



What is ‘sibling support’? Defining the social support sector serving siblings of people with disability

Ariella Meltzer

Centre for Social Impact, UNSW Sydney, 704, Level 7, Science Engineering Building (E8), UNSW, Sydney, NSW, 2052, Australia

ARTICLE INFO

Keywords:

Siblings
Disability
Sibling support

ABSTRACT

‘Sibling support’ is a form of support for the brothers and sisters of people with disability within medical, health and social care practice, promoting outcomes for them such as improved self-expression, mental health, well-being, skills and networks. There has been significant research interest in sibling support, however most has only evaluated individual interventions. There has been little-to-no research that has examined what sibling support is as a sector or overall field of practice. This paucity of research on sibling support as a field of practice is a problematic gap as it prevents recognition of sibling support as a distinct service type/sector, and may ultimately prevent sibling support from getting due support, acknowledgement, funding and promotion.

Drawing on a study of national-level sibling support providers in the USA, UK, Canada, New Zealand and Australia, this article therefore seeks to describe sibling support as a sector and field of practice: the principles underpinning it, purposes/functions it addresses and delivery methods used. The article also discusses variation and emerging practice between sibling support providers, as well as the importance and implications of the findings for building greater recognition of sibling support within medicine, health and social care, particularly within the context of policy changes and increasing conditions of austerity, requiring more targeted decisions about what service types service systems support and promote.

1. Introduction

Where one sibling has a disability, the brother or sister without the disability commonly has a range of distinctive experiences across the life-course. These experiences may include complicated and conflicting emotions about their sibling’s disability (Leane, 2019; Mauldin and Saxena, 2017); and complex family system dynamics, including possible difficulties in relationships with parents (Wolf et al., 1998), exposure to violence/challenging behaviour (Benderix and Sivberg, 2007) and possible impacts on life outcome areas such as marriage and divorce rates (Wolfe et al., 2014). They may also need to navigate disability service systems (Arnold et al., 2012; Burke et al., 2017) and have extra caregiving responsibilities (Mauldin and Saxena, 2017). Siblings of people with disability also commonly have unique lived experiences of complex concepts – such as ‘inclusion’, ‘acceptance’ or ‘quality of life’ and even of ‘space’ and ‘time’ – where they hold insights into the value of their brother or sister’s life that are not easy to reconcile with the dominant messages about disability in popular culture (Gaal et al., 2010; Pavlopoulou and Dimitriou, 2020). Similarly, they may not always see their disability-inflected sibling relationships included in common

cultural understandings of ‘siblinghood’ (Meltzer, 2017, 2018).

This range of experiences has meant that siblings of people with disability have often been the recipients of ‘sibling support’. Sibling support is a form of support offered within medicine, health and social care that aims to respond to the distinctive life experiences of siblings of people with disability. Formal definitions of sibling support are rare to non-existent in the research literature. However, broadly, sibling support is usually underpinned by either a clinical/therapeutic model or a social/peer support model, and commonly seeks to promote outcomes for siblings of people with disability such as improved self-expression, mental health, wellbeing, skills and networks (Kramer et al., 2021; Meltzer and Muir, 2021). It is commonly run by either dedicated sibling support organisations or medical, health and social care agencies focused on disability and the family.

Sibling support has been an expanding area over many years. However, the research evidence-base behind it is not well developed. There are many studies evaluating the effectiveness of individual programs/interventions, usually those that are therapeutically- or clinically-based (Evans et al., 2001; Granat et al., 2012; Haukeland et al., 2020; Hill, 2016; Lobato and Kao, 2002; McCartney, 2008; Roberts et al., 2015;

E-mail address: a.meltzer@unsw.edu.au.

<https://doi.org/10.1016/j.socscimed.2021.114466>

Received 2 June 2021; Received in revised form 24 September 2021; Accepted 7 October 2021

Available online 9 October 2021

0277-9536/© 2021 Elsevier Ltd. All rights reserved.

Rubin et al., 2017), but also some peer support (D'Arcy et al., 2005), future planning (Lee and Burke, 2021) and leadership/advocacy-based models (Burke et al., 2018). The occasional study has offered a meta-analysis of outcomes from different interventions (Tudor and Lerner, 2015) and some studies have offered theoretical frameworks for conceptualising the impact sibling support can make (Meltzer and Muir, 2021; Kovshoff et al., 2017; Saxena and Adamsons, 2013).

However, there has been little-to-no research that has – at a higher conceptual level – examined what sibling support is as a sector or overall field of practice: who provides it, the philosophical principles that under-pin it and the scope of different delivery options used. This paucity of research is a notable and problematic gap, as without this kind of conceptual work there is little to describe the boundaries of 'sibling support' as a sub-sector within medicine, health and social care. Without this description, sibling support risks being under-recognised as a discrete service offering and there is little to link the evaluations of individual programs/interventions. Further, this under-recognition may prevent sibling support from getting the support and acknowledgement that it deserves as a distinct service type/sector, and also may prevent it being funded and promoted within medical, health and social care environments that are experiencing increasing conditions of austerity, requiring more targeted decisions about what service types to support and promote (Power and Bartlett, 2019). For this reason, it is critical that further work is done to describe and recognise sibling support as a distinct field of practice, to support its ongoing work and existence.

For these reasons, this article seeks to provide a conceptual, cross-country description of sibling support. The article reports on a study of national-level sibling support providers in five Western, English-speaking locations: the USA, UK, Canada, Australia and New Zealand. It seeks to answer the following research questions:

1. What is sibling support?
2. With what models is sibling support provided?

In answering these questions, the article describes how sibling support is defined and delivered in the countries listed above. In doing so, it specifically focuses on the philosophical foundations of sibling support and its delivery models in a program-content sense. The result is the first empirically-based cross-country description of what sibling support is and how is offered.

2. Methods

This article draws from a cross-country qualitative study of national-level sibling support providers in five Western, English-speaking locations: the USA, UK, Canada, Australia and New Zealand. These countries were chosen because historically they have had the most established sibling support initiatives and because they are relatively comparable socio-politically. The study was approved by an Australian Human Research Ethics Committee, in accordance with international protocols, with written consent from participants and their organisations.

