls, conducted over a maximum 8-week period, offered by a support service with national reach where parents could reach out themselves on voluntary basis	Yes	Quantitative: Acceptability of the training and coaching service and helpfulness of remote P2PS (measured by surveys) Qualitative: Parents were asked about their experiences Quantitative measurements were administered at the start and 40 days after the end of the intervention. Qualitative measurements were administered 40 days after the end of the intervention	Remote P2PS appears promising for providing emotional and evidence-based informational support to family members parenting a child with substance use problems. Peer-parents found the training very useful and parents receiving support reported a high degree of satisfaction with their peer-parent and the services provided.

TABLE 1 (Continued)

Author and year	P2P support intervention, duration, provided by	Training peer-parents	Measurements and time point <sup>d</sup>	Conclusions
Dew et al. (2019)	In-person, phone-based and Facebook-based, group- and iP2PS, duration: unknown, offered through a disability advocacy organization, on voluntary basis	No	Qualitative: Semi-structured face-to-face or telephone interviews Measurements were administrated at an unknown time point	Well-established processes that enhance the potential of P2PS programs include a paid program coordinator to foster connections between parents and facilitate activities, a range of engagement strategies to cater to individual preferences, time and capacity constraints, and significant training, support and monitoring for those involved in iP2PS relationships.
Hurst (2006)	In-person and phone-based, group- and iP2PS, duration: unknown, offered by a NICU to parents of a preterm baby hospitalized in the NICU on voluntary basis	No	Qualitative: parent satisfaction survey (PSS) and a utilization survey Measurements were administrated 2 years after the start of the intervention which is for each parent at a different time point	There is a need for P2PS to offer multiple formats for support services to address families' emotional and informational needs and facilitate greater parental involvement in their baby's care.
Jamison et al., (2017)	In-person and phone-based, iP2PS, duration: at least 12 meetings over a 6-month period, offered by a national institute and was brought to the attention of parents by a school professional, clinician or other knowledgeable individual on voluntary basis.	Yes	Quantitative: Evaluate the P2PS (measured by Maternal Autism Knowledge Questionnaire (MAKQ), Caregiver Strain Questionnaire (CGSQ), Parenting Stress Index (PSI) Short Form, Social Support Survey (SSS), Family Empowerment Scale (FES) and Autism Service Utilization Questionnaire) All measurements were administrated at the start and after 3 and 6 months	The P2PS significantly decreased parental stress as compared to treatment as usual within the community. No significant changes were observed in parents group or the control group on measures of parental support, empowerment or service utilization. Parents and controls both showed an improvement in ASD knowledge over time, with no significant difference between groups.
Kutash et al., (2011)	Phone-based, iP2PS, duration: 9 months (school year), offered by a research team at two public schools that served only youth identified as ED, where parents could reach out themselves on voluntary basis	Yes	Quantitative: Feasibility of implementing a school-based P2PS program (measured by Vanderbilt Mental Health Services Efficacy Questionnaire (VMHSEQ), Family empowerment scale - family subscale (FES), Caregiver Strain Questionnaire (CGSQ), Support Functions Scale (SFS) - short version, The Ohio Youth Problems, Functioning, and Satisfaction Scales—Hopefulness Subscale (parent version)) Qualitative: Open-ended on parent satisfaction with the intervention All measurements were administrated at the start and at the end of the intervention	There are strong indications that a relatively low-cost program, with few logistic barriers, can be implemented as a school-focused intervention that has the goal of improving academic achievement as well as improving emotional functioning in a high-need group of youth who have ED. The feasibility of a P2PS program using the telephone is also encouraging.
McCrossin & Lach, (2022)	Not described delivery, iP2PS, duration: unknown <sup>f</sup> , offered by a volunteer-based organization, where parents could reach out themselves on voluntary basis	Yes	Qualitative: Semi-structured interview Measurements were administrated at unknown time point	Those building or implementing P2PS programs should intentionally adopt a family resilience lens in their training and in their representation of these programs when communicating to others the complex work that they do. The peer support and family resilience model in this

TABLE 1 (Continued)

