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Title:
# A realist review of programs for siblings of children who have an intellectual/developmental disability: Implications for current and future support

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# A realist review of programs for siblings of children who have an intellectual/developmental disability: Implications for current and future support

## Abstract

We conducted a realist review of 31 studies assessing support programs for siblings of children with intellectual/developmental disabilities. Grey literature was also included. Applying the realist paradigm, we identified program contexts, mechanisms that promote program effectiveness, and outcomes of programs. We found that contextual information was often lacking in the research and no studies examined the effectiveness of individual program components. Mechanisms of validation, time with parents, and respite were observed as beneficial for the siblings. From our analysis we developed four program theories that reflect the siblings' experiences in the various programs. Based upon the four theories we offer recommendations to guide program development.

Objective: Our purpose is to answer the question: What mechanisms or components of programs, groups or interventions improve psycholgical and social aspects of the lives of siblings of chldren who have intellectual/developmental disabilities(IDD)? Secondly, using a realist review format, we develop program theories and recommendation that can guide current and future sibling support programs.

Background: There is evidence that having a sibling with IDD can affect the physical health, behavior, and mental health of siblings who do not have IDD. As a result, support programs have been developed for these non-disabled siblings.

Methods: We conducted a realist review of 31 studies assessing support programs for siblings of children with IDD. Grey literature was also included. Applying the realist paradigm, we identified program contexts, mechanisms that promote program effectiveness, and the outcomes of the programs.

Results: We found that contextual information was often lacking in the research and no studies examined the effectiveness of individual program components. However, the mechanisms of validation of feelings and experiences, time with parents, and respite were observed as beneficial for the siblings. From our analysis and using a realist review paradigm, we developed four program theories that reflect the siblings' experiences in the various programs.

Conclusion: The four program theories derived from this realist review can be summarized as "I am not the only one"; "I have needs too"; "I need my parents attention": and "I need a break"

Implications: Based upon the four theories we offer recommendations to guide program development.

## Key Words

Intellectual disability, developmental disability, sibling, support program

# Introduction

There is evidence that the number of children diagnosed with an intellectual/developmental disability (IDD) is increasing in developed countries (Houtrow et al., 2014; Marquis et al., 2018). Using data from the U.S. National Health Interview Survey, Zablotsky et al. (2019) found that from 2009 to 2011 and 2015 to 2017, there were significant increases in the prevalence of any developmental disability, and in the prevalence of Autism Spectrum Disorder and intellectual disability. Many of these children with IDD have siblings. Several studies have noted that families that include a child with IDD tend to have a greater number of children than comparison families (Burke, Urbano, & Hodapp, 2011; Ha et al., 2008; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).

In general, sibling relationships are some of the longest lasting and most influential relationships in people's lives (Buchanan & Rotkirch, 2021). There is a considerable body of research examining the effects of having a sibling with an IDD upon the health, behavior and mental health of siblings who do not have IDD (Marquis et al., 2019). Often research has been premised on assumptions that effects are always negative (Hastings, 2016). However, evidence has also been found that having a sibling with IDD can have positive effects (Havermans et al., 2010; Macks & Reeve, 2007). Other studies have found no significant impact upon siblings without disability (Cuskelly & Gunn, 2006; Hastings & Petalas, 2014; Rossiter & Sharpe, 2001) . Mounting evidence demonstrates that any effects upon siblings without IDD are not solely a result of having a disabled sibling. Instead sibling outcomes result from complex interactions among social determinants of health, the characteristics of the child with IDD, characteristics of the siblings without IDD, and family factors (Kovshoff et al., 2017; Marquis et al., 2019).

Many researchers have called for support for the well-being of siblings of children with IDD (Burke & Montgomery, 2001; Garrido et al., 2020; Naylor & Prescott, 2004). Consequently, a variety of policies, programs and interventions have been developed. However, very little is known about the effectiveness of these interventions. The few assessments that have been conducted have focused on single programs that differ widely in service delivery, target group and expected outcomes (Evans et al., 2001; Kryzak & Jones, 2017; Roberts et al., 2015). Four systematic reviews (Claudel-Valentin et al., 2020; Hartling et al., 2014; McKenzie Smith et al., 2018; Tudor & Lerner, 2015) concluded that interventions for siblings of children with disabilities or chronic health conditions may be beneficial but that programs need to clearly identify intended results, types of siblings who would benefit and the most effective methods of delivery.

To pinpoint which program components are efficacious for which groups of siblings entails an examination of not only program outcomes but also how the programs bring about or fail to deliver improvements in sibling wellbeing.  In contrast to systematic reviews, realist reviews provide a fuller picture of interventions because their purpose is to describe "What works, how, why, for whom, to what extent and in what circumstances, in what respect and over what duration?" (Wong et al., 2013, p. 17). Realist reviews are designed to address complexity and to analyze evidence of why and when interventions are effective. A systematic review does not address these critical issues (Booth et al., 2020).

