SIBAWARE GUIDELINES

Guidelines and principles to inform inclusive practice for services working with siblings and families of children & adults with disability.

Siblings
australia inc

for siblings of children and adults with disability/illness

About this Guide

The SIBAWARE Guidelines are designed to offer organisations and individual practitioners a solid framework to both strengthen support for siblings and acknowledge their role more effectively in policy and strategy.

The acknowledgment of siblings has largely been left out of disability and mental health policy and national strategy and has long been the focus of the advocacy of Siblings Australia. Whilst there are sibling supports embedded in disability and mental health services across the country, these are few and far between. Through forty years of consistent advocacy, the role siblings play in the lives of their brother or sister with a disability and the importance of strong sibling relationships, is starting to be recognised although there is still a long way to go.

Currently, there is no coordinated approach to sibling support services across Australia. The purpose of the SIBAWARE guidelines is to provide a consistent framework for sibling support across states and territories and across the different sectors in which they might interact – the disability, health, education and family/community services sector:

Siblings Australia has a commitment to evidence-based practice, sector wide collaboration and regular family and stakeholder engagement. Whilst it is hoped this resource will be a useful guide to siblings, families and service providers, it is not a substitute for professional advice.

The driving force behind Siblings Australia has been the commitment to ensure siblings are recognised as being at risk for their own mental and physical health concerns. If they are connected to sources of support, they are more able to manage the challenges they might face, but also more likely to have a stronger relationship with their brother or sister with disability.

Many siblings, parents and service providers have contributed to the content in this document. Our acknowledgement goes to all those who have shared their stories and added to the growing understanding of sibling needs.

It is hoped that this resource will always be used as a means to empower and strengthen families.

If organisations would like to be able to use the logo, SIBAWARE™ to indicate to families and other professionals that they take a whole family approach, they can find more information through the Siblings Australia website.

Who is this Guide For?

The SIBAWARE Practice Guide is designed to be a valuable resource for those who work with vulnerable families across a range of child-, adult-, and family-focused service and support settings in disability, health, education, and community services.

The Guide Aims to:

1. Ensure young siblings access support to manage the challenges they face
2. Strengthen the relationship with their brother or sister with disability.

The above approaches both work towards ensuring that siblings have improved capacity to ensure a 'good life' for their brother or sister with disability and themselves, over a lifetime.

It provides a framework of sibling focused information and resources to guide organisations with the incorporation of ideas into practice and, where appropriate, into strategic plans around sibling inclusiveness.

Implementation of the principles and practices outlined in this document will require a collaborative approach and is the responsibility of all organisations, groups and individuals that impact, or have the potential to impact, on the quality of life of families.

This guide should also help families to develop reasonable expectations of the professionals who work with them. It is relevant to all siblings and families, but has a stronger focus on early intervention with younger siblings. We have included a separate section related to adult siblings.

Included in this guide is a *Self Assessment*, intended for individual practitioners and organisations to understand their current approaches to siblings and be able to identify areas of future improvement. To support the ongoing practice improvement in the area of sibling support, there is also a *SIBAWARE Services Toolkit* which offers organisational practices and reflections to ensure the inclusion of siblings in policy and practice.

Lastly, it is recommended that approaches are sensitive and relevant to families' particular circumstances, for example, families from non-English speaking backgrounds, Aboriginal and Torres Strait Islander communities, sole parents etc.

Siblings Australia acknowledges that these guidelines act as an overarching framework for practice. We would like to see more support given to different cultural groups to lead and develop sibling relevant resources

Introduction

Disability and chronic illness are a part of life for hundreds of thousands of Australian families.[1] In childhood, such chronic conditions may affect a child's development, and their ability to participate in their family and in the community. The additional needs of these children can require large amounts of time and resources. Over time these challenges can have a cumulative effect and families are at risk of a range of emotional and psychological difficulties.

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[1] The Australian Institute of Health and Welfare, Australian Bureau Statistics 2019

Sibling relationships are usually the longest of any relationship and are complex and ever-changing. Siblings are crucial to the long-term wellbeing, social inclusion and safety of people with disability. Like all sibling dynamics, the relationship can be both a positive and lifelong connection, perhaps challenging and painful, or all of these experiences mixed together. When disability is involved, the relationship may need more support to be as strong as it can be. The relationship itself in these circumstances is crucial, regardless of whether a sibling plays any caregiver role or not.