Author and year	P2P support intervention, duration, provided by	Training peer-parents	Measurements and time point <sup>d</sup>	Conclusions
McCrossin et al. (2022)	Not described delivery, IP2PS, duration: unknown <sup>f</sup> , offered by a volunteer-based organization, where parents could reach out themselves on voluntary basis	Yes	Qualitative: Semi-structured interview Measurements were administrated at unknown time point	article demonstrates how P2PS can modify family belief systems, help navigate complex networks of care, and support negotiation for access to meaningful resources. P2PS can play a complementary role to professional services in helping parents feel understood and access services that are meaningful to them. Parents can benefit from developing navigation skills; however, their role demands significant self-reflection and emotional investment.
Moody et al. (2019)	In-person and phone-based, IP2PS, duration: At least once a month for a period of six months <sup>g</sup> , offered by a support program, promoted through listservs, parent support groups, and word-of-mouth from three local clinics in university, hospital and community-based settings. Parents could reach out themselves on voluntary basis	Yes	Quantitative: Family quality of life and functioning (measured by family quality of life scale (FQoL) and family adaptability and cohesion evaluation scale-IV (FACES-IV)); acceptability (measured by program acceptability and satisfaction questionnaire) Qualitative: Open-ended questions focused on service use; and semi-structured telephone interviews All measurements were administrated at the end of the intervention.	The P2PS program was generally acceptable to participants and impacted several areas of family quality of life and family functioning, regardless of the amount of formal services the family received elsewhere.
Pollock et al., 2022	In-person and phone-based, iP2PS, duration: in total 203 contacts <sup>h</sup> , offered at different clinical setting across the health system and was embedded in clinical teams, on voluntary basis	Yes	Qualitative: Records, meeting minutes, notes and descriptive documentation Measurements were gathered for each parent at a different timespan	Implementing a P2PS for parents of children and youth with special healthcare needs in a large, academic medical centre was attainable, and enhanced their healthcare team's ability to provide family-centred support for paediatric patients through the provision of emotional and tangible support.
Preyde and Ardal (2003)	In-person and phone-based, group and iP2PS, duration: on average 9 contacts, offered at two different NICUs, to parents of a preterm baby hospitalized in the NICU on, voluntary basis	Yes, on a volunteer basis	Quantitative: stress (measured by Parental Stressor scale: neonatal intensive care unit); anxiety (measured by State Anxiety Inventory (SAI) and Trait Anxiety Inventory); depression (measured by Beck Depression Inventory (BDI) - short form) and providing social support (measured by multidimensional scale of perceived social support) Measurements (except SAI) were administrated at the start and all measurements were administrated at the end of the intervention	Support from individual, trained peer-parents was found to be effective in helping mothers deal with the stress of very preterm birth.

TABLE 1 (Continued)

Author and year	P2P support intervention, duration, provided by	Training peer-parents	Measurements and time point <sup>d</sup>	Conclusions
Shilling et al. (2015a, 2015b)	In-person, iP2PS, duration: varying duration per participants <sup>e</sup> , offered by a charity in community-based settings where parents could reach out themselves on voluntary basis	Yes	Qualitative: Interviews and focus groups Measurements were gathered for each parent at a different timespan	(Part 1) Parents as well as peer-parents perceived positive outcomes from their involvement in P2PS although there is also potential for less positive impact on those offering support. (Part 2) Organizational and process factors as well as characteristics of the parents offering and receiving support contribute to the sense of shared experience in iP2PS. These factors interact to influence whether P2PS is effective and should be explicitly considered when designing and evaluating services.

Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autism spectrum disorder; BBDD, brain-based developmental disorder; NICU, Neonatal Intensive Care Unit.

<sup>a</sup>Only the researched populations are described.

<sup>b</sup>Only the participants are described who participated in the intervention and the study.

<sup>c</sup>The ethnic and cultural background is described with, if reported, diversity aspects.

<sup>d</sup>Only the surveys relevant to the scoping reviewer are described.

<sup>e</sup>This study explored the Face2Face scheme program.

<sup>f</sup>This study explored the Family Support Program coordinated by the Family Support Institute of British Columbia.

<sup>g</sup>This study explored the Colorado Parent Mentoring Program (CPM).

<sup>h</sup>This study explored the Family Partner Program.

In three studies, a more diverse ethnic population was described (Kutash et al., 2011; Pollock et al., 2022; Preyde & Ardal, 2003); one study reported a population with a Black and/or Hispanic background (Jamison et al., 2017); and four studies described a population with mainly parents of a white/Caucasian ethnic background (Dew et al., 2019; Hurst, 2006; Pollock et al., 2022; Shilling et al., 2015a, 2015b).

