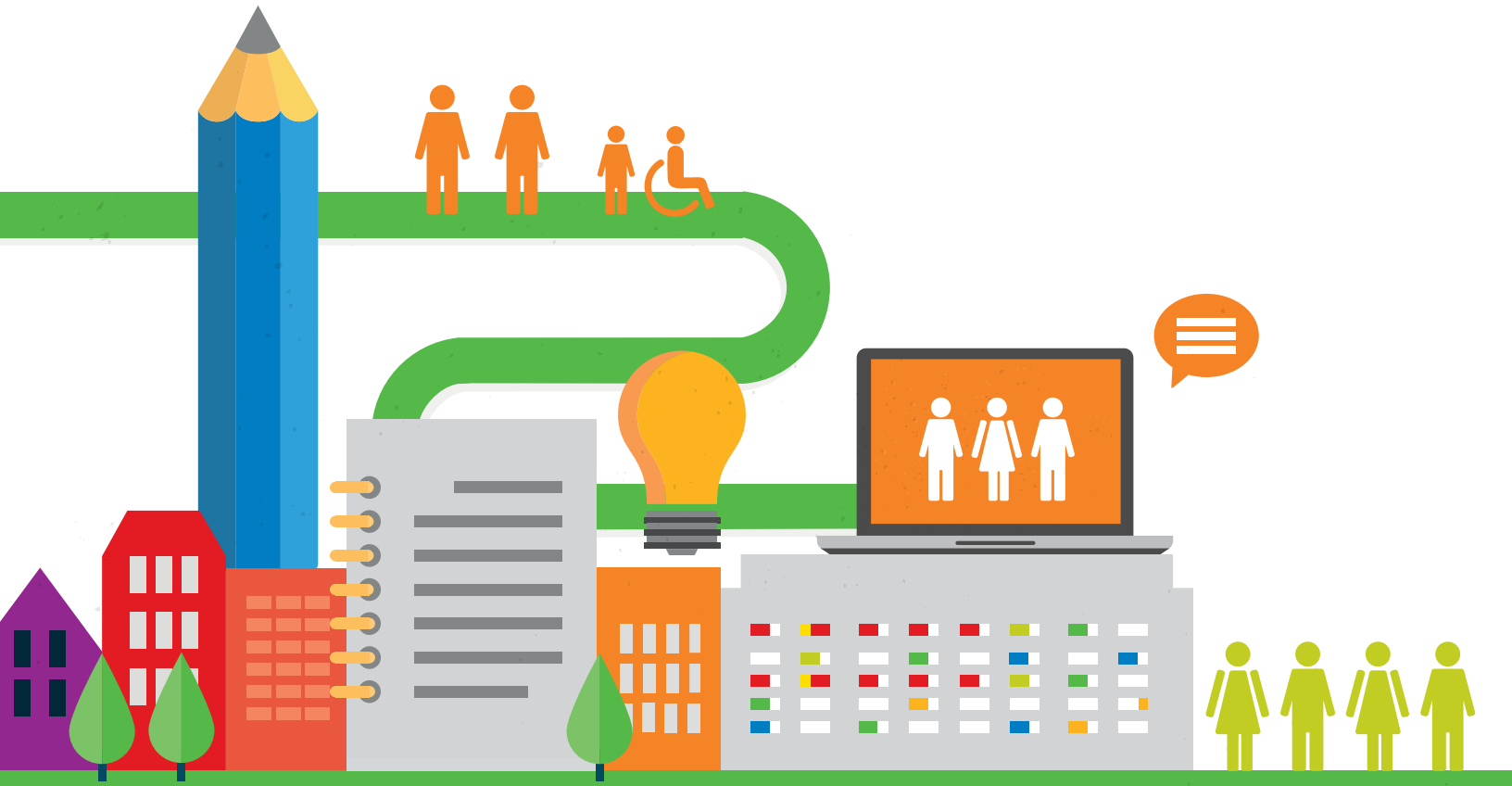
Rapid evidence review:

Peer support

for families of children with disabilities



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Evidence to Care (EtC) at Holland Bloorview Kids Rehabilitation Hospital is a specialized team of knowledge translation experts supporting the hospital in its commitment to transform care through evidence, knowledge generation, and translation. Through collaborative efforts, EtC strives to make research evidence accessible in promoting evidence-based care in the field of childhood disability.