The foundational concept of a realist review is context plus mechanisms produce outcomes (C + M =O) (Pawson, 2018;Wong et al., 2013). Contexts are the situational influences on an intervention (Greenhalgh et al., 2017b). Contexts can originate from multiple levels: the micro-level (i.e. age), meso-level (i.e. family income), and macro-levels (i.e. government policies)

(Emmel et al., 2018). Other contextual factors include the training and abilities of program staff and the program setting (Lemire et al., 2020).

Mechanisms are “an explanatory account of how and why programmes give rise to outcomes” (Greenhalgh et al., 2017b, p. 2). Program mechanisms are the resources offered by programs and how participants interpret and act upon them (Greenhalgh et al., 2007). In realist theory, mechanisms interact within contexts to produce outcomes. Unlike a systematic review, realist reviews also go beyond simply describing existing interventions. Realist reviews produce a program theory or theories which can inform current and future programs and interventions. “The program theory (or logic of intervention) is defined as the set of hypotheses that explains how and why the intervention is expected to produce its effects” (Lacouture et al., 2015, p. 5). .

Using a realist review, this study addresses the complexity of interventions for siblings of children with IDD by examining context (age of the child, type of IDD, site of the program etc.), mechanisms (how the programs function) and outcomes (see Table 1 in the Appendix). Our purpose is to answer the question: what mechanisms or program components of support programs, groups or interventions improve psychological and social aspects of the lives of siblings of children who have IDD? Our review then seeks to construct program theories and identify program components with the goals of recommending approaches for current programs and offering guidance for developing new programs for siblings of children with IDD.

## Method

This review was initiated with the formation of a review team. The team was composed of the primary investigator ( Sandra Marquis), a methods specialist (Renee O’Leary), and an advisory group (Nikita Hayden and Jennifer Baumbusch). The review was conducted between November 2020 and May 2021.

## Development of Guiding Theories

Many realist review authors have recommended developing mid-level theory early in the review process to help guide the literature search (Greenhalgh et al., 2017a; Wong, 2019). Mid-level theories are the foundation of developing program theories that are specific to a particular program  (Greenhalgh et al., 2017a).

> Middle-range theories and programme theories operate at different levels of abstraction… Middle-range theories are formal theories. They often provide a bridge to a wealth of existing research and knowledge about a topic. They are invariably more abstract than programme theories, which seek to explain how and why different outcomes are generated by a specific programme in different contexts. (Marchal et al., 2018).

The review team identified three candidate mid-level theories as guides for data collection and evaluation and for developing program theories. The three theories often overlap.

**Social model of disability and stigma.** The social model of disability was developed in the 1990s (Oliver, 1996). The theory characterized disability not as the result of individual bodies and capabilities, but as the result of lack of acceptance by society and society's failure to provide the necessary supports. Within the social model, the experience of disability is characterized by oppression, isolation, stigma and deeply entrenched cultural definitions of normal and abnormal (Charlton, 2006; Shakespeare, 2006).

Stigma can be extended to those associating with stigmatized individuals (Goffman, 1963). Considerable evidence exists that non-disabled siblings of disabled children can experience stigma (Burke, 2010; Neely-Barnes et al., 2010). For siblings, stigma can result in: distress at witnessing their disabled sibling being stigmatized (Barr & McLeod, 2010; Moyson & Roeyers, 2012; Stalker & Connors, 2004); embarrassment when their sibling behaves outside of social norms (D'Arcy et al., 2005; Schongalla, 2003); and reduced interaction with peers (Bågenholm & Gillberg, 1991). Non-disabled siblings may also experience being bullied (Barr & McLeod, 2010; Moyson & Roeyers, 2012; Stalker & Connors, 2004)

**Role strain.** Role strain is "the felt difficulty in fulfilling role obligations" (Goode, 1960, p. 483) occurring when the "total role obligations are over-demanding" (ibid, p. 485). Stoneman (2005) identified role strain in siblings of children with IDD. Two potential sources of role strain have been identified; these are care-giving and worry. The literature has identified care-giving responsibilities or increased household responsibilities of children who have a sister/brother with a disability (Bågenholm & Gillberg, 1991; Burke, 2010; Cridland et al., 2016; Damiani, 1999; Gettings et al., 2015; Naylor & Prescott, 2004). The "unusual expectations and responsibilities imposed on siblings for caregiving or domestic work increase the likelihood of role strain" (Gold, 1993, p. 148).

Non-disabled siblings of disabled children experience worry. Concerns for the well-being of their disabled sibling is a common source of worry (Connors & Stalker, 2003; Dodd, 2004; Moyson & Roeyers, 2012; Naylor & Prescott, 2004). Worries also include concern for parents (Barr & McLeod, 2010; Dodd, 2004; Gettings et al., 2015) and hurting parents' feelings (Scelles et al., 2012) or adding to parents' stress (Amicarelli, 2019; Roberts et al., 2015; Sykes, 2010). IN addition, these children worry about their future care-giving roles as their parents age (Damiani, 1999; Eisenberg et al., 1998). The literature shows that these worries may be affected by the gender of the non-disabled sibling and the gender of the child with the disability (Orsmond & Seltzer, 2000).