### 3.2 | Themes in iP2Ps

Results of the thematic analysis were organized per research question. We identified three distinct themes that effectively described the impact of iP2Ps on parents. These themes were (1) emotional and psychological well-being, (2) quality of life and (3) practical issues. Four themes were identified describing challenges and facilitators of iP2PS: (1) benefits and burden of giving support, (2) matching parent-pairs, (3) logistic challenges and solutions and (4) training and supervision of parents providing peer support. Each theme is described below in more detail.

#### 3.2.1 | Impact of iP2Ps on parents

##### *Emotional and psychological well-being*

This theme 'Emotional and psychological wellbeing' included perceived impact on parents of iP2PS on emotional and psychological well-being. Nine articles reported that parents experienced a sense of connectedness with their peer-parent and a reduced sense of isolation (Blake et al., 2019; Bray et al., 2017; Dew et al., 2019; Hurst, 2006; Kutash et al., 2011; McCrossin & Lach, 2022; Moody et al., 2019; Pollock et al., 2022; Shilling et al., 2015a). Parents described that the iP2PS helped them to overcome the feeling of social isolation and provided them with a wider social circuit. In particular, openly sharing experiences and feelings with another parent was identified as very helpful (Blake et al., 2019; Dew et al., 2019; Hurst, 2006; Kutash et al., 2011; McCrossin et al., 2022; McCrossin & Lach, 2022; Pollock et al., 2022; Shilling et al., 2015a). To be able to share openly, parents needed to experience that their needs and well-being were important and that they were truly heard and understood (Bray et al., 2017; Hurst, 2006; Kutash et al., 2011; McCrossin & Lach, 2022; Pollock et al., 2022). Parents experienced support as reciprocal and thereby different compared with the support of a healthcare provider (Blake et al., 2019; Dew et al., 2019; McCrossin et al., 2022; McCrossin & Lach, 2022). Five out of the nine studies (Blake et al., 2019; Carpenter et al., 2020; Jamison et al., 2017; Kutash et al., 2011; Preyde & Ardal, 2003) reported quantitative findings on the impact of iP2PS on the emotional and psychological well-being of the parents. Four of these studies (Blake et al., 2019; Carpenter et al., 2020; Kutash et al., 2011; Preyde & Ardal, 2003) showed (statistically significant) positive effects, and one study (Jamison et al., 2017) reported no improvements. Besides the feeling of being heard, many studies reported that parents receiving iP2PS experienced personal growth

and improved emotional stability (Blake et al., 2019; Bray et al., 2017; Carpenter et al., 2020; Hurst, 2006; McCrossin & Lach, 2022; Moody et al., 2019; Pollock et al., 2022; Shilling et al., 2015a). For example, in the study by Bray et al. (2017), several parents described the mutual support as lifting them through periods of feeling very low. Personal growth is described as promoting self-esteem, learning coping strategies, improving decisiveness, experiencing less stress, discovering internal resources and strengths, improvement in parental empowerment and resilience and use of verbal reinforcement (Blake et al., 2019; Carpenter et al., 2020; Hurst, 2006; Jamison et al., 2017; Kutash et al., 2011; McCrossin & Lach, 2022; Moody et al., 2019; Shilling et al., 2015a). Four quantitative studies (Blake et al., 2019; Carpenter et al., 2020; Jamison et al., 2017; Kutash et al., 2011) reported on personal growth in parents receiving iP2PS. Kutash et al. (2011) reported improvements in parental empowerment yielding a small to moderate effect size, whereas Jamison et al. (2017) did not find a significant improvement in caregiver empowerment. Blake et al. (2019) observed a non-significant improvement in parental resilience. Moreover, Carpenter et al. (2020) observed statistically significant improvement in use of verbal reinforcement. Three quantitative studies (Bray et al., 2017; Jamison et al., 2017; Preyde & Ardal, 2003) demonstrated improvements in parental stress, although not all with statistically significant effects.

##### *Quality of life*

Many studies demonstrated the positive impact of iP2PS on the quality of life and family life of parents receiving support (Blake et al., 2019; Carpenter et al., 2020; Kutash et al., 2011; McCrossin & Lach, 2022; Moody et al., 2019; Pollock et al., 2022). The iP2PS was found helpful in managing the day-to-day aspects of caring for a child with a BBDD (Blake et al., 2019; Carpenter et al., 2020; McCrossin & Lach, 2022; Moody et al., 2019; Pollock et al., 2022). Parents reported a more positive outlook on their life and the belief that things would get better (Blake et al., 2019; Carpenter et al., 2020; Moody et al., 2019). Carpenter et al. (2020) and Kutash et al. (2011) reported a statistically significantly greater proportion of parents experiencing improvements in family life resulting in a reduction in arguments with their child and reduced impact of caring for a child with BBDD. By contrast, findings of Moody et al. (2019) indicated no enhancements in family cohesion or flexibility. Nonetheless, they did report a statistically significant improvement in parental quality of life.