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CONFLICT OF INTEREST DECLARATION

The contributing members have no conflict of interest to declare.

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CONTACT INFORMATION

Shauna Kingsnorth, PhD
Evidence to Care Lead
Clinical Study Investigator
Holland Bloorview Kids Rehabilitation Hospital
150 Kilgour Road, Toronto, ON M4G 1R8
1.416.425.6220 x3547
skingsnorth@hollandbloorview.ca
www.hollandbloorview.ca

Rapid evidence review:
Peer support for families of children with disabilities

Background

Evidence to Care at Holland Bloorview Kids Rehabilitation Hospital created a **Peer Support Best Practice Toolkit** resource for individuals developing and providing peer support programs for families of children with medical complexity[1] and other lifelong disabilities. To support development of the Toolkit and identify evidence-informed best practices in peer support, a rapid evidence review was conducted to address the following research question:

What does the evidence tell us about the effectiveness of peer support for families of children with disabilities?

Further, this review aimed to explore: What are the different ways peer support can be offered (e.g. online, in-person, parent matching; formal vs. informal programs)? Are any of these approaches found to be more effective than others? Who should deliver peer support programs (e.g. volunteer vs. paid facilitator; parent vs. professional)? When should peer support be initiated?

For the purposes of this review, the definition of peer support described by Sartore and colleagues (2013) was chosen, which defines peer support as, "*…the existence of a community of common interest where people gather (in-person or virtually by telephone or computer) to share experiences, ask questions, and provide emotional support and self-help"* (p. 2). Consistent with this definition, this review focuses on the provision of social and informational support for family caregivers, rather than training or other parenting/sibling programs that aim to improve parenting skills or child behavior.

Methodology

A rapid evidence review was conducted to identify 'review-level' articles on the topic of peer support for families of children with medical complexity and lifelong disabilities. The search strategy was created in consultation with a Research Librarian and included terms related to peer support, families, and pediatrics. For this review, family was defined broadly to include all caregivers who may benefit from peer support (e.g. mothers, fathers, siblings, grandparents).

As research specific to children with medical complexity and their families is limited (given this small population of children with intensive care needs), diverse samples inclusive of disability more broadly were examined. Screening by diagnosis was done manually to ensure relevant papers were captured.

Four databases were searched (Medline, PsycINFO, Embase, and CINAHL) in April 2015. Google and hand searching of peer-reviewed literature were also undertaken. Two reviewers independently reviewed all titles, abstracts, and full text articles for relevance using the following inclusion criteria: (1) Published in English between January 2004 - April 2015; (2) Focused on peer support interventions; (3) All or a subset of the sample included families of children/young adults with disabilities; (4) Review-level article (e.g. systematic review, meta-analysis, scoping

1. Children with medical complexity have substantial health needs and functional limitations, often rely on technology for care (e.g. ventilator, feeding tube), have chronic condition(s), are frequently hospitalized and under the care of many different health care providers (Cohen et al., 2011).

review); and (5) Examined caregiver stress-related outcomes. Primary studies were excluded.

One reviewer extracted data for included reviews and recorded information on the objective of the review, the inclusion/exclusion criteria, number and type of included studies, and key findings using a standardized form. Systematic reviews were scored using the AMSTAR (Assessing the Methodological Quality of Systematic Reviews) checklist (Shea et al., 2007). A second reviewer confirmed accuracy.

Findings

1402 unique records were identified through database and hand searching, of which six met the inclusion criteria, including: five systematic reviews and one literature review.[2] Of the included reviews, a broad range of study designs (qualitative and quantitative), varied use of standardized tools, and diverse outcomes were reported. Given the significant heterogeneity within the primary articles captured among the reviews, no meta-analyses were identified. Reviews differed in their quality; with low to moderately high AMSTAR ratings among the five eligible articles. A summary of all included reviews is provided in Appendix A.[3]

Of the included reviews, **only one focused exclusively on peer support interventions for families of children with disabilities.** In this systematic review, Shilling and colleagues (2013) reviewed qualitative and quantitative studies on peer support for parents (i.e. through one-to-one or group meetings led by parents). Although the importance of the unique experience parents shared with other families was highlighted, findings were mixed based on study design, type of data, and targeted outcome. Overall, the authors concluded *"qualitative studies strongly suggest that parents perceive benefits from peer support programmes, an effect seen across different types of support and conditions. However, quantitative studies provide inconsistent evidence of positive effects"* (Shilling et al., 2013, p. 602). While limited, these positive benefits pertained to enhanced social identity, greater practical knowledge and related psychological constructs (e.g. strength, motivation).