In recent years the acknowledgement and recognition of the role children play as key influencers of the development of their sibling through relational interactions and role modelling. From an early age, siblings are part of the first social network for a child with disability and they can contribute much in terms of assisting the development of their brother or sister. [2]

Why Support Siblings?

The context for sibling support includes the following considerations:

- The whole family is affected when a child or children have a disability
- Siblings can face their own challenges and need support themselves to reach their own potential

- The whole family plays a key role in the wellbeing and development of a child with disability.
- A stronger sibling relationship in childhood will increase the chances of a strong relationship over a lifetime
- Siblings can play a huge role in ensuring the wellbeing, social inclusion and safety of a person with disability over a lifetime.

Experiences of Siblings

Importantly, there is no one sibling experience just as there is no one experience of disability. Various factors will influence the relationship, including:

- the type of disability
- respective ages and birth order
- gender of both the sibling and the child/adult with disability
- family and friends' attitudes, social networks, socio-economic status
- cultural factors
- the type and level of support accessed.

For example, children who grow up as the only sibling (they are the only non-disabled child in the family), might face particular stresses not only in childhood but also into

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[2] Interventions for children on the autism spectrum: A synthesis of research evidence, Department of Industry, Science, Energy and Resources 2020

adulthood, especially if social networks are not strong. Also, children who grow up in sole parent families, or with a child with disability who has particularly difficult behaviours, including aggression, might be more vulnerable. It also seems that different cultures, socio-economic status might make it easier or more difficult for siblings.

The sibling experience can be confusing; on the one hand many siblings feel love and protection towards their brother or sister and their lives are enriched through this relationship. Others report feeling resentment, embarrassment, guilt, sorrow and fear. There can be challenges within the family but also, outside the family, reactions can be distressing, especially for younger siblings. These are not either/or experiences, meaning siblings may feel a whole range of emotions throughout their life. The complexity of sibling relationships can lead to low self-esteem, shame or a sense of worthlessness[3].

All these difficulties are exacerbated by limited access and availability of appropriate services. Adding to service access challenges is the practicalities of the needs of the child/children with disability being the sole focus of support. This is driven by the way services have historically been funded and aligned with the medical model of disability, which does not take a whole family approach.

As they become older, siblings can worry about the support roles they, as siblings, may need to play in the future. There may be guilt and concerns around moving away from the family home, pursuing relationships or an education or a career. One of the most common concerns is relating to the care needs of a sibling once the parents or caregiver becomes less able to provide care or dies and what this means for life plans and relationships.

Families in the early years

Families with disability, experience many of the same joys and loving connections as other families do. Not all siblings of children with disability experience difficulty, however growing up with the added stresses placed on family function, can put siblings at a higher risk for developing a range of psychological and physical health concerns.

Appropriate, timely support services for families are crucial to enable siblings and their families to function more positively. There is a greater need for services who focus on promotion of quality of life for all family members through a social model lens rather than medicalised models of service delivery that are deficit based and focus on fixing the individual.

Service providers have an opportunity to strengthen and support families to enhance protective factors that improve family mental health and functioning, and to identify and reduce risk factors that hinder this process. A stronger family unit will have a more positive influence on the development and wellbeing of a child with disability.

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[3] Lamorey, Suzanne. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In Nancy D. Chase (Ed.), *Burdened Children: Theory, Research and Treatment of Parentification.* Thousand Oaks, California: Sage Publications

Families in the adult years

The roles that siblings take on are varied. Adult Siblings may require support to deal with any emotional legacy of growing up with a brother or sister with disability. Some have grown up with very positive experiences, and others have struggled with a range of difficult emotional issues. Many siblings report they have not had any opportunity to express or explore their experiences in childhood as they may have not been provided the space and support to appropriately do so.

As siblings age they might find they want, or are expected, to take on a greater caregiving role with their brother or sister. Adult siblings report that they might need to juggle or negotiate a range of issues related to their brother or sister with disability including; accommodation, finances, health, employment, recreation. In addition to these issues, adult siblings may also have responsibilities with ageing parents and their own young families. This caregiving role may be either direct or indirect and, if needed suddenly, can be taken up with little knowledge of what care has been provided previously.