##### *Practical issues*

Although improvements in emotional and psychosocial well-being are often considered as the most important aspect of iP2PS, many studies also highlighted the benefits of gaining assistance with practical matters (Blake et al., 2019; Carpenter et al., 2020; Kutash et al., 2011; McCrossin et al., 2022; McCrossin & Lach, 2022). Parents reported to feel more knowledgeable and have a better understanding of their child's BBDD (Blake et al., 2019; Carpenter et al., 2020). Moreover, peer-parents provided practical support on how to navigate through the system and connected the parent to resources (Kutash et al., 2011; McCrossin et al., 2022; McCrossin & Lach, 2022). In

qualitative results, parents commented positively on assistance with practical matters during iP2PS, whereas the quantitative findings by Jamison et al. (2017) did not reveal statistically significant improvements in emotional/informational support (including the offering of advice, information, guidance or feedback) and tangible support (described as the provision of material aid or behavioural assistance) (Sherbourne & Stewart, 1991).

### 3.2.2 | Challenges and facilitators of iP2PS

#### *Benefits and burden of giving support*

Although all studies focused on the impact of iP2PS on parents receiving iP2PS, six articles also reported on the impact of iP2Ps on parents who provided the support (Blake et al., 2019; Bray et al., 2017; McCrossin et al., 2022; McCrossin & Lach, 2022; Shilling et al., 2015a, 2015b). Two studies (Bray et al., 2017; Shilling et al., 2015b) highlighted that it was crucial for the peer-parent to have the emotional and personal capacity to support another parent. Additionally, in Shilling et al. (2015a), peer-parents and professionals reported that peer-parents may experience negative effects of giving support, like emotional burnout and anxieties around personal effectiveness. McCrossin and Lach (2022) suggested that by improvising, moving slowly and seeking support from the network, peer-parents can build confidence in their skills. Aside from the potential negative impact, parents reported many benefits of giving support such as a reduced sense of isolation, emotional stability and feeling rewarded by seeing the growth and transformation of the parents they worked with (Blake et al., 2019; McCrossin et al., 2022; Shilling et al., 2015a). Bray et al. (2017) illustrated statistically significant improvements among peer-parents in difficulties and frequency of parental stress, non-significant improvements in health-related quality of life and family functioning and a marginally statistically significant improvement in psychological distress and parental mental well-being.

#### *Matching parent-pairs*

Establishing a sustainable connection between a parent and a peer-parent (a match) was identified as challenging. Four studies (Carpenter et al., 2020; Moody et al., 2019; Preyde & Ardal, 2003; Shilling et al., 2015a, 2015b) actively reported a match-making protocol. Matches were made based on various characteristics including demographics, child characteristics, gender, parenting style and socio-economic status. Moody et al. (2019) matched on eight characteristics, and Carpenter et al. (2020) only based the match on time zone compatibility. Some studies did not employ a matching process; instead, they directly connected parents seeking support with those able to provide it. In three studies, where connections were established based on availability, some parents expressed disappointment with their respective match (Blake et al., 2019; Dew et al., 2019; Hurst, 2006). Reasons for perceived mismatch were differences between the child's BBDD or type of problems, child's gender, personal differences, geographic distances and lack of compatibility (Blake et al., 2019; Dew et al., 2019; Hurst, 2006; Shilling

et al., 2015b). Shilling et al. (2015b) reported that some parents expressed that matching on diagnoses was essential, whereas others perceived that the shared experience of disability was a sufficient commonality. Moody et al. (2019) suggested a support group model that allows parents and peer-parents to naturally select each other rather than relying on a centralized process. Other than matching, parents in Hurst (2006) emphasized the importance of having the same peer-parent throughout the process.