Other included reviews were broader in their population focus, but inclusive of families of children with disabilities. For example, two reviews examined peer support via the Internet for parents (Niela-Vilen, Axelin, Salantera, & Melender, 2014; Nieuwboer, Fukkink, & Hermanns, 2013). Although these reviews also reported benefits associated with peer support (e.g. parent satisfaction, provision of information, emotional support) identified through qualitative sources, evidence from the emerging body of quantitative studies were again not conclusive (Niela-Vilen et al., 2014; Nieuwboer et al., 2013). With the proliferation of social networking, social media and access to the internet, there is a major opportunity for research coupled with a significant need for rigorous evaluation. Looking at more traditional face-to-face modalities, Robbins and colleagues (2008) reached similar conclusions in their synthesis of evidence on parent-to-parent matching programs. Specifically, they found, *"results from descriptive and qualitative studies were unanimous in their documentation that parents found parent-to-parent support programs helpful and valuable"* (Robbins et al., 2008, p.6).

Two reviews were identified that focused on interventions to support siblings of children with disabilities (Hartling et al., 2014; Tudor & Lerner, 2015). Both reviews looked broadly at varied

2. Three reviews (one scoping, two literature reviews) did not examine effectiveness of peer support, per se, but rather how and why parents access peer support interventions and recommendations for program development. These reviews were not included in this rapid review, but are located in the reference list (Harder+ Company Community Research, 2012; Paterson, Brewer, & Stamler, 2013; Plantin & Daneback, 2009).

3. A protocol for an upcoming Cochrane review was also identified through the search but was not included in the final number as the review is still underway and findings have not yet been published.

interventions (e.g. peer support groups, family therapy, camp), with one addressing siblings of children with chronic illness and disability and the other review focused on siblings of youth with developmental disabilities (Hartling et al., 2014; Tudor & Lerner, 2015). Outcomes of interest related to disability knowledge, anxiety, affect, and behaviors. More compelling evidence was noted for programs with a psychosocial or psychoeducational component versus recreationally-based programs. However, the variability and overall quality of included studies (e.g. in outcomes assessed, interventions included, small sample sizes, lack of comparison groups) made it challenging to draw conclusions on the effectiveness of sibling peer support interventions. Both reviews highlighted a dearth of empirical evidence and raised the importance of better understanding the needs of these siblings to determine what interventions they are most likely to benefit from to tailor programs accordingly (Hartling et al., 2014; Tudor & Lerner, 2015).

Discussion

Findings were varied across reviews on the effectiveness of peer support for families, with **overall promising findings from qualitative studies and mixed or no effects from quantitative studies**. Although the research on peer support interventions for families of children with disabilities is emerging, "harm" was not associated within the identified interventions (Niela-Vilen et al., 2014; Shilling et al., 2013).

A number of common barriers to examining peer support effectiveness and areas for future research emerged across reviews.

First, there is no single delivery model. Peer support can be offered in a variety of ways (e.g. through in-person support groups, internet, matching programs). Of the included studies, many focused on only one of these approaches, and thus comparisons across approaches were not explicitly addressed. Within approaches, peer support interventions vary significantly in their design and structure, format, and outcomes assessed (Hartling et al., 2014; Nieuwboer et al., 2013; Robbins et al., 2008; Shilling et al., 2013). Whilst these aspects reflect a high degree of program customization, they nonetheless make it challenging to draw conclusions on overall effectiveness of peer support and offer tangible recommendations to support program development.