**Siblings Embedded Systems Framework.** The Siblings Embedded Systems Framework (Kovshoff et al., 2017) was developed to understand and contextualize the multiple interacting factors and processes influencing experiences of siblings of children with autism. The Framework draws upon three concepts: family systems perspective (Whiteman et al., 2011), bio-ecological systems theory (Bronfenbrenner, 1979) and the Double ABCX model (McCubbin & Patterson, 1983). As a result, the Siblings Embedded Systems Framework includes consideration of interactions among family members, factors relating to the context of communities and societies in which families are embedded (macrosystems, exosystems, mesosystems and microsystems), and the dynamic processes and cumulative stressors that siblings experience.

## Literature Search

Multiple search techniques were used in the review: data base searching, reference searching and citation searching. Six databases were searched: CINAHL, Embase, PsychInfo, Medline, Social Science Abstracts, and ProQuest Dissertations and Theses. The search keywords were sibling, support, disability and children. The search timeframe was 2000-2020. English and French language publications were included.

The inclusion criteria were studies involving participants aged 19 years old or younger who had a sibling with an intellectual disability as defined by the DSM-5 (*Diagnostic and Statistical Manual of Mental Disorders DSM-5*, 2013). The exclusion criteria were:

- Studies involving only siblings of children with health problems or disabilities other than IDD. If IDD was included in a range of health and disability problems, the study was included.
- Outcomes other than psychological/social/behavioural
- Studies involving adult siblings (defined as aged 20 years or older)
- Interventions only for the benefit of the siblings with disabilities
- Programs or intervention providing information on siblings for parents without including sibling involvement

Grey literature sources were also searched. These included program and association websites and publications and resources referred to on the websites. Literature retrievals were managed with Mendeley bibliographic software.

## Literature Selection

Publications were reviewed and included if they provided data on the relationship of an intervention to a context, mechanism, outcome or program theory (Berg & Nanavati, 2016). A list of studies and articles excluded after full paper review is available in Appendix A in Supplementary Materials. The search and literature selection are reported in a PRISMA flow diagram (Appendix A Figure 1). The selection of a study or of a description of a program was based upon the contribution of the document to theory-building as recommended for realist reviews (Turner et al., 2018).

## Literature Analysis

Data and findings from the literature were collected in a report form with standard bibliographic information and information regarding context, mechanisms, outcomes (see Tables

2-4 in Appendix A Supplementary Materials. Grey literature sources are listed in Table 5 Appendix A Supplementary Materials. Data extraction was conducted by one reviewer and then 100% checked by a second reviewer for accuracy and completeness. Data extraction criteria are listed in Appendix A Table 1. Studies were not excluded for quality as that reduces the available evidence (Pawson et al., 2005). RAMSES publication standards for realist syntheses state that the inclusion or exclusion of studies "cannot be based on an overall assessment of study or document quality" (Wong et al., 2013).

## Results

### Overview of Study Data

Tables 2 through 5 in Appendix A in Supplementary Materials provide study overview information. The review retrieved 31 studies published between 2000 and 2020 (see Appendix A, Table 2). Seven studies were of Sibshops or modified Sibshops, three of Siblink or modified SibLink and two reported on SibworkS. The remaining studies reported on individual, unique programs. Twelve studies were from the United States, eight from the United Kingdom, two each from Australia, Canada, and Norway, one each from France, Greece, Cambodia, Sweden, and Ireland.

No studies provided detailed contextual information. Only three studies measured the effects of type of disability on sibling outcomes; all three of these studies reported that type of disability had no effect on outcomes. Four studies reported on the effects of age of the sibling on sibling outcomes; with mixed results. Four studies used gender as a variable in assessments and all four of these studies reported that gender had no effect. Only two studies used severity of disability as a variable, again with mixed results. No results were reported by ethnic background or income of participants.

Understanding recruitment issues is critical to understanding barriers to program participation. Only one program stated that recruitment was not a problem; this program provided funding for travel, child care, and meals (Fjermestad et al., 2020). The number of families that declined taking the programs and the reasons that they declined were not reported in 17 studies. Thirteen studies reported low numbers of entries into the program compared to the number invited to join. Reasons given for low recruitment included:

- the cost of travel to the program (Gettings et al., 2015);
- lack of childcare for the child with the disability (Amicarelli, 2019; Gettings et al., 2015; Hansford, 2013);
- disinterest on the part of the sibling (Haukeland et al., 2020);
- conflict with other activities (Gettings et al., 2015);
- disinterest on the part of parents (Gettings et al., 2015; McCullough & Simon, 2011);
- concerns regarding privacy (Scelles et al., 2012);
- conflict with parent’s work schedules (Hansford, 2013);
- and lack of time (Granat et al., 2012; McCullough & Simon, 2011).

None of the 31 studies analyzed individual program components. In every case, program assessment was done for the entire program at the end of the program. This makes it difficult to determine which program components, (for example crafts, discussions, etc.) were effective or ineffective in achieving program goals.