#### *Logistic challenges and solutions*

Because of the often complex care of a child with BBDD, parents encountered difficulties finding time to engage in iP2PS in their already busy lives (Bray et al., 2017; Carpenter et al., 2020; Hurst, 2006). Moreover, the peer-parent providing support often faced similar busy schedules, adding more difficulties in organizing a meeting. In Hurst (2006), many parents expressed that the peer-parent being the one initiating the contact was very helpful as they found themselves unable to do so in their current state. Another logistic challenge was to find the right time to offer support (Kutash et al., 2011; Shilling et al., 2015b). Kutash et al. (2011) noticed parents dropping out of the peer support program if they were caring for youth between 17 and 18 years old. The authors suggested that these parents, who already experienced challenges with their child with BBDD for many years, may have given up the possibility of iP2PS helping them. Parents and peer-parents, in the study by Shilling et al., 2015b), recognized that early intervention might be most beneficial to parents struggling with a child with BBDD, although many argued that it might be too difficult to cope with early on in the process. Parents needed to build a degree of confidence before they can share their stories with others. Determining the ideal moment for both parents was emphasized as a challenging. On the other hand, Shilling et al. (2015b) also highlighted that flexibility (e.g., in location of P2PS sessions) of iP2PS was viewed as positive, especially in the relaxed and informal context. Some studies reported the benefits of a phone-based delivery of iP2Ps to overcome geographical distance (Carpenter et al., 2020; Kutash et al., 2011; Preyde & Ardal, 2003). In contrast, Dew et al. (2019) reported that many parents preferred in-person meetings over phone-based support. Two studies (Hurst, 2006; Pollock et al., 2022), providing both in-person and telephone support, showed that the majority of the contacts were in person, and fewer were conducted by telephone.

#### *Training and supervision of parents providing peer support*

In 11 of the 13 studies, the peer-parents received training before providing iP2PS. This training varied between a voluntary 5-h training (Preyde & Ardal, 2003) and a 40-h training delivered over a 10-week period (Shilling et al., 2015a, 2015b). The description of the training these peer-parents received varied widely across the studies. Although certain studies did not reveal any training specifications, others provided comprehensive explanations. In many studies, the training specification primarily centred around aspects like self-care, communication skills, boundary issues and enhancing disease knowledge. Moreover, in most studies, the qualifications or competencies of

the trainer were not described. However, most trainings appeared to be associated with a more professional delivery style of iP2PS, as the description of the training indicated a service delivered by a professional. In six (Bray et al., 2017; Carpenter et al., 2020; Jamison et al., 2017; Kutash et al., 2011; Pollock et al., 2022; Shilling et al., 2015a, 2015b) out of the eight studies (Bray et al., 2017; Carpenter et al., 2020; Jamison et al., 2017; Kutash et al., 2011; McCrossin et al., 2022; McCrossin & Lach, 2022; Pollock et al., 2022; Shilling et al., 2015a, 2015b) that addressed the supervision of peer-parents, it was observed that the supervision was conducted by a professional. In two studies (McCrossin et al., 2022; McCrossin & Lach, 2022), peer-parents received support from the regional network coordinator, who was also a parent of a child with a BBDD. Although the majority of the articles provide a fairly comprehensive overview of the training, there is limited reporting on how and why the specific training aspects were selected and which are perceived beneficial in the context of iP2PS. Two studies (Carpenter et al., 2020; Shilling et al., 2015b) examined the perception of peer-parents of the training, and both studies reported that this was experienced as very positive. Training, supervision and other forms of professional guidelines and boundaries were perceived as very important to safely provide iP2PS (McCrossin et al., 2022; Pollock et al., 2022; Shilling et al., 2015b). The study by Dew et al. (2019), not providing supervision or guidelines, reported that some parents withdrew from the program because of factors such as lack of role clarity and uncertainty about how to maintain boundaries. Shilling et al. (2015b) reported that parents and peer-parents described the importance of boundaries to maintain a degree of professionalism to protect both the parent and the peer-parent. Nonetheless, these boundaries occasionally led to disappointment when parents hoped for more than could be provided (Shilling et al., 2015b). Maintaining a professional relationship during iP2PS was viewed as important in some studies (McCrossin et al., 2022; Pollock et al., 2022; Shilling et al., 2015b). In contrast, a few studies reported the benefits of peer pairs becoming friends and expanding their social circuit (Blake et al., 2019; Dew et al., 2019; Hurst, 2006).