2.1. Participants

Participants in the research were people in a senior leadership role in a national-level organisation providing sibling support in one of the countries listed above. People in a senior leadership role were chosen because, given the unit of analysis for the research was the organisation rather than the perspectives of individual staff, those in a senior leadership role were considered the most appropriate to speak on behalf of their organisation. In most cases, one person was invited to participate per organisation, so there would be one figurehead who could speak conclusively on behalf of the organisation. There was an exception for one organisation where there had been a very recent leadership change and so both the former and current director took part. In total, 13 people participated from 12 organisations.

To find the participants, an online scan of sibling support provider websites was completed to systematically identify all sibling support providers in the selected countries, who were then invited to participate if they were assessed to provide national-level services (based on published information on their websites/social media). Once identified, providers were contacted at a publicly listed email address. Roughly two-thirds of invited organisations participated (12 of 17).

Sibling support providers had the choice to be named in the research, so their practice could be recognised. All providers agreed and are listed below in Table 1, divided between:

1. *Sibling-only providers* (those providing support exclusively to siblings of people with disability).
2. *Siblings-among-others providers* (those supporting siblings among other service beneficiaries; e.g. people with disability, parents or 'young carers', a group which includes young adult siblings of people with disability but also young people providing support to parents or grandparents with a chronic illness or disability).

Table 1 also includes notes on the age and size of the organisations within the two groups. More details about the business models, funding, staffing and leadership/governance of the organisations are available elsewhere, still however in aggregated form to protect organisations' privacy (Meltzer, 2021).

2.2. Data collection

Data collection consisted of semi-structured interviews via Zoom, conducted by the article's author and a research assistant. The interviews were 45–60 min long and covered:

- (1) The definition of sibling support;
- (2) Models of sibling support, including philosophy, delivery method, business model, funding, staffing and governance;
- (3) Similarities and differences between sibling support providers;
- (4) Enablers, constraints, benefits and challenges in implementing sibling support; and
- (5) Future opportunities for sibling support.

The interviews were played out loud through computer speakers and recorded with a digital audio-recording device, and transcribed verbatim.

Table 1
Sibling support provider organisations who participated.

Sibling-only providers	
Organisations in this group ranged between one and 30-years-old. All were small; none had more than three full-time-equivalent paid staff members, although many also included work by volunteers.	
Siblings Australia	AUS
Sibs UK	UK
Sibling Support Project	USA
Sibling Transformation Project	USA
Siblings With A Mission	USA
Sibling Leadership Network	USA
Sibling Collaborative	CAN
Siblings-among-others providers	
Some organisations in this group were 50–60-years-old, yet in most cases their focus on siblings was more recent – only starting in the last couple of decades. While some of the organisations had hundreds of staff, in most cases only one-to-two of the staff were available for programs servicing siblings, whereas the rest of the workforce was dedicated to other programs (e.g. support services, sport, recreation) and/or other beneficiaries (e.g. people with disability, parents). The most staff that any organisation in this group had who all could service siblings was 35.	
Little Dreamers Australia	AUS
Sense	UK
Parent to Parent New Zealand	NZ
Special Olympics	USA/global
Young Caregivers Association	CAN

2.3. Data analysis

The transcribed data was analysed thematically by one researcher, the article’s author, using a line-by-line approach for each transcript and a two-stage process conducted in NVivo 12. The aim of the two-stage process was to first divide the data into pre-set sections based on the research questions and focuses of the study, and then to do a more detailed thematic analysis of participants’ responses within each of these sections. Given the diversity of sub-topics the data collection had covered, the purpose was to section the data into relevant sub-sections for publication, here in this article and elsewhere (Meltzer, 2021).

In the first stage, the data was coded to pre-set categories/sections based on the broad areas asked about in the research:

- (1) Definition of sibling support (inclusions, exclusions);
- (2) Models of sibling support (philosophy, delivery methods, business models, funding, staffing, leadership/governance);
- (3) Assessment of sibling support (successes, challenges, similarities/differences between providers, future opportunities); and
- (4) System for sibling support (enablers, constraints).

In the second stage of data analysis, Braun and Clarke’s (2006) thematic analysis process was followed, using an open-coding process, to generate sub-nodes within each of the pre-set nodes mentioned above, this time based entirely on participants’ accounts. It is the refined and final versions of these themes based on participants’ accounts that appear in this article – the final set of themes are represented by the grey boxes in Fig. 1, with the white boxes showing further detail in how these themes manifested.

Attention was paid throughout the analysis to cross-country comparisons, by noting similar responses across countries as well as differences. Importantly however, given the small number of organisations from each country, care had to be taken in the write up of the cross-country comparisons so as not to disrupt the confidentiality of the participant organisations. Cross-country comparisons are therefore only reported where they did not present ethics or privacy concerns.

Notably, the final analysis was returned to and checked by participant organisations for accuracy of representation of their organisation

and work, and some adjustments were made as a result.

Of note, this article includes findings about the nature of sibling support service models. A second set of findings covering a business-operational perspective on sibling support was also compiled and is published separately (Meltzer, 2021).

3. Findings

The following sections outline the research findings, also summarised in Fig. 1. Of note, the findings across the five countries were remarkably similar, indicating a relatively cohesive model of sibling support cross-nationally. However, where cross-country comparisons were evident, they are noted.

3.1. Underpinning principles of sibling support

Sibling support providers identified three central principles (foundational beliefs) of sibling support, which underpinned all work they did. These principles were consistent across all five countries.

3.1.1. Siblings as a recognised part of the family system

A central principle for almost all sibling support providers was that siblings must be recognised as a critical part of the family system. Providers commonly noted that in other disability services, the definition of family was often very parent-centric. They emphasised the importance of recognising siblings as part of the family as well, not only for the sake of their own support, but also because of interconnected outcomes for all family members, including the person with disability:

“I think one way that [medical service providers] could understand the importance of [sibling support] is just by recognising that sibling outcomes are connected to patient outcomes, and to the overall family outcomes. If a sibling is supported, the person with the disability or condition will have better outcomes as well” (P.09).

Some providers explained that they thought other “organisations that deal in caregiving or disability should automatically embody siblings in their work” (P.01), but that since they so often do not, sibling support is needed as a separate field of practice in response.