## Contextual Factors Identified in Program Functioning

In spite of a lack of detail in the studies reviewed, contextual factors were identified by the reviewers as important for program functioning. These factors were fun, peer group settings, confidentiality (for children and for parents), trust (between siblings and program facilitators, siblings and their parents and parents and program facilitator), opportunities to listen to others' experiences and feelings, opportunities to talk about experiences and feelings, facilitators who reinforced for children the commonality of their experiences and feelings, time away from their sibling with a disability; and increased time with parents.

"Fun" was identified by siblings as the most important aspect of programs (Burke & Montgomery, 2001; Carter et al., 2016; D'Arcy et al., 2005; DeVries & Sunden, 2019; Dodd, 2004; Granat et al., 2012; Naylor & Prescott, 2004; Schongalla, 2003; Smith & Perry, 2005). The importance of fun has also been identified in a systematic review (Tudor & Lerner, 2015) and in the grey literature (*Siblings With a Mission*, n.d.; *Sibshops — Sibling Support*, n.d.). In the majority of cases fun activities were not planned play therapy, but simply fun. As discussed by Tudor & Lerner (2015) "The enjoyment of groups may simply reflect children having fun, with TD [typically developing] siblings responding as any child would". It should be noted however, that all activities, including "fun" activities should be age appropriate  (Carter et al., 2016; Dailey, 2013; Giallo & Gavidia-Payne, 2008; Hansford, 2013).

All but one program used peer group settings. As part of a peer group, siblings were with other children who had common experiences; and within this atmosphere, there were informal opportunities to share experiences and feelings. In addition, many programs provided structured opportunities to listen to others' experiences and to speak about experiences and feelings. Both informal and formal opportunities to share commonalities were important.

However, confidentiality was raised as a concern in seven studies. Both parents (Scelles et al., 2012) and children (Gettings et al., 2015) spoke about confidentiality. Siblings told researchers that they were not comfortable talking about their difficulties with their disabled sister/brother with other people (Amicarelli, 2019; Corsano et al., 2016; D'Arcy et al., 2005) or with their parents (D'Arcy et al., 2005; DeVries & Sunden, 2019; Schongalla, 2003). Therefore, assurance of confidentiality was an important consideration for siblings and for parents. Based on this concern, confidentiality should be assured formally and should be based upon trust. Torun and Zahl (2017) identified trust as a critical component of sibling support programs. Trust has also been identified as critical in other types of support programs (Usher et al., 2015). Trust between children and their parents and between families and program facilitators is important. Trust requires sensitivity from facilitators and takes time to build. Therefore, length and frequency of programs, the venue, the training and attitude of program facilitators and their gender, race or ethnicity may all impact levels of trust.

The studies contained evidence that siblings of children with IDD feel that they receive less parental attention than their disabled sister or brother (DeVries & Sunden, 2019; Dodd, 2004; Granat et al., 2012; Haukeland et al., 2020; McCullough & Simon, 2011; Naylor & Prescott, 2004; Schongalla, 2003). A lack of child/parent communication and feelings of being left out can negatively affect sibling mental health (Incledon et al., 2015; Long et al., 2013).

The support programs fostered time with parents in a variety of ways, both formal and informal. Some programs provided group sessions that included siblings and their parents (Fjermestad et al., 2020; Lobato & Kao, 2002, 2005). Other programs had special events to which parents were invited (Granat et al., 2012), or camps that children and their parents attended together (Haukeland et al., 2020), or homework assigned to children that included talking to their parents (Giallo & Gavidia-Payne, 2008; Sykes, 2010). Informal time together occurred through discussion between parents and children about program sessions (McCullough & Simon, 2011; Sykes, 2010). In some cases, these discussions were prompted by program information sheets sent home for parents (DeVries & Sunden, 2019; Roberts et al., 2016). Informal time with parents also occurred during the time spent travelling from home to support groups (Scelles et al., 2012; Smith & Perry, 2005; Williams et al., 2003).

The factors identified above provided some evidence of benefit to participants and/or participant satisfaction. Eight studies reported that siblings appreciated "fun" aspects of programs. Sixteen studies found that siblings appreciated being able to share their feelings and experiences. In ten studies, siblings felt that the support program had lessened their sense of isolation. Seven studies indicated that siblings were happy with additional attention from their parents. Six studies reported that siblings valued the time away from their disabled sibling.

Eleven of 15 studies that measured mental health found no significant differences in the majority of scores of tests related to self-reported sibling mental health. This lack of significant improvement in sibling mental health may be due to a number of factors. Programs may be ineffective. Testing instruments may be inappropriate or administered inappropriately. Siblings may be initially under-reporting negative feelings and experiences but then increase disclosure of these feelings over the course of the program as they feel more comfortable. Their increased willingness to self-report negative feelings may then result in the appearance of poorer mental health at the end of the program.

Alternatively, siblings attending the programs may not be experiencing significant mental health issues (Hastings & Petalas, 2014b) and, therefore, are not in need of improvement in their mental health. Programs may be primarily attracting siblings without mental health issues, or children are generally not experiencing significant mental health problems as a result of having a sibling with IDD. As Tudor and Lerner(2015) state, “sibling is not a diagnosis”. Studies involving larger samples, with control groups and longer follow-up times are needed to address these questions effectively.