## 4 | DISCUSSION

### 4.1 | Impact of iP2Ps on parents

This review examined the impact of various iP2PS programs on parents as well as the challenges and facilitators of iP2PS interventions. Promising positive effects were identified of iP2PS on the emotional and psychological well-being and quality of life of parents receiving the support. Key elements included a sense of connectedness with their peer-parent and a reduced sense of isolation (Blake et al., 2019; Bray et al., 2017; Carpenter et al., 2020; Dew et al., 2019; Hurst, 2006; Kutash et al., 2011; McCrossin & Lach, 2022; Moody et al., 2019; Pollock et al., 2022; Shilling et al., 2015a). Parents felt that their needs and well-being were important and that they were heard and understood (Bray et al., 2017; Hurst, 2006; Kutash et al., 2011; McCrossin & Lach, 2022; Pollock et al., 2022). Parents

also gained assistance with practical matters (Blake et al., 2019; Carpenter et al., 2020; Kutash et al., 2011; McCrossin et al., 2022; McCrossin & Lach, 2022). Other reviews focusing on individual and group P2PS among parents of children with various BBDD or other disabilities/chronic diseases found similar results including positive effects on sharing experiences, parental empowerment, social connections, emotional and psychological well-being and practical support (Chakraborti et al., 2021; Lancaster et al., 2023; Shilling et al., 2013; Wong & Shorey, 2022).

Interestingly, iP2PS may also have a positive impact on parents who give the support, such as a reduced sense of isolation, emotional stability and feeling rewarded by seeing the growth and transformation of the parents they worked with (Blake et al., 2019; McCrossin et al., 2022; Shilling et al., 2015a). A recent study investigating peer support for carers of patients with Parkinson's disease revealed that motivations behind offering peer support included sharing experiences, utilizing own knowledge and skills and wanting to give something back to others (Geerlings et al., 2022). Although there are clear differences between partners of Parkinson's disease and parents caring for children with BBDD, some aspects may be similar and further research is needed in this area. Two studies in the current study (Bray et al., 2017; Shilling et al., 2015b) highlighted the importance for the peer-parent to have the emotional and personal capacity to support another parent. However, most of the studies did not delve into the impact on the peer-parent of offering support. In a systematic review by Shilling et al. (2013) on P2PS for parents of children with chronic disabling conditions, it was found that giving support was as important as receiving it. Peer-parents expressed a strong motivation to extend the same support they had received, to other parents. Although there is limited evidence specifically focusing on the impact of iP2PS among parents of children with BBDD, similar conclusions could be inferred to this population. However, future studies investigating iP2PS would ideally explore the effects of iP2PS not only on the receiving parents but also on those providing the support.

### 4.2 | Challenges and facilitators related to iP2PS programs

We identified several challenges associated with iP2PS: (a) iP2PS style, (b) individual needs and (c) whether to offer training and supervision for peer support providers. Parents who receive support may have varying expectations regarding the relationship with their peer-parent. Certain parents expressed the need for boundaries, where other parents argued that these boundaries led to disappointment when parents hoped for more than could be provided (Dew et al., 2019; McCrossin et al., 2022; Pollock et al., 2022; Shilling et al., 2015b). These distinct approaches, one emphasizing a more professional attitude and the other supporting friendships and a sense of equality among parents, each have advantages and disadvantages. Parents may prefer one style over the other based on their individual preferences and needs. Kane et al. (2023) conducted a study focusing on peer support training among various peer support providers,

highlighting that the presence of role ambiguity can have a negative impact on maintaining boundaries and the well-being of these peer support providers. As a result, Kane et al. (2023) suggested a more professional peer support style. However, these styles of iP2PS have not been well-defined in previous literature, nor is there available data on which style works for whom. We recommend that future studies exploring iP2PS take this into account, to gain better understanding and definition of various iP2PS styles and how to tailor style to the needs of the parent receiving support.

Another unresolved question is whether peer-pairs should be matched, and if yes, based on which characteristics. The possibility to match parents to peer-parents on selected characteristics seemed preferable for some participants (Blake et al., 2019; Dew et al., 2019; Hurst, 2006; Moody et al., 2019; Shilling et al., 2015b). However, other parents reported that the shared experience of parenting a child with a disability was sufficient common ground (Shilling et al., 2015b). Moreover, determining the appropriate timing and method of delivery of iP2PS can also present challenges. Certain studies have highlighted the advantages of phone-based delivery (Carpenter et al., 2020; Kutash et al., 2011; Preyde & Ardal, 2003), whereas others, offering both phone-based and in-person delivery, revealed a preference of in-person interaction when it comes to iP2PS (Hurst, 2006; Pollock et al., 2022). There are no easy solutions for these problems because of the variability of individual needs. An iP2PS model where parents can indicate their preferences like matching (i.e., specific diagnoses or a wider scope of BBDD), manner of support (i.e., phone-based or in-person) and kind of support (i.e., professional or befriending) may be preferable to conform to everyone's needs. Future studies should prioritize examining a flexible service that allows parents to selectively choose and adjust various options in the P2PS, to determine whether it is feasible and better aligns with the individual needs of each participant. In addition, iP2PS might be more appealing for ethnic or culture minorities to participate in case they could be matched with peer-parents that speak the same language or have the same cultural background (Chakraborti et al., 2021).