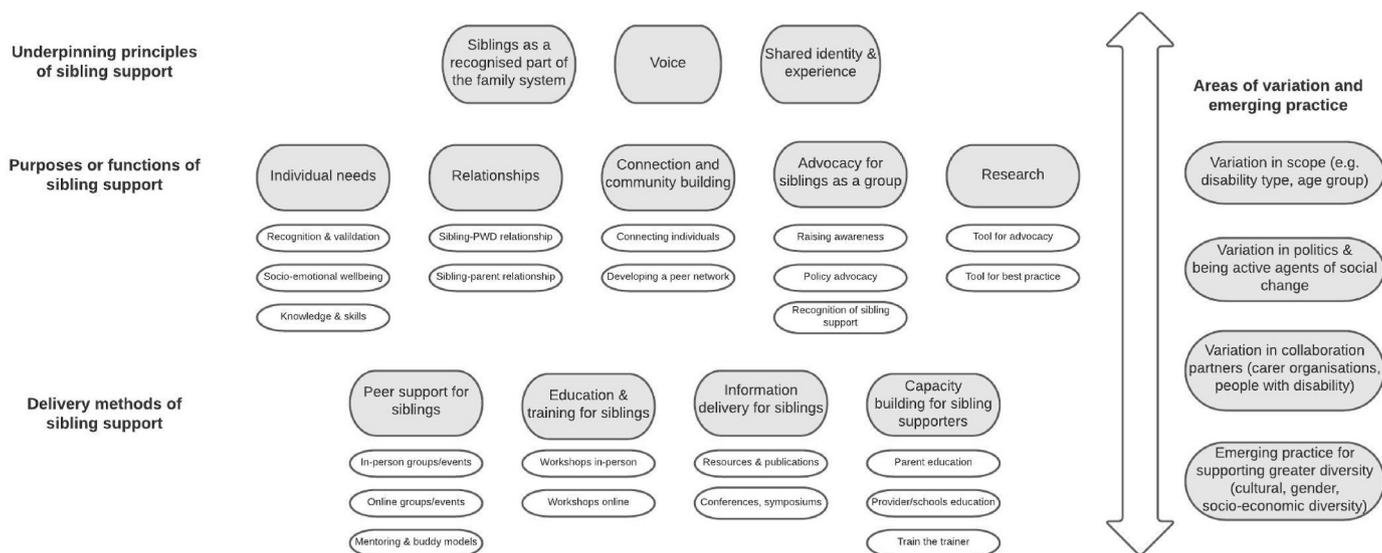


Fig. 1. Concept diagram defining sibling support.

3.1.2. Voice

Connected to often having less recognition within the family, sibling support providers noted that “a lot of times we hear that ... siblings often feel like they don’t have a voice” (P_09). For this reason, providers acknowledged that a central principle of sibling support was to “amplify [siblings’] voices” (P_08) and to make sure they feel heard, not only by their family, but also by disability services and broader society:

“... whether they’re adult sibs or young sibs, sibs just want to be heard. You can’t always fix the situation, but if you feel you’ve been heard, it makes all the difference in the world” (P_03).

Sibling support providers noted that amplifying siblings’ voices meant “that the needs of the sibling are understood and are addressed in their own right, not as an add-on to a program for parents or people with disability” (P_06).

3.1.3. Shared identity and experience

A final underpinning principle of sibling support was that it both responds to and is built on siblings’ shared identity and experience, by providing a dedicated “community” (P_10) or “caucus space” (P_05) for siblings to share experiences.

Notably, the providers recognised that the support siblings experienced in these types of dedicated spaces was generated by their shared experience itself and grew from a “peer-to-peer” model (P_06), rather than being delivered by either “ivory tower” specialists or service providers (P_03) or by others, such as parents, providing support to siblings:

“We’re not there to provide all the answers. We’re there to humbly accept the fact that the siblings are the people who are the real experts in the room, and if given a chance, they have a lot of internal resources and wisdom to share with one another” (P_03).

Together with the other principles of recognising siblings as part of the family system and amplifying their voices, the principle of providing spaces to recognise shared sibling experiences defined almost all forms of sibling support.

3.2. Purposes or functions of sibling support

Beyond its underpinning principles, providers also spoke about the purposes/functions that sibling support aimed to address. Several functions were about supporting individual needs, however there were also a range of broader functions related to relationships, community, advocacy and research. While not every organisation catered to every purpose/function, these purposes and functions were relatively consistent across the five countries.

3.2.1. Individual needs

Many sibling support providers were primarily focused on supporting individual-level outcomes in the following areas:

- **Recognition and validation.** Providers described a key function of sibling support being acknowledging and validating the distinctive life experiences of siblings of people with disability. Several providers made comments such as “We also do acknowledgement ... acknowledging the place that you’re in” (P_01) or “Validation is a huge piece of what we do” (P_03). Validation usually meant having a welcoming forum for expressing the concerns, resentment and difficulties siblings experienced, especially where siblings felt embarrassed or ashamed of their feelings. It also included normalising experiences that young siblings commonly had that others their age may not (e.g. their brother or sister being hospitalised, calling ambulances, coping with challenging or unusual behaviour).
- **Social-emotional wellbeing.** While purposefully distinct from a clinical/therapeutic model (see ‘exclusions’ below), providers discussed sibling support having the function of promoting siblings’

social-emotional wellbeing. For some, this meant promoting siblings’ mental health, including “improv[ing] their self-esteem and how they feel about themselves” (P_04). For others, it was about fostering a more general sense of “mindful self-compassion” (P_01).

- **Knowledge and skills.** Facilitating useful knowledge and skills among siblings of people with disability was another function of sibling support. This included both directly providing information and resources that would be useful to siblings, as well as providing a peer forum for siblings to share information with each other; both methods were seen as useful, with one provider commenting, “There is a trove of information about services and resources that gets shared every day information is a kind of support” (P_03). In other cases, providers worked on skill development among siblings (e.g. advocacy, disability service system navigation and organising skills), so that they not only had information, but also knew how to apply/use it.