Fifteen programs had the goal of improving sibling problem solving and coping, of these, only five studies demonstrated an improvement in these areas. Thirteen programs had the goal of improving sibling knowledge about disability; ten of these reported an increase in the children’s knowledge related to the siblings’ disability. However, there is no long-term evidence that increased knowledge improves mental health or coping. Previous studies have found no correlation between knowledge of autism and the adjustment or mental health of non-disabled siblings (Ross & Cuskelly, 2006; Tudor & Lerner, 2015).

The majority of studies did not give any specifics on what was being taught to siblings about disability. However, the type of information can be inferred from the tools used to measure changes in knowledge. For example Brouzos et al. (2017) and Hansford (2013) used the Knowledge of Autism Syndrome (KAS) tool developed by Ross and Cuskelly (2006). This tool is based upon the Diagnostic and Statistical Manual of Mental Disorders (4th edition) and measures knowledge of autism including prevalence, aetiology, and cognitive ability. Granat et al. (2012) and Lobato and Kao (2002, 2005) used the Sibling Knowledge Interview tool developed by Lobato and Kao. This assessment determines the children’s knowledge about the impairment, affected body parts, and the cause and treatment of their sibling’s disability. Based upon our examination , no programs provided siblings with information from a social model of disability perspective.

# Discussion

## Issues in the Interpretation of Outcomes

In this review, evaluating outcomes of sibling support programs was hampered by the same methodological issues and biases identified in previous systematic reviews (Claudel-Valentin et al., 2020; Hartling et al., 2014; McKenzie Smith et al., 2018; Tudor & Lerner, 2015). The issues are numerous and include: small sample sizes; lack of control groups; no or short follow-up times; and grouping children of siblings with a wide variety of disabilities within one study. The studies reviewed failed to account for variables known to affect child health, including family income, ethnicity, parent health, and others. As well, generalizability of findings is limited due to differences between programs in: the qualifications and focus of staff; program formats (camps, recreational times, play therapy etc.); outcomes measured (knowledge, anxiety, behavior, program satisfaction, etc.); and assessment tools. In addition, there were large differences between programs in their focus or goals. Program goals included prevention of future problems in sibling mental health, treatment of sibling mental health, and identification of at-risk siblings. Several programs had multiple goals. The lack of clearly articulated goals and measurements for those goals often hampered assessment of programs.

The authors of this review identified additional issues with study design and interpretation, not discussed in previous reviews. Many studies reported problems with recruitment. Low recruitment contributes to biasing the sample and may be indicative of programs that only appeal to or are accessible to particular segments of the population. Missing data was not addressed in the majority of studies, although two studies identified missing data as an issue in assessment (Jones et al., 2020; Roberts et al., 2016). In addition, reasons for absenteeism or early drop-out were not examined.

Recruitment and retention issues may be indicative of problems with the programs. The majority of programs were used by white, middle income families. Barriers to participation for other population groups were not examined. Systemic issues such as racism and classism may well be impeding access to support for families. A long history of interventions with racialized stereotypes, deficit-focused over-sight, and forced family separation has created a deep mistrust of child services in many populations (Haight et al., 2018; Merritt, 2021; Stephens, 2021).

Lastly, there was evidence of reporting bias in the studies reviewed. Very few studies reported negative results (Roberts et al., 2015). One study identified that parents and staff were reluctant to jeopardize programs by providing negative feedback (Scelles, 2012, p.257).

## Realist Interpretation of Findings

Because the reviewed studies provided so little detail on demographic variables, and because none of the studies assessed individual program components, it was not possible in this review to connect context variables such as gender, family income or program venue, with potential mechanisms or with outcomes. However, the reviewers identified three common and important mechanisms that may contribute to the effectiveness of programs and to sibling well-being. These mechanisms were: validation, increased communication with parents and respite. There is overlap among the three mechanisms particularly between the mechanisms of validation and increased communication with parents.

**Validation.** The first step in validation of sibling experiences may occur when parents enroll their children in a support program. By doing this, parents are acknowledging that their children may have needs or concerns specific to being the sibling of a child with IDD. This recognition by parents may affect sibling well-being and may also explain in part the lack of a difference in outcomes between experimental groups (siblings attending a program) and control groups (siblings on a waitlist or attending a recreational program only).

Another form of validation may have occurred when siblings learned that their relationship with their disabled sibling was similar to other siblings' and that their experiences were not unique. This experience led to feelings of relief and a reduction of a sense of isolation (Burke & Montgomery, 2001; McCullough & Simon, 2011; Naylor & Prescott, 2004; Scelles et al., 2012; Schongalla, 2003). Validation may help to reduce stigma and role strain. Simply listening to others talk about experiences may lead to validation. Children talking about their own experiences may also lead to validation. During the group children learned that it was acceptable to voice negative feelings and disclose unpleasant experiences (Amicarelli, 2019; Brouzos et al., 2017; Burke & Montgomery, 2001; D'Arcy et al., 2005; Dailey, 2013; DeVries & Sunden, 2019; Dodd, 2004; Hansford, 2013; McCullough & Simon, 2011; Torun & Zahl, 2017).