Furthermore, the majority of studies offered and implemented a form of training varying between a voluntary 5-h training (Preyde & Ardal, 2003) and a 40-h training delivered over a 10-week period (Shilling et al., 2015a, 2015b), with often ongoing supervision. The more intense training programs appeared to be associated with a more professional delivery style of iP2PS, as the description of the training indicated a more professional attitude. Yet, there remains a scarcity of information concerning the rationale behind the selection of particular training components and their perceived benefits within the context of iP2PS. Furthermore, despite the implementation of some form of training in the majority of the studies, only two studies examined the perception of peer-parents of the training program, and both studies reported positive feedback (Carpenter et al., 2020; Shilling et al., 2015b). These two studies reported on the content of the training program, namely, this comprised (1) 40 h of training over a 10-week period (Shilling et al., 2015a, 2015b) and (2) 20 h of training over 2.5 days (Carpenter et al., 2020). Supervision was delivered in both studies by professionals. Although these studies provide

preliminary data on the mode of delivery and effects of training and supervision for peer-parents, existing knowledge is insufficient to determine whether these training programs and ongoing supervision are needed for effective iP2PS, and if yes, in what form. In a study by Kane et al. (2023), the importance of peer support training was examined among various peer support providers. The study emphasized that training is paramount to the emotional well-being of peer support in case training addresses topics on experiencing vulnerability and how to take care of themselves. This highlights the necessity for future studies exploring iP2PS to also address which aspects of training and supervision for peer-parents are effective for optimal outcomes of iP2PS.

Furthermore, little is known about the feasibility of incorporating a P2PS program into standard healthcare practices. Three studies (Hurst, 2006; Pollock et al., 2022; Preyde & Ardal, 2003) embedded their P2PS program into regular healthcare services and one study (Kutash et al., 2011) incorporated it within the educational framework, whereas the majority of the studies worked throughout communities. Despite the notion of minor initial challenges and boundary regulation issues, comprehensive insights into effectively implementing a successful P2PS program in conjunction to regular healthcare services are lacking. Subsequent, future research should prioritize identifying the key elements that contribute to the effectiveness of a P2PS program when introducing it into the care management of these families dealing with BBDD.

### 4.3 | Strengths and limitations

A strength of this study is its comprehensive exploration of both parents receiving support and parents giving support, as well as the examination of challenges and facilitators associated with iP2PS. To our knowledge, this is the first review of literature on iP2PS among parents of children with BBDD. This study also had some limitations. Although we conducted a comprehensive search and studied reference lists for cross-references, it is possible that some studies may not have been found. The search string of this study included the term 'parent' for addressing caregivers of children with BBDD, potentially missing studies using alternative terms with similar intent or meaning. Additionally, only PubMed was utilized for this search. Another limitation is that this study exclusively focused on iP2PS with the purpose of providing emotional and social support, while excluding studies addressing (psycho-)educational objectives. Parents may also benefit from interventions with a more didactic character for dealing with day-to-day situations (Bracht et al., 2013; Broom et al., 2017; Kutash et al., 2013) but as we were primarily interested in emotional and well-being aspects, we considered (psycho-) educational interventions beyond the scope of this review. A downside of this choice is that the included studies were all set in North America, Europe and Australia, as P2PS interventions in low- and middle-income countries tended to focus on (psycho-)educational interventions for parents. As social and cultural contexts differ in countries and regions, the results of this study may be influenced by cultural bias. For example, Giannotti et al.

(2021) suggested that there may be varying impacts of caring for a child with ASD living in Italy or Japan, leading to differing needs among parents. This observation could also be applicable to parents of children with other BBDDs and their needs in P2PS. At last, this review focused on individual delivery of P2PS; therefore, this study does not allow for a conclusive determination of the effectiveness of iP2PS in comparison with group-facilitated P2PS. Some studies offered a variety of P2PS interventions including individual and group support but did not directly compare the impacts of the various forms of P2PS (Blake et al., 2019; Bray et al., 2017; Dew et al., 2019; Hurst, 2006; Preyde & Ardal, 2003).