3.2.2. Relationships

Beyond the needs that sibling support addresses for individuals, providers also described some types of sibling support serving a relational function – that is, providing support to the shared relationship between either (a) a sibling and the person with disability or (b) a sibling and their parents. While generally this was one of functions less commonly mentioned, some noted the importance of this kind of relational support:

“If we can get in early, support the whole family, help the family become stronger, the relationships within the family stronger, then that’s going to be better for everyone in the family in the long term” (P_07).

Relational support was framed in terms of, for example, improving interactions between siblings with and without disability and their level of satisfaction with their sibling relationship. It was also framed as about improving interactions and communication between parents and adult siblings.

3.2.3. Connection and community building

Connection and community building was one of the most common functions of sibling support. Connecting individuals with other siblings was one of the fundamental purposes of sibling support for most providers:

“I think sibling support has a few different components, and I think one is certainly connection, so connecting siblings to one another so that they can feel less isolated and more understood and less alone” (P_03).

Some described this function as “connections for peer support” (P_12) or as about siblings having “their own peer network of people” (P_06). It was seen as a function of sibling support that went beyond the immediate family context to build something more: a wider community based on shared lived experience. Some providers who were predominantly focused on this function of sibling support therefore saw themselves as providing “a more outward-looking type of sibling support ... [we’re] looking at the family within a wider community context” (P_08).

3.2.4. Advocacy for siblings as a group

Advocacy on behalf of siblings of people with disability as a group was identified as another major function of sibling support. While not all providers engaged in advocacy, for those who did, it was a very significant part of their work. Some advocacy was about ensuring siblings were acknowledged and catered for in relevant policy (e.g. policies for disability services or medical/caregiving leave):

“The policy and advocacy arena [is our] other focus area. [That] is really trying to get the sibling voice at the policy table ... There are

many family support policies that don't specifically include siblings and so that is a big part of ... [our] work" (P_12).

Other types of advocacy included more generally raising awareness about siblings of people with disability and their support needs (e.g. among parents, service providers, schools, media) and advocating for funding/recognition for sibling support organisations. Depending on their national policy and funding context, some providers had been forced to spend a very significant amount of time advocating for such funding/recognition – this was most commonly the case in countries outside the USA; USA-based sibling organisations generally appeared to be able to secure somewhat more recognition, although obtaining ongoing funding remained difficult.

3.2.5. Research

While not a direct form of sibling support, many sibling support providers also either engaged in their own research projects or spent time supporting research done by academics. Engagement with research served two purposes. Firstly, research was valued as a tool for the advocacy function of sibling support:

"In terms of research, we really try to encourage more research on the sibling experience and we try to get that research into the hands of siblings and their families, so they can advocate for their needs" (P_12).

Secondly, research was also a tool for best practice and continuous improvement, to ensure that providers' current ways of giving support were effective and to support their expansion into new areas or offering their support to new demographics of siblings.

3.2.6. Exclusions

Providers were also clear about what they saw as excluded from sibling support. While clinical/therapeutic support programs are sometimes offered to siblings in medical and psychological contexts, none of national-level sibling support providers included in the research provided this type of support, and many were clear that they did not provide "a clinical model", "therapy" (P_03) or "counselling" (P_10). In addition, all providers were clear that while they commonly support parents, service providers and other community members to understand sibling issues and to be able to support siblings, it was not the purpose of sibling support to provide support to these other groups in their own right. Policing this boundary could sometimes be difficult when others (particularly parents) tried to enter sibling community spaces to learn more about sibling needs.

3.3. Delivery methods of sibling support

Providers also described the range of delivery methods (i.e. programs and activities) they used to implement sibling support. Notably, many of the delivery methods could be used to operationalise multiple purposes/functions of sibling support. While not every delivery method was offered by every provider, the scope of delivery methods was relatively consistent across all five countries.

3.3.1. Peer support for siblings

A dominant delivery method was bringing siblings together for peer support. Providers described three types of peer support. Firstly, they spoke about in-person peer support groups and events, e.g. workshops, meetups, fun days, camps and retreats. These were locally-based and were often (but not exclusively) for child- and youth-aged siblings. Many combined fun activities (e.g. indoor games, outdoor adventure activities) with discussion activities about being a sibling of someone with a disability, with the combination being critical to the delivery model:

"I think that the reason [our peer support workshops have] been so successful and popular is because they really centre around two

universal languages. One is ... the shared experience of having a sibling with a disability. The second equally important one is play ... we know that when kids play and engage and have fun, they also feel more comfortable to do the discussion parts of it, to talk and to share their experiences" (P_03).

Many in-person peer support groups for children and young people also covered topics related to self-care, coping, stress management and wellbeing (in general, without a formal therapeutic focus), including interactive activities, such as crafts and personal goal-setting.

The second type of peer support was online groups and events. The most longstanding form of support in this category was online communities of siblings, i.e. bringing large groups of siblings together for online discussion and sharing of experiences/information (often divided by age group). Most of these communities are currently hosted through Facebook, although one provider had a dedicated hub website. In addition, as the research was undertaken during the COVID-19 pandemic, several other online peer support options had also more recently been offered, including small online discussion groups facilitated over video-chatting platforms; online games, movies, book clubs and fun activity sessions for children and young people; and the adaptation of some of in-person peer support workshops to an online model. These adaptations were particularly, although not exclusively, the case in the USA, UK and Canada, who had had the most serious pandemic experience. Providers noted that these new options had often been very successful, for example, saying "really deep bonds ... seem to form, even virtually" (P_01).

The final type of peer support was a range of mentoring, role model and buddy schemes, where pairs of siblings were directly matched to each other (or sometimes with an external mentor) for support, sometimes in-person but more commonly online. This was a rarer form of peer support, one that only a few providers offered, although others noted it as a future aspiration.

3.3.2. Education and training for siblings

A second common delivery model was education and training for siblings. Here, providers commonly offered interactive workshops either in-person or online on a range of topics that are useful for siblings to know about and that would build knowledge and skills that were either directly or indirectly relevant to supporting themselves and/or their brothers or sisters with disability. For children and young people, common topics included dealing with bullying, information about different types of disabilities and, less commonly, life skills, such as tutoring for school, CV-writing, cooking or financial literacy. Common topics for adults included disability service system navigation, guardianship laws and planning for the future care, housing, employment and finances of the person with disability. More recently, some providers had covered other rights-based topics with adults, such as ableism and intersectionality, voting rights and sex education for people with disability, and also focused on building civic skills among siblings, for example, leadership, advocacy and community organising skills. While some educational workshops have historically happened in-person, most run by national-level providers increasingly appear to be conducted online, particularly during the COVID-19 pandemic.