Second, although included reviews commented on the effectiveness of peer support, there was a lack of analysis and discussion detailing who benefits most from peer support, when, how, and by whom (e.g. who should deliver peer support programs? when should peer support be initiated?). By majority, participants were new parents or parents of children coping with social or health related issues, with some consideration of siblings. **The current lack of understanding can be attributed to a 'no one size fits all' approach to providing peer support and the strong emphasis on a family-centered design.** By their nature, peer support interventions are tailored to meet families' unique needs as evidenced across these reviews (Robbins et al., 2008; Shilling et al., 2013). The importance of taking a needs based perspective was also addressed in the two systematic reviews on peer support for siblings (Hartling et al., 2014; Tudor & Lerner, 2015). Specifically, Hartling et al. (2014) states, *"…more careful consideration needs to occur regarding what well-sibling interventions are intended to effect and, hence, what the most appropriate outcome measures are for their evaluation. Secondly, programs may need to more appropriately identify and target well siblings who require intervention, or those at high risk of negative outcomes"* (p. E36).

It should also be noted that of the included reviews, some were not specific to disability, while others defined disability broadly (e.g. included families of children with asthma, diabetes, cancer, physical disability). **Overall there was a lack of studies exclusively targeting caregivers of children with medical complexity and lifelong disability.** Within the field, aspects of peer support

interventions lend themselves to generalization. As Shilling et al. (2013) stated in their review, *"… it was reasonable to assume that any potential benefits of parental peer support were likely to be generic across children's long-term health conditions, rather than specific to any groupings of conditions"* (p. 602). However, given the intensive family stressors and care needs of children with more complex diagnoses, further exploration is needed to better understand how a child's diagnosis impacts the efficacy of peer support for these families (Hartling et al., 2014; Shilling et al., 2013).

Lastly, **the majority of reviews explicitly identified a need for more rigorous research on peer support interventions** with greater exploration of meaningful indicators and responsive outcome measures. Across studies, it was difficult to determine if the lack of conclusive evidence from experimental studies was due to an absence of high quality designs or if the outcome measures and timeframes selected were unable to detect significant change (Niela-Vilen et al., 2014; Shilling et al., 2013). Overall, the need for more research may not be surprising, as Niela-Vilen et al. (2014) and Tudor & Lerner (2015) both noted that most of the included papers in their reviews were from the last 15 years. Identification of 'gaps' in our understanding yield opportunities for continued research, acting as a basis for the current knowledge base to grow.

Work to watch

A noteworthy upcoming Cochrane review by Sartore and colleagues (2013) will review evidence on peer support interventions for parents and carers of children with complex needs. This comprehensive review will likely make an important and unique contribution to the field as it will include family carers from a wide range of pediatric conditions and will be inclusive of varied peer support modalities (e.g. online, in-person) to allow for comparisons through subgroup analysis. Additionally, the protocol outlines key questions that will be addressed in the review that align with the questions addressed in this rapid review (e.g. effectiveness of different approaches to providing peer support, optimal group composition, timing of interventions) (Sartore et al., 2013).

Strengths and limitations

A rapid review aims to quickly assess literature on a topic in a defined window of time. We focused on review-level papers; pooling of research evidence through rigorous synthesis is considered essential in the evaluation of healthcare interventions. A strength of this review was the use of two reviewers to screen all titles, abstracts, and full text articles for inclusion. Another strength is that whilst terms related to 'peer support', 'families', 'pediatric', and 'review' were included in the search strategy, screening by population (i.e. disability) was performed manually to ensure applicable papers were not missed. However, there is a risk that some reviews may have been excluded due to a lack of accurate population descriptors. It should be noted that with any evidence review with expedited timelines, there is always a risk that relevant papers may have been overlooked. As this review examined review-level papers only, primary studies falling outside of their specified publication window were not included.

Conclusions

Peer support interventions have been shown to have a number of potential benefits for families, albeit the evidence is still emerging – particularly for families of children with complex medical needs and lifelong disabilities. The modest evidence base indicates that families strongly value peer support; however, varied interventions, target populations, study designs and outcome measures assessed throughout the included studies prevent meaningful conclusions on overall effectiveness. The upcoming Cochrane review by Sartore et al. (2013) will provide further insight on this topic and directions for future research.