## 5 | CONCLUSIONS

Parents of children with BBDD endure hardships and inequities in accessing care, and additional support for parents caring for children, adolescents and adults with BBDD is deeply needed. Individual P2PS has been shown to have a positive impact on the emotional and psychological well-being of parents, as well as the overall quality of life for families caring for a child with a BBDD. Individual P2PS offers peer-parents an opportunity to support others who are facing challenges similar to those they have experienced themselves. Assuming that parental well-being is a key contributor to the outcomes of children with BBDD, iP2PS is a highly promising intervention. However, many questions still need to be addressed regarding the benefits of different iP2PS styles, methods of tailoring support to individual needs and the necessity and key elements of training and supervision for peer support providers. Future research should focus on defining these components and evaluating the benefits of establishing effective iP2PS that can be provided as standard care practice for these parents.

### AUTHOR CONTRIBUTIONS

**Amber Postma:** Writing—review and editing; investigation; writing—original draft; methodology; visualization; formal analysis; data curation; validation; conceptualization; resources. **Marjolijn Ketelaar:** Conceptualization; validation; supervision; resources; methodology; investigation; writing—review and editing. **Justus van Nispen tot Sevenaer:** Conceptualization; investigation; methodology; data curation. **Zahra Downs:** Investigation; data curation. **Diane van Rappard:** Conceptualization; investigation; validation; methodology; supervision; resources. **Marian Jongmans:** Supervision; resources; validation. **Janneke Zinkstok:** Conceptualization; investigation; methodology; validation; supervision; resources; writing—review and editing.

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### CONFLICT OF INTEREST STATEMENT

All authors have no conflict of interest to declare.

### DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article

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## APPENDIX A

**TABLE A1** PRISMA-ScR Checklist.

PRISMA-ScR Checklist	Item	PRISMA-ScR checklist item
Title	1	Identify the report as a scoping review.
Abstract	2	Provide a structured summary that includes (as applicable) background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.
Introduction		
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.
Methods		
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.
Information sources <sup>a</sup>	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.
Selection of sources of evidence <sup>b</sup>	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.
Data charting process <sup>c</sup>	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.
Critical appraisal of individual sources of evidence <sup>d</sup>	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).
Summary measures	13	Not applicable for scoping reviews.

(Continues)

TABLE A1 (Continued)

PRISMA-ScR Checklist	Item	PRISMA-ScR checklist item
Synthesis of results	14	Describe the methods of handling and summarizing the data that were charted.
Risk of bias across studies	15	Not applicable for scoping reviews.
Additional analyses	16	Not applicable for scoping reviews.
Selection of sources of evidence	17	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.
Characteristics of sources of evidence	18	For each source of evidence, present characteristics for which data were charted and provide the citations.
Critical appraisal within sources of evidence	19	If done, present data on critical appraisal of included sources of evidence (see item 12).
Results of individual sources of evidence	20	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.
Synthesis of results	21	Summarize and/or present the charting results as they relate to the review questions and objectives.
Risk of bias across studies	22	Not applicable for scoping reviews.
Additional analyses	23	Not applicable for scoping reviews.
Discussion		
Summary of evidence	24	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.
Limitations	25	Discuss the limitations of the scoping review process.
Conclusions	26	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.
Funding	27	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.

Abbreviations: JBI, Joanna Briggs Institute; PRISMA-ScR, Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews.

<sup>a</sup>Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms and Web sites.

<sup>b</sup>A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

<sup>c</sup>The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

<sup>d</sup>The process of systematically examining research evidence to assess its validity, results and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of 'risk of bias' (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion and policy documents).

## APPENDIX B: SEARCH STRING

("parents"[MeSH Terms] OR "parent\*\*"[All Fields]) AND ("social support"[MeSH Terms] OR "mentors"[MeSH Terms] OR ("mentor s"[All Fields] OR "mentored"[All Fields] OR "mentoring"[MeSH Terms] OR "mentoring"[All Fields] OR "mentors"[MeSH Terms] OR "mentors"[All Fields] OR "mentor"[All Fields]) OR "peer group"[MeSH Terms] OR "social support\*\*"[All Fields] OR "peer group\*\*"[All Fields] OR "parent-to-parent"[All Fields]) AND ("disabled children"[MeSH Terms] OR "child\*\*"[All Fields] OR "infan\*\*"[All Fields] OR "child"[MeSH Terms] OR "infant"[MeSH Terms] OR "infant, premature"[MeSH Terms] OR "infant, newborn"[MeSH Terms])