3.3.3. Information delivery for siblings

Information delivery for siblings was another major delivery model, encompassing two common avenues. The first was providers producing a range of resources/publications. A small number of providers focused on print resources (e.g. edited books containing sibling accounts; pamphlets on sibling issues), however, information available online was more widespread. Common forms of online information included providers running social media accounts, distributing email-newsletters or having information about sibling experiences listed on their websites. A few providers ran, or had run in the past, online directories of organisations and resources that helped siblings at a local-level. One provider

had a relatively unique model of running a 'story column': a curated blog where individual siblings could write their own post and have it distributed by the provider. The provider commented on the benefits of this model, explaining that the 'stories' could be indexed in different ways (e.g. searched by topic or by disability diagnosis) and that the information contained in the 'stories' was presented in a static searchable form.

The second form of information delivery was through conferences/symposiums. These were run by only a few of the providers, although usually involved collaboration with other providers beyond those directly hosting. Conferences/symposiums usually contained an element of siblings meeting for peer support, but also involved information delivery through practitioner/research presentations, information sessions, discussion groups and resource distribution. These conferences/symposiums were usually major events on the 'sibling calendar', attracting significant interest from both siblings and sibling supporters. Most had traditionally been run in-person, but some providers had run, or were planning to run, them online due to the COVID-19 pandemic.

3.3.4. Capacity building for sibling supporters

A final common delivery model was capacity building for 'sibling supporters', i.e. people who support siblings: parents, disability service providers, medicine/health/social care professionals and schools. Several providers conducted information sessions and training for parents and service providers, and responded to inquiries sent in by parents about how to manage the dynamics between siblings and children with disability in their family. Others incorporated parent- and service provider-training into their other activities, e.g. having parent sessions at a sibling conference/symposium. One provider had a unique model of providing individualised sessions for parents:

"I have also been providing one-on-one sessions with parents, where I can go into more detail about their family, and give parents specific ideas on how they can support the child that's the sibling of a child with disability" (P_07).

A small number of providers also ran training to inform schools about how to identify and support siblings. 'Train the trainer' models were also common, where sibling support providers trained staff from other medical, health and social care organisations in how to deliver their model of peer support workshops, sometimes offering a certification as a facilitator of their model. 'Train the trainer' models were an important way of expanding sibling support, as many providers had few staff and could not run all peer support workshops directly.

3.3.5. Other delivery methods

Beyond the common delivery methods above, there were innovative models being run by single providers. Examples included: 'Make-A-Wish'-type experiences for young siblings; personalised social-emotional coaching; micro-grants for siblings; and organising groups of siblings for political action.

3.4. Areas of variation and emerging practice

Beyond the relatively cohesive model of sibling support identified above, there were some areas of variation and emerging practice. It is in these areas that the most differences were evident across the five countries, based on their various policy and political contexts. These differences are noted in the findings below.

3.4.1. Variation in scope

The providers of sibling support varied on some aspects of the scope their work covered. For example, while most focused on siblings of people with disability only, some accepted siblings of people with mental health conditions and/or time-limited illnesses (e.g. cancer), while others purposefully referred such siblings on to other family

support organisations. Similarly, most providers worked across all disability types, although some mentioned a particular focus on, for example, intellectual and developmental disabilities or rare syndromes. Many providers worked across different age groups, although some focused on children or adults only. These types of scope decisions appeared to depend partly on capacity of the organisation, partly on philosophy the organisations' leadership and partly on how many organisations there were serving siblings in a particular country (i.e. whether the support load could be shared or not). In the USA, where there are many more sibling-focused organisations, there was somewhat more scope for individual providers to specialise, whereas, it was more common (although not universal) for organisations in the other countries to be all-rounders in their scope decisions.

3.4.2. Variation in approaches to politics and being active agents of social change

Sibling support providers varied in their approach to politics and being active agents of social change. Aligned with the purposes and functions of sibling support described earlier, many providers saw themselves as providing individual, relational and community-level support only, and therefore largely avoided a political nature to their work. While they acknowledged that politics could be something siblings themselves wanted to discuss, they saw that such discussions could often (but not always) side-track sibling discussions away from being "warm, safe and supportive" (P_03) and thereby pose a threat to the individual support function of their work.

For the providers who had a greater focus on the advocacy function of sibling support, politics and orientation to being active agents of social change took on a larger focus. These providers spoke about wanting to support siblings to be "agents of change" (P_08). They often needed to negotiate whether they focused on policy only or also politics. Some organisations did this by being as politically non-partisan as possible, but taking positions on specific policies relevant to disability:

"As an organisation, one thing we very clearly steer clear of is taking political positions. We take positions on policies sometimes that impact people with disabilities and their families, but we very much stay in the camp of being non-partisan and that's important for our work ... [however] we do [sometimes] take stands on some things that are controversial and do have a political nature to them" (P_12).

Others had a more explicitly political approach (e.g. activism/campaigning), with the rationale that such activism was a critical part of sibling support, because without it, the system-generated difficulties experienced by siblings and their families would never change:

"I think that we're going to be dealing with injustices no matter what ... and if we don't intentionally work to dismantle those injustices and transform the systems that we're dealing with, we're going to constantly be hitting our head against the wall ... I think that we [in sibling support] both need to be healing the systems that we're in and feeling understood, and then, also, pushing on the systems [from the] outside" (P_05).

The variation on the issue of politics and being active agents of social change shows a spectrum of sibling support providers, in part determined by what providers saw as the purpose/function of their work, but also determined by the internal philosophy of each organisation and by the extent to which an imperative to define a political position was part of the national culture in which they were located (i.e. the issue of politics was more commonly mentioned in some countries than others).

3.4.3. Variation in collaboration partners

There was also variation on providers' collaboration partners. While some engaged in significant partnerships already, most acknowledged scope to engage in further collaboration – both within sibling support (sibling support providers better collaborating with each other) and

with other sectors (disability, mental health, child protection, education etc). Two particular groups were however the subject of significant variation in collaborative practice.