Program components that facilitate validation are peer group settings, confidentiality, opportunities to listen to peers talk about their feelings and experiences, opportunities to talk about their own feelings and experiences, and activities that reinforce the validity of sibling experiences. Program facilitators who are trusted and who reinforce the validity of sibling experiences are also important.

Evidence to support validation as a mechanism was found in numerous sibling comments (DeVries & Sunden, 2019; Gettings et al., 2015; McCullough & Simon, 2011; Roberts et al., 2015; Sykes, 2010), parent comments (Dailey, 2013; Dodd, 2004; Evans et al., 2001; Gettings et al., 2015; Schongalla, 2003), and in researcher comments (Brouzos et al., 2017; Burke & Montgomery, 2001; Gettings et al., 2015; Granat et al., 2012; Hansford, 2013; McCullough &

Simon, 2011; Naylor & Prescott, 2004; Scelles et al., 2012; Schongalla, 2003; Tichon & Yellowlees, 2003). The grey literature also emphasizes the importance of sharing experiences (Allen et al., 2008). This was seen in online sites (*Autism Speaks*, 2018), the advertising of sibling support groups (*SibLink*, n.d.; Skotko & Levine, n.d.) and the goals of several sibling support programs (*Sibs*, n.d.; *Sibshops Standards of Practic - Sibling Support Project*, n.d.). "The most frequent feedback we hear from siblings after they come to a sibling group, workshop or session is: 'I am not the only one who has a brother or sister like mine'." (*Sibs*, n.d.).

Additional examples of sibling comments that support the importance of validation:

"They helped you to realise you're not the only one, other people have brothers and sisters like you" said a program participant, while another stated "You kind of think no-one else has disabled brothers and sisters" (Burke & Montgomery, 2001, p. 32)

"I'm not alone" and "other people go through the same things as me" were two responses to the open-ended question *What do you think is the most important thing you learned today?* (Schongalla, 2003, p. 150)

A Sibs Talk participant learned that they were not the only one, writing "There are millions of children who have disabled siblings like me" (Hayden et al., 2019, p. 415)

A sibling stated that they were "relieved to hear that another child often cried on her own at night" (Scelles et al., 2012, p. 256)

"I don't have to keep things to myself. That it is not my brother's fault he is how he is. I have learnt that I can share things with you." (Hayden et al., 2019, p. 415)

"It's is easier to talk about your sibling with people who know what it is like." (Burke & Montgomery, 2001, p. 31)

**Increased communication with parents**. Research has shown that healthy relationships with family members and peers is central to the well-being of children in general (Hill, 1999). A lack of child/parent communication and feelings of being left out can negatively affect child mental health (Haukeland et al., 2020; Incledon et al., 2015; Long et al., 2013; McCullough & Simon, 2011). The studies reviewed contained evidence that siblings of children with IDD feel that they receive less parental attention than their disabled sister or brother (DeVries & Sunden, 2019; Dodd, 2004; Granat et al., 2012; Haukeland et al., 2020; McCullough & Simon, 2011; Naylor & Prescott, 2004; Schongalla, 2003). Enrolling a child in a sibling program can be an initial step by parents in recognizing sibling needs and concerns. As discussed earlier, many programs facilitated an increase in the time that parents spent with siblings.

Siblings of children who have IDD may be reluctant to share their feelings and experiences with parents due to concerns about burdening their parents or failing in their family roles as parent helpers (Graff et al., 2012; Scelles et al., 2012; Schongalla, 2003; Sykes, 2010). Support programs can facilitate communication between parents and non-disabled children. Gettings et al. (2015) found that a reduction in the concerns of siblings was associated with an increase in feeling empowered to talk to parents about their concerns. Haukeland et al. (2020, p. 2211) reported that "improvements in sibling-reported mental health measures were partly accounted for by the quality of parent-sibling communication." Another study reported that as a result of the program, siblings felt that parents and other family members had an increased understanding of their feelings and needs (Gettings et al., 2015).

Evidence for the mechanism of increased parent/child communication is also found in comments by parents (Giallo & Gavidia-Payne, 2008) and researchers (D'Arcy et al., 2005; DeVries & Sunden, 2019; Lobato & Kao, 2002, 2005; McCullough & Simon, 2011; Naylor &

Prescott, 2004; Scelles et al., 2012). The grey literature also emphasizes the importance of one-on-one time with parents for non-disabled siblings (*Autism Society*, n.d.; *Autism Speaks*, 2018; *Sibs*, n.d.; Krueger, n.d.-a, n.d.-b).