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Appendix A: Summary of included reviews

Author/ year/ country	Review type	Objective	Inclusion/exclusion criteria	Targeted outcomes	Included studies	Key findings
Hartling et al. 2014 CAN	Systematic review [AMSTAR: 8]	Synthesize evidence on the benefits of sibling-oriented care aimed at improving behavioural and emotional outcomes in well siblings of children with chronic illness or disability	Included: • Studies evaluated a program, support service, or therapy • Children (<18 years) who were well siblings of children with a chronic illness or disability • Examined peer review and grey literature • Studies reported quantitative data for at least 1 well sibling outcome • Randomised or non-randomised controlled trial, interrupted time series, controlled or uncontrolled before-after studies • Articles written in English or French • Date range searched: 1985 to 2008 (dates of included studies: 1989-2007) Excluded: • No further criteria specified	Outcomes examined: • Psychological health (anxiety, social adjustment, affect, affect, self-concept) • Family functioning • Behavioural functioning • Knowledge of disability	14 papers: • 14 Quantitative (2 RCTs, 3 Controlled Clinical Trials, 9 Uncontrolled Before-and-After Studies)	• In higher-quality controlled trials, benefits of sibling-oriented care included reduced anxiety, improved mood and behavioral adjustment; however, these findings were not consistently demonstrated across studies • Study differences made it difficult to draw general conclusions • Little consideration of the role of temporality (i.e. sibling initial diagnosis vs. long-term management) • Future evaluations need to clearly identify intended purpose of care (what improvements are intended) and which types of siblings are most likely to benefit
Niela-Vilen et al. 2014 FIN	Systematic review [AMSTAR: 5]	Explore Internet-based peer support interventions and their outcomes for parents	Included: • Internet-based community as an intervention, or component of intervention • Mothers and/or fathers or pregnant women • Parents had to interact and communicate with each other through Internet-based community • Papers with diverse methodologies including qualitative and quantitative designs • Examined peer-reviewed literature • English publications only • No limit on date (dates of included studies:1998-2013) Excluded: • 'Self-management program', 'therapy', 'treatment', 'education-intervention', or 'training' • Focused on teenaged parents • Studies where both parents and children participated in the same group	Synthesis of qualitative themes Outcomes examined: • Psychological health (coping, social support, meaning of illness, depression, anxiety, stress) • Parenting skills (parenting stress, satisfaction, self-efficacy)	38 papers: • 9 Quantitative (0 RCTs) • 4 Mixed-methods • 25 Qualitative	• Majority of studies targeted mothers • Qualitative data (from varied sources including online postings) showed positive benefits • For mothers, peer support provided emotional support, information and membership in a social community • For fathers, it provided support for the transition to fatherhood, information and humorous communication • Mothers more active users • In general, parents were satisfied with Internet-based peer support • No costing data noted • Evidence on the effectiveness from quantitative measures inconclusive, but no harmful effects reported

Appendix A: Summary of included reviews continued.

Author/ year/ country	Review type	Objective	Inclusion/exclusion criteria	Targeted outcomes	Included studies	Key findings
Nieuwboer et al. 2013 NLD	Systematic review [AMSTAR: 3]	Describe characteristics of online parenting resources and report on outcomes of different types of evaluation studies for online parenting Web sites	Included: • Primary components of studied resource delivered online (actual sites on the Internet) • Primary target group of these resources is parents who were expecting and/or had children aged between 1 and 21 years • Child characteristics included physical disability/illness, mental health problems or preterm • Examined peer reviewed literature • Papers with diverse methodologies including qualitative and quantitative designs • Articles published before 2010 (dates of included studies: 1998-2010) Excluded: • Descriptive articles on online information for parents • Editorials, commentaries, reviews and conference papers	Synthesis of qualitative content/ themes Outcomes examined: • Psychological health • Parent satisfaction • Parenting skills • Behaviour functioning	75 papers: • No breakdown provided [2 categories: Content analytic and experimental studies (13 had random assignment)]	• Internet offers a variety of opportunities for sharing peer support and consulting with professionals • Content analytic studies show a strong focus on online exchanges and peer support, whereas information pages and professional training and support are frequent themes in experimental studies • Content analytic studies show parent satisfaction with resources • Experimental studies show some positive effects, however, difficult to generalize due to small samples, mixed outcomes, etc.
Robbins et al. 2008 USA	Literature review [AMSTAR: N/A]	Uncover evidence of the effectiveness of parent-to-parent support; and examine the concepts, constructs, and key elements that should be considered when designing a program	Included: • Few details provided • Studies examining parent-to-parent support, from the level of a single program to a survey of programs nationwide • No limits on study design • Studies with diverse samples (e.g. mental health, disability, general parenting) • Articles published during or after 1990 (dates of included studies: 1991-2008) Excluded: • Studies that did not examine parents receiving support from parents who had shared similar experiences • Dissertations	Outcomes examined: • Psychological health (anxiety, depression, anger, coping) • Family functioning (empowerment) • Behaviour functioning • Service use	31 papers: • 9 Random Control Design • 3 Quasi-Experimental • 4 Qualitative • 11 Descriptive • 4 Topical Discussion	• Great diversity in nature of programs and in settings in which they are offered • Very few rigorous studies evaluating effectiveness of parent-to-parent • Results from descriptive and qualitative studies unanimous in documentation that parents found support programs helpful and valuable • While empirical base is limited, results from studies are encouraging