Firstly, in the Commonwealth countries included in the study (Australia, NZ, UK and Canada) where 'carers' and 'young carers' are significant policy concepts, whether and how to collaborate with 'carer' organisations was a significant issue. Some sibling-only providers understood the issues experienced by siblings to be distinct from those experienced by 'carers' in general, who might be caring for a parent, grandparent, spouse or other family member with a disability or illness, rather than brother or sister. As a result, some sibling-only providers did not want sibling support to be grouped together with carer support or for siblings to automatically be seen as 'carers' or 'young carers' and had not sought much collaboration with carer organisations. In other cases, sibling-only providers had sought past collaboration with carer organisations, but without success or finding reciprocal interest. Interestingly, at the time of this research, some sibling-only providers were aiming for more collaboration with carer organisations, partly to achieve greater recognition for sibling support and partly to build a broader network:

"The young carer policy arena is much thicker than the sibling arena, so I think we need to piggy-back it a little bit to try and get that messaging out there and do some more partnership working" (P_11).

Notably, several of the providers who serviced siblings among other beneficiaries had come to sibling support as a consequence of servicing 'young carers', and described working across the needs of young people in families affected by disability, illness, chronic illness, old age and drug/alcohol addiction, regardless of the young person's relationship to the person affected. As a result of working from an approach that was not sibling-only, they saw the need to work across the boundaries of sibling, carer/young carer and other family support and to be collaborative with a wide range of organisations. While seeing some experiences that were unique to siblings, these providers did not tend to believe that the experience of siblings was always completely distinct from that of other young people in families affected by health conditions, and some (particularly those with a strong caregiving focus) felt that more depended on the type of disability or support needs present than the relationship to the person. The variety on the issue of collaborating with carer organisations suggests the possibility of at least some sibling support providers seeking to extend connections with carer organisations in the future. Providers acknowledged that this would require getting past "a tendency to be precious about your group" (P_11) and the difficulties of "everyone ... competing for the same donated dollar" (P_10).

Secondly, there was also variation in the extent of collaboration with people with disability and the organisations representing them. While all sibling support providers had deep respect for people with disability, there were different perspectives about the extent to which sibling support should collaborate with them and draw them into sibling-led conversations/spaces. For some, collaboration with people with disability did not appear to be an explicit part of their model and was simply a topic that did not come up in their interviews. These tended to be the providers focused mostly on individual, relational and community-level support only. Their decision not to broach collaboration with people with disability was possibly because – consistent with their support-focused purpose – they wanted to create space for siblings to discuss the difficulties and challenges of having a brother or sister with disability, and judged this to be easiest when people with disability were not a part of the conversation.

While supporting the need for recognition and validation of the difficulties experienced by siblings, other providers expressed a desire not to support a model of sibling support that was so centred on discussing difficulties and challenges that it became uncomfortable to have people with disability as part of the conversation. These were typically some of the providers who had advocacy as a large purpose/function of

their work and who were more comfortable stating that they were engaged with politics and being active agents of social change. These providers variously spoke about advocating "with" not "for" people with disability (P_12); having "no time and no place for the burden narrative", whereby people with disability are seen as a burden upon their siblings and family (P_01); and "coming at [sibling support] from a framework of really looking at and examining ableism and using a social model of disability" (P_05).

Many of these providers were taking active steps to include people with disability in some aspects of their work, such as creating dedicated projects, research and leisure activities that include people with disability together with their siblings; doing advocacy work and campaigning together, with siblings as allies to disability advocates; paying people with disability to run workshops for siblings; creating Board positions for people with disability; and checking and collaborating with organisations representing people with disability when doing advocacy work. These providers took these actions while still having dedicated spaces for sibling-only peer support discussions, acknowledging that it was sometimes difficult to know when and when not to draw people with disability in.

3.4.4. *Emerging practice for supporting greater diversity*

Several providers described an emerging area of practice to encourage greater diversity within sibling support. These were all providers based in the USA and UK, where issues of cultural and other forms of intersectional diversity have pushed most clearly onto the political agenda in recent years. Work in this area was done by providers focused mostly on individual, relational and community-level support as well as those whose work included a bigger component of advocacy.

One provider spoke about wanting their work to be "more diverse than the white women that are in most family support disability organisations" (P_05), listing both cultural background and gender identity as areas where more diversity was required. Another mentioned wanting to better support siblings from low socio-economic communities. Cultural diversity was however the most widespread focus. Providers noted the need "to be very intentional" (P_12) about fostering greater cultural diversity. They described current actions for this purpose including intentionally training culturally-diverse sibling support facilitators; seeking ideas from culturally-diverse communities about how to deliver appropriate support; specifically recruiting culturally-diverse siblings to their programs, with a quota/target; offering sponsorship to cover costs to attend events; offering multi-lingual resources; being intentional about ensuring culturally-diverse siblings were included in panel discussions; trying to find funding for outreach workers; educating their leadership team on issues of cultural diversity; trying to increase the diversity of the leadership team; and doing research to continue to develop best practice for diversity. While they used different approaches, work towards greater diversity was the most cohesive area of required change mentioned by providers.

4. Discussion and conclusions

This article has sought to describe the current sibling support sector in the USA, UK, Canada, Australia and New Zealand. While sibling support is commonly offered to siblings of people with disability and is gaining increasing research attention within medicine, health and social care, most research to date has been evaluations of individual programs/interventions. There has so far been little-to-no research into the overall conceptual basis behind sibling support: i.e. what it is, who provides it, the philosophical principles that underpin it and the scope of different delivery options used to implement it. This paucity of research is problematic as it prevents recognition of sibling support as a distinct service type/sector, and may ultimately prevent sibling support from getting the support, acknowledgement, funding and promotion it deserves and needs, particularly within conditions of increasing austerity (Power and Bartlett, 2019). Drawing on interviews with national-level

sibling support providers across five countries, this article has therefore sought to provide some initial research into these areas.