Sibling comments that supported the importance of increase time with parents included:

"I feel left out" (DeVries & Sunden, 2019, p. 147)

"Sometimes I want to be alone with just mom or dad" (DeVries & Sunden, 2019, p. 149)

"I feel like the others – left out. I don't seem to have much time without my brother." (Naylor & Prescott, 2004, p. 203)

**Respite.** Studies provided evidence that children appreciated time away from their disabled sibling and fun activities which were not shared with their disabled sibling (Amicarelli, 2019; Burke & Montgomery, 2001; Carter et al., 2016; Dailey, 2013; Dodd, 2004; Gettings et al., 2015; Naylor & Prescott, 2004). Another benefit of programs for children was the experience of being a care-receiver rather than their frequent role of care-giver (McCullough & Simon, 2011).

Sibling comments that support the importance of respite included:

"Child 5 said, "I don't like my home. My happy place is away from my home" particularly being away from the sibling with a disability.

Child 6 also indicated that "It's not really my happy place." (DeVries & Sunden, 2019, p. 149)

"It's helped me in a lot of ways. It's prevented me from having to play tea parties with my sister. It means that I'm not with W so much. My own privacy from W and time away." (Naylor & Prescott, 2004, p. 203)

"I had somewhere to go where [disabled sibling] wasn't." (D'Arcy et al., 2005, p. 52)

## Program theories

Based upon the evidence in the studies and the three mechanisms discussed above, we propose four program theories. These theories are grounded in the initial candidate mid-level theories of the social model of disability, role strain and the Siblings Embedded Family Systems Framework. The program theories address the isolation and stigma characterized by the social model, the inter-relatedness of macrosystems, exosystems, mesosystems and microsystems delineated in the Siblings Embedded Family Systems Framework and the tensions of role strain described in role strain theory. As with the mechanisms, there is overlap among the four proposed program theories.

**I am not the only one.** By getting together in a peer group for fun activities, as well as formal discussion and education, siblings learn from peers and realize that they are not alone in their feelings and experiences. Their feelings and experiences can be validated by both peers and program facilitators. This can happen if the sibling shares their own experiences or only listens to others. When children feelings and experiences are validated their sense of isolation, stigma and role strain may be reduced. In addition, within the program, children may experience support and a sense of community outside their immediate family (Tichon & Yellowlees, 2003). These experiences may produce an increase in well-being.

***Program recommendations.***

a. Programs should include a component that gives children opportunities to hear the experiences of other siblings, to have their experiences affirmed or echoed by other siblings, and learn that their experiences and emotions are shared by other siblings.

b. In a mixed group of children with a sibling with IDD or physical disabilities, six of 16 siblings reported that they did not hear anyone talking about an experience like theirs (D'Arcy et al., 2005). This suggests that programs should not combine children with siblings with IDD with children with a chronic illness or only a physical disability. For example, many of the experiences of having a sibling with Down syndrome will not be similar to having a sibling with cancer. Due to the small number of participants, it may not be feasible to divide siblings of children with IDD into disability specific groups. However, with larger groups, this may be feasible and advisable as it may increase the likelihood that siblings will have common experiences. In addition, when possible, children should be divided into groups based upon the characteristics of their siblings' disability.
c. Not all siblings feel comfortable in a group (Dodd, 2004; Scelles et al., 2012). This program goal could be achieved through watching a video, participation in an online group, reading about the experiences of other siblings or receiving affirming online posts or messages (Dailey, 2013).
d. As siblings age, peer support becomes more important (Hill, 1999). Peer support through online forums, websites and social media should be considered for teenage and young adult siblings.

**I have needs too.** Siblings of children with IDD may feel that their needs have been recognized when they attend a support program. The recognition of sibling needs and experiences by program facilitators and especially by parents may result in a lessening of role strain and feelings of isolation. However, siblings need time to build trust in the group and to feel comfortable relating their experiences honestly. The majority of programs found that siblings under-report their difficulties in an attempt to lessen the burden on their parents and/or to maintain the idea that "everything is fine" (Scelles et al., 2012; Sykes, 2010). Some siblings may not feel comfortable at any time talking about their needs, but could still benefit from hearing about others' experiences and by having their own needs validated by facilitators and parents.

***Program recommendations.***

a. Trust must be built into programs (Hill, 1999). This includes the trust of both the children and of the parents. Trust may increase the likelihood of participation in programs by families from a variety of socioeconomic and ethnic backgrounds. Program goals, formats and assessments and use of data should be clear to parents and children. Parents and children should be provided with confidentiality and a safe environment in which to share experiences. Trust between parents and their non-disabled children should also be nurtured in order for parents to feel comfortable with their children attending the program and for children to feel comfortable sharing their learning, feelings and experiences with their parents.

b. Building trust and nurturing a safe environment takes time. Therefore, programs should be offered more frequently and over longer periods of time (a minimum of 6-8 weeks rather than over a few days).

c. Consideration should be given to who is facilitating the program. "Research demonstrates that it is the personal qualities of professional helpers which are the main criteria by which young people judge a service. This means that they tend to confer trust to individuals, rather than agencies or approaches." (Hill, 1999). Gender may be a consideration in building trust and ensuring that children are comfortable in support programs. Although often not specifically stated, the majority of facilitators are most likely female. Increasing the number of male facilitators in the programs may increase the number of boys and fathers who attend. Programs also did not provide information on the ethnicity or race of facilitators. Having program facilitators from a variety of backgrounds may increase the number of participants from non-white, non-middle income groups.

d. Careful consideration should be given to what measures of mental health and well-being are used and when they are used. Researchers need to be aware that assessments conducted at the start of a program may not accurately reflect the children's feelings and experiences as these initial measures are conducted before a trusting relationship has been formed.