Policy and Service Delivery Gaps in Sibling Support

Despite the emphasis on 'families' within policy and practice documents relating to children and adults with disability, the reality is very different. A recent mapping project further confirmed what the organisation had found over many years, as follows:[4]

- Very few siblings access any support services
- Very few parents are assisted to support their children who are siblings
- There are no policies or strategic national approaches to sibling support
- Current mental health/disability programs/policies for young people do NOT meet the needs of siblings
- There are no standard, co-ordinated policies with regard sibling support approaches
- There are no clear pathways to fund capacity building supports for siblings, either through the NDIS or mainstream services
- There has been little evaluation done of existing programs and no best practice guidelines for building in sibling support to services
- There is no national co-ordination of services for siblings, little, if any, collaboration; local programs are rare and sporadic

- There are significant deficiencies in both the understanding and skills of practitioners regarding sibling contributions and needs, across all sectors

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[4] Siblings Australia Mapping Project 2017 FINAL-Siblings-ILC-Mapping-Project-Report.pdf (siblingsaustralia.org.au)

The SIBAWARE Approach

The SIBAWARE Approach is grounded in the following principles.

The SIBAWARE Principles

S- Sibling relationships are varied and ever changing
I- Individual needs of siblings to be respected
B- Building Capacity within the whole family can improve family connection

A- Awareness about the experiences and responsibilities of being a sibling
W-Whole Family Approach is crucial to understand the needs and contributions of the family
A- Acknowledge, value and embed siblings in support services & policy
R- Relationships as Siblings are key, regardless of caregiving roles
E- Early Intervention for sibling support

The principles of SIBAWARE form the four pillars of Sibling Inclusive Services.

Four Pillars of Sibling Inclusive Services

1. Recognition and Prevention
2. Whole Family Approach
3. Sibling Relationship First
4. Community Connection

The Four Pillars of Practice Explained

The SIBAWARE principles are designed to be embedded in service delivery, policy and practice.

The four pillars of practice are not new. They are aligned with best practice approaches to working with families and international evidence. The pillars of practice are designed to strengthen the focus on siblings and promote the review and reformation of current models of working to expand conversations, approaches and inclusion of siblings.

Whole family approach

All family members are recognised and supported

The Family and the environment are the most influential and essential systems in a

child's life. It is essential then, that we develop an ecosystem that is designed upon a whole-of-family approach, that is centred around family capacity building and family goals, and that this includes parents and sibling goals. Evidence highlights the strong link between how well families are able to care for their children and the social, emotional, and physical circumstances in which they are living.

It is widely accepted that family centred practice is evidenced as a best practice principle across disability and family focused services. Working from a family-centred approach ensures there is a partnership between families and professionals in which knowledge and information is shared equally.

The key ways of embedding family centred practice are:
- Ensuring the strengths of the family are promoted and developed
- Appropriate information, knowledge, skills and expertise are in place to deliver quality supports to families
- The capacity of the child, family and collaborating providers involved with the child is built through coaching, capacity building supports and collaborative teamwork.
- Feedback and learnings from the child, family and other professionals is used to improve support delivery

The challenge with family centred practice is that there is often a gap between theoretical understanding and true implementation. This gap has been influenced by the way services are funded and the way families respond to the needs of their child with disability. Often this results in family centred practice not necessarily taking a whole family approach.

Family Centred Practice includes Siblings

Whilst many services state they are family centred, this often involves thinking only of primary caregivers and their relationship with the child with disability.

However, intervention strategies focused on the family and/or caregivers is the foundational principle of best practice. True family-centred, strengths-based practice recognises the whole family as the focus for services, and further recognises the family as a whole rather than siloing an individual, or individual and primary caregiver.

Family-centred practice considers family strengths, specificities of family life and family priorities to shape interventions. This also recognises the critical role of all family members as change agents in children's lives, and their ability to shape outcomes.

Within the early childhood intervention approach, in particular, plan goals are aligned with areas such as communication, social interaction and learning. However, most funded supports focus on ways of strengthening communication, social interaction and learning outside the family context, within the community. There is a gap in understanding and practice, that a child with disability and his/her family members might need support too, in order to strengthen family relationships.

If a child with disability has difficult behaviours, there are relevant therapists who engage with the child to support their social development. It is unlikely that such

approaches would centre on siblings, to help them understand the behaviour of their brother/sister, or to nurture and strengthen the relationship between them.

One of the key themes of the NDIS is 'relationships' but again the emphasis is on strengthening relationships within the community rather than in the family. Whilst there is a line item within the NDIS for 'parent/carer training' there is nothing to recognise increasing