The findings highlight that an overall definition of sibling support can be broken into: (1) *its underpinning principles* – siblings as a recognised part of the family system, voice, and shared identity and experience; (2) *its purposes or functions* – individual needs (recognition and validation, social-emotional wellbeing, and knowledge and skills), relationships, connection and community building, advocacy for siblings as a group, and research; (3) *its delivery methods* – peer support, education and training, and information delivery for siblings, as well as capacity building for sibling supporters; and (4) *areas of variation* (scope, orientation to politics and social change, and collaboration partners) and *emerging practice* (supporting greater diversity).

While the underpinning principles of sibling support remained the same across all countries and almost all providers, not all providers necessarily catered to every purpose/function and delivery method of sibling support. What is profiled in this article therefore represents a scope of practice from which providers often focused on some parts over others. Providers' views about what they saw to be the purpose/function of sibling support influenced the variations between their practice. National location also influenced variation. The policy and political orientations of each country – including prevailing policy concepts (e.g. 'carer'/'young carer' policy in Commonwealth countries) and extent of focus on diversity and intersectionality (most evident in the USA and UK) – had a notable impact on how sibling support providers implemented their work. Many providers were also adapting to meet the demanding conditions of the COVID-19 pandemic and their actions in this regard reflected the extent to which COVID-19 had impacted their individual countries. It was in these areas that cross-country variation showed up the most.

The implications of the findings are two-fold. Firstly, with clear description of what sibling support is on a sector-level across countries, there is a greater likelihood of the valuable work undertaken in and outcomes achieved through sibling support being better recognised by the medical, health and social care communities. This greater recognition may, over time, hopefully help to create more opportunities for sibling support to be built into new service systems and funding structures and for sibling support to therefore receive more support, acknowledgement, funding and promotion from the medical, health and social care sectors it is a part of. This would be an important development, particularly as disability/health/medical service systems around the world adapt to changing service philosophies (e.g. rise of personalisation/individualisation in disability support) (Carey et al., 2019) and changing economic conditions (e.g. austerity, COVID-19 economic crisis) (Kassa and Pavlopoulou, 2021; Power and Bartlett, 2019), meaning that there is a critical need for sibling support to have enough recognition and a well-developed enough evidence-base to stay on the agenda.

Secondly, the findings included here can prompt critical reflections for the continued development of sibling support. As sibling support continues to develop into the future, it will be helpful for sibling support providers to have a cohesive framework as an overall field of practice to help recognise their similarities and differences and plan for collaboration and complementarity. The framework presented in this article can help contribute to this goal.

Similarly, the findings here can also help to identify the next horizons that may need to be addressed by sibling support as a field. For example, the findings show that sibling support providers span a spectrum where some provide individual, relational and community support only while others also provide advocacy and research. Navigating where they land in the nexus of providing support versus advocacy is a decision for each individual organisation, yet as a field/sector there will be pressure on sibling support providers as a group to continue to represent siblings at a policy-level. Some of this pressure is already evident in the findings – e.g. where providers were forced to spend more time advocating for recognition of sibling needs and sibling support than they would have

preferred. In a climate of increasing austerity and changes towards individualisation/personalisation in disability services in several countries in the research (e.g. Australia, UK, Canada) and associated declines in some of the policy and block-funding measures that have typically been used to service families of people with disability in the past (Carey et al., 2019; Power and Bartlett, 2019), there is a likelihood that the need for this representation may continue and even expand in the future. In this context, a critical question for sibling support providers is what kind of voice they want to have as a group in influencing and challenging the policy landscape around siblings, disability, caregiving and family, and how they balance this responsibility with each organisation's individual, relational and community support commitments at a more micro-level? These tensions are not easy to navigate and the answer may differ for individual organisations, yet there is also an imperative to navigate this question as a whole field. The framework provided in this article can offer a basis of reflection to help in these decisions, as individual organisations and as a field or collective.

In a similar vein, the findings show that sibling support providers have undergone significant adaptation to the COVID-19 crisis and are aware of siblings' changing needs in the face of the pandemic. Alongside the question of what role sibling support providers want to have in influencing the policy landscape around siblings in general, there is then also a related issue of what kind of role these providers can have in responding to critical contemporary issues, such as the pandemic and pandemic recovery (Kassa and Pavlopoulou, 2021)? The organisations who participated in this research showed that they have already adapted their delivery methods significantly to continue to provide support throughout the COVID-19 crisis, but the ongoing effects of the pandemic for siblings and families are harder to predict and there will be a need for ongoing forms of support throughout the recovery period. Over time, this could potentially change the framework of underpinning principles, purposes/functions and delivery methods presented in this article, however this remains to be seen and will depend on the decisions that individual sibling support providers and the field as a collective make now and over forthcoming years. The framework presented in this article nevertheless provides a baseline for thinking through (and tracking) where the changes may occur and what they might look like.

While this article offers new insights, it nevertheless also has limitations. By focusing on the USA, UK, Canada, Australia and New Zealand, it is limited to a largely white, English-speaking and high-income country version of sibling support. Further, the research was limited to speaking to a single person in a senior leadership role within each national-level sibling support organisation that participated, thereby excluding both multiple perspectives within a single organisation and smaller local-level providers. When combined with the cultural similarity in the sample noted above, the sample can therefore be critiqued as relatively homogenous. Work that covers more varied or heterogeneous perspectives (across different languages, cultures, national income-levels, and different staff and organisational sizes) should be included in future research and would potentially yield more diverse and detailed results.

In additional limitation is that clinical/therapeutic-based programs are not covered in this article. The article focuses on social support only, as this is what the national-level providers offered. However, some clinically/therapeutically-based programs are available to siblings, run by certified psychologists and allied-health providers. Further research that uncovers more about these types of programs and integrates this information with the framework offered here is also needed.

With this continued development, the work offered here has the potential to expand understanding and recognition for sibling support in the future, potentially contributing to further support received by siblings of people with disability.

Credit author statement

Ariella Meltzer - Conceptualization; Data curation; Formal analysis;

Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Visualization; Roles/Writing - original draft; Writing – review & editing.

Funding

UNSW COVID-19 Gender Equity Grant.

Acknowledgements

I wish to thank the participants in the research, as well as Ms Isabella Saunders, who assisted with collecting the data.