Appendix A: Summary of included reviews continued.

Author/ year/ country	Review type	Objective	Inclusion/exclusion criteria	Targeted outcomes	Included studies	Key findings
Shilling et al. 2013 UK	Systematic review [AMSTAR: 8]	Review evidence on the benefits of peer support for parents of children with disabling conditions in the context of health, well-being, impact on family, and economic and service implications	Included: • Informal or formal support offered to parents by parents in one-to-one or group meetings • Parents and caregivers of children with chronic disabling conditions including disabled, chronically, or seriously ill children and young people • Examined peer reviewed and grey literature • Included broad range of outcomes • No limit on language, child's condition, setting, study design, or date (dates of included studies: 1996–2011) Excluded: • Internet or telephone support • Professionally led or parenting skills training interventions • Bereaved parents, parents of infants in the neonatal intensive care, or parents of children receiving treatment for cancer • Editorials, opinions, letters and reports published only as abstracts from conference proceedings	Synthesis of qualitative themes Outcomes examined: • Psychological health • Family function • Experience of parents receiving support • Accessing services and information	17 papers: • 7 Quantitative (7 RCTs) • 1 Mixed-methods • 9 Qualitative	• Qualitative studies suggest benefits from peer support, across different types of support and conditions • Four themes emerged: (1) shared social identity, (2) learning from the experiences of others, (3) personal growth, and (4) supporting others • Quantitative studies provide inconsistent evidence of positive effects on anxiety, depression, coping and related psychological constructs • Could not aggregate data across studies • No costing data identified

Appendix A: Summary of included reviews continued.

Author/ year/ country	Review type	Objective	Inclusion/exclusion criteria	Targeted outcomes	Included studies	Key findings
Tudor & Lerner 2015 USA	Systematic review [AMSTAR: 5]	Evaluate current state of literature on intervention and support for siblings of youth with developmental disabilities (DD) and provide recommendations for research and practice	Included: • Studies aimed to evaluate an intervention or support group for children or adolescents who have a sibling with a DD • Participants in studies included at least 1 participant who was a sibling of a child with DD • Sibling participants between 3-17 years • DD diagnoses of affected siblings to fall within "neurodevelopmental disorders" category outlined in DSM-5 • Studies with diverse samples (e.g. chronic illness, physical disability) • No limits on article quality • Examined peer-reviewed experimental papers • Articles written in English only • Articles published before June 2012 (dates of included studies: 1985-2012) Excluded: • Sibling intervention or support program not carried out (e.g. proposals, recommendations) • Study samples that did not include any siblings of youth with DDs	Outcomes examined: • Psychological health (stress, coping, depression) • Family functioning • Behavioral functioning • Knowledge of disability • Sibling relationships • Sibling enjoyment	16 papers • 16 Quantitative (5 Controlled Before-and-After, 11 Uncontrolled Before-and-After)	• Common outcome themes identified across studies included: support, self-esteem, knowledge about disability, sibling relationships, emotional and behavioral adjustment, and sibling enjoyment • Despite common outcome themes, the selected articles reported variable outcomes and overall results • Need for effective assessment of sibling needs (being a sibling is not the only consideration), identification of family system factors, details regarding benefits of psychoeducation about DD, improved research methods, and more unified approach to sibling intervention research

Holland Bloorview

Kids Rehabilitation Hospital

A teaching hospital fully affiliated with the University of Toronto

Holland Bloorview Kids Rehabilitation Hospital
150 Kilgour Road
Toronto, ON M4G 1R8
Tel: 416-425-6220
Toll-Free: 800-363-2440
Fax: 416-425-6591
E-mail: info@hollandbloorview.ca
www.hollandbloorview.ca