**I need my parents' attention.** The results of family systems, including parental coping and parenting styles for the mental health of siblings of children with IDD has been recognized in the literature (Kovshoff et al., 2017; Marquis et al., 2019). For all children, time and attention from parents is critical for fostering feelings of being valued.

***Program recommendations***.

a. Parent participation should be built into program curricula. Ideally one or two sessions that include a parent should be scheduled. This gives siblings time with their parents, and opportunities to share concerns, needs and program learning within a safe environment.

b. However, parent participation can be constrained by parent work schedules, lack of time, and transportation and child care problems. Programs should include funding to support parent participation by paying child care and transportation costs. Scheduling sessions outside of work times or in a variety of time slots is also important.

c. Increased communication between children and parents can be facilitated through information sheets explaining program components. In addition, homework could be provided regularly to siblings and parents. Homework should be fun and engaging as well as encouraging open and safe communication between parents and children.

d. The programs that reported parent interactions indicated involvement by a greater proportion of mothers compared to fathers (Amicarelli, 2019; Fjermestad et al., 2020; Gettings et al., 2015; Giallo & Gavidia-Payne, 2008; Haukeland et al., 2020). This is probably a consequence of gender differences in the roles that mothers and fathers often fulfill when they have a disabled child (Gray, 2003; Hastings et al., 2005). Consideration should be given to increasing the involvement and opinions of fathers in support programs.

**I need a break.** Many siblings of children with IDD live in stressful circumstances (Gettings et al., 2015). In addition, families with children with IDD tend to have lower incomes than families without children with IDD, and parents in these families often have many demands on their time resulting in less time for recreational activities and individual attention for non-disabled children (Marquis et al., 2019a). Support programs can offer personal respite and fun activities for siblings and therefore help to reduce their stress.

***Program recommendations***.

a. Games, play, arts and crafts, camps, and excursions are valuable program components. These activities serve to attract children to support programs and keep them coming back.

b. The data from studies in this review indicate that support programs attract more girls than boys. Programs need to offer a variety of fun activities that appeal to girls and boys. Play and fun activities should also be age appropriate.

c. Face-to-face or group activities may not be the best intervention for all children. Older siblings in particular may prefer support through the internet or social media (Strohm, 2008). In some cases, family therapy rather than individual-focused programs may be the best option.

d. Respite benefits are not permanent. Programs should be available on a regular basis so that siblings can anticipate having time away.

## Conclusion

Systematic reviews of interventions for siblings of children with IDD have noted the importance of context but have not identified this critical factor in their assessments (Claudel-Valentin et al., 2020; Hartling et al., 2014). This realist review found descriptions or information about context was rarely reported in program evaluations.  Without detailed contextual information it is not possible to provide recommendations for specific program components. Future studies of sibling support programs should include examination of contextual factors such as income, ethnicity and gender of participants and facilitators, as well as detailed examination of the components of the support programs. Using a realist methodology, this study was able to identify some mechanisms used in the programs and to form recommendations for future program formation and improvement of current program outcomes.

In addition, this review indicates that consideration should be given to other means of supporting families that would support both disabled and non-disabled siblings. These include meso-level and macro-level interventions. An example of a meso-level intervention is providing funding for respite for families  (*Beyond the limits: Mothers caring for children with disabilities*, 2000; *Sibworks Program | Siblings Australia*, n.d.; Dowling & Dolan, 2001) so that parents can spend one-on-one time with each of their children (*Autism Speaks*, 2018; Schongalla, 2003).

IDD continues to be treated as the problem of the individual or the individual family (Meltzer & Kramer, 2016). All the support programs reviewed in this study that had the goal of increased knowledge of disability provided information that was medically based and focused on individual problems. This emphasis on disability as a problem or illness will reinforce the "otherness" or abnormality of disability and does not address society's influence. Support for siblings of children with IDD and their families should include recognition of the importance of societal influences, a key context. At the macro-level, societal changes that stress inclusion and value diversity will benefit families with a child with IDD. As Schongalla (2003, p. 77) stated: "If children feel alone, confused, angry, or worried, it may be that the community and larger systems have not supported the family adequately, so that they may support the nondisabled siblings. "

The evidence of mental health issues in siblings of children with IDD calls for our attention and care. This realist review has examined 31 programs for these children. Despite the methodological shortcoming of these studies, we were able to observe how validation, parent-child communication, and respite time function in the programs to promote children's wellbeing. Using the evidence, we offered pragmatic recommendations for program design and delivery. We have also considered the wider social context of support. By using the realist review approach to examine interventions, this project enhanced understanding of supports for siblings of children who have IDD and contributes to their care.

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