References

- Arnold, C.K., Heller, T., Kramer, J., 2012. Support needs of siblings of people with developmental disabilities. *Intellect. Dev. Disabil.* 50, 373–382.
- Benderix, Y., Sivberg, B., 2007. Siblings' experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families. *J. Pediatr. Nurs.* 22, 410–418.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 77–101.
- Burke, M.M., Lee, C.E., Carlson, S.R., Arnold, C.K., 2018. Exploring the preliminary outcomes of a sibling leadership program for adult siblings of individuals with intellectual and developmental disabilities. *Int. J. Dev. Disabil.* 66, 82–89.
- Burke, M.M., Lee, C.E., Arnold, C.K., Owen, A., 2017. The perceptions of professionals toward siblings of individuals with intellectual and developmental disabilities. *Int. Dev. Disabil.* 55, 72–83.
- Carey, G., Crammond, B., Malbon, E., 2019. Personalisation schemes in social care and inequality: review of the evidence and early theorising. *Int. J. Equity Health* 18, 1–10.
- D'Arcy, F., Flynn, J., McCarthy, Y., O'Connor, C., Tierney, E., 2005. Sibshops: an evaluation of an interagency model. *J. Intellect. Disabil.* 9, 43–57.
- Evans, J., Jones, J., Mansell, I., 2001. Supporting siblings: evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour. *J. Intellect. Disabil.* 5, 69–78.
- Gaal, B.J., Pinelli, J., Crooks, D., Saigal, S., Streiner, D.L., Boyle, M., 2010. Outside looking in: the lived experience of adults with prematurely born siblings. *Qual. Health Res.* 20, 1532–1545.
- Granat, T., Nordgren, I., Rein, G., Sonnander, K., 2012. Group intervention for siblings of children with disabilities: a pilot study in a clinical setting. *Disabil. Rehabil.* 34, 69–75.
- Haukeland, Y.B., Czajkowski, N.O., Fjermestad, K.W., Silverman, W.K., Mossige, S., Vatne, T.M., 2020. Evaluation of "SIBS": An intervention for siblings and parents of children with chronic disorders. *J. Child Family Stud.* 29, 2201–2217.
- Hill, L.A., 2016. *Sib Kinnect: Supporting Siblings of Children with Disabilities Using a Telehealth Approach*. Boston University.
- Kassa, C., Pavlopoulou, G., 2021. *Lonely Lockdown: Life for Siblings of Disabled Children in the UK* (London, UK).
- Kovshoff, H., Cebula, K., Tsai, H.-W.J., Hastings, R.P., 2017. Siblings of children with autism: the siblings embedded systems framework. *Curr. Dev. Disorders Rep.* 4, 37–45.
- Kramer, J., Meltzer, A., Strohm, K., 2021. Social support when a sibling has a disability. In: Buchanan, A., Rotkirch, A. (Eds.), *Brothers and Sisters: Sibling Relationships Across the Life Course*. Palgrave, pp. 257–267.
- Leane, M., 2019. Siblings caring for siblings with intellectual disabilities: naming and negotiating emotional tensions. *Soc. Sci. Med.* 230, 264–270.
- Lee, C.E., Burke, M.M., 2021. A pilot study of a future planning program for siblings of people with intellectual and developmental disabilities. *Intellect. Dev. Disabil.* 59, 70–83.
- Lobato, D.J., Kao, B.T., 2002. Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *J. Pediatr. Psychol.* 27, 711–716.
- Mauldin, L., Saxena, M., 2017. Mutual exchange: caregiving and life enhancement in siblings of individuals with developmental disabilities. *J. Family Issues* 39, 2232–2264.
- McCartney, J.L., 2008. *Siblings as Caregivers for Adults with Severe Mental Illness: A Therapist-Led Intervention to Invite Well Siblings into Caregiving Conversations*. Massachusetts School of Professional Psychology, Massachusetts.
- Meltzer, A., 2017. 'I couldn't just entirely be her sister': The relational and social policy implications of care between young adult siblings with and without disabilities. *J. Youth Stud.* 20 (8), 1013–1027.
- Meltzer, A., 2018. Embodying and enacting disability as siblings: Experiencing disability in relationships between young adult siblings with and without disabilities. *Disabil. Soc.* 33 (8), 1212–1233.
- Meltzer, A., 2021. The operation of the social support sector serving siblings of people with disabilities: a cross-country analysis. *Soc. Pol. Admin.* (early view) 1–15.
- Meltzer, A., Muir, K., 2021. An ecological and systems thinking approach for support to siblings with and without disabilities. *Soc. Theory Health* (early view) 1–17.
- Pavlopoulou, G., Dimitriou, D., 2020. In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister. *Res. Dev. Disabil.* 97, 103556.
- Power, A., Bartlett, R., 2019. Ageing with a learning disability: care and support in the context of austerity. *Soc. Sci. Med.* 231, 55–61.
- Roberts, R.M., Ejova, A., Giallo, R., Strohm, K., Lillie, M., Fuss, B., 2015. A controlled trial of the Sibwork\$ group program for siblings of children with special needs. *Res. Dev. Disabil.* 43–44, 21–31.
- Rubin, E., Baigell, L., Lauer, E., Ostrowsky, L., Janopaul-Naylor, E., Barnett, G., Mackenzie, J., Patel, N., Kotl, Y., Pressman, A., Venter, J., 2017. Sibling support program: a family-centered mental health initiative. In: Presented at the Community Engagement and Research Symposia 7.
- Saxena, M., Adamsons, K., 2013. Siblings of individuals with disabilities: reframing the literature through a bioecological lens. *J. Family Theory Rev.* 5, 300–316.
- Tudor, M.E., Lerner, M.D., 2015. Intervention and support for siblings of youth with developmental disabilities: a systematic review. *Clin. Child Family Psychol. Rev.* 18, 1–23.
- Wolf, L., Fisman, S., Ellison, D., Freeman, T., 1998. Effect of sibling perception of differential parental treatment in sibling dyads with one disabled child. *J. Am. Acad. Child Adolesc. Psychiatry* 37, 1317–1325.
- Wolfe, B., Song, J., Greenberg, J.S., Mailick, M.R., 2014. Ripple effects of developmental disabilities and mental illness on nondisabled adult siblings. *Soc. Sci. Med.* 108, 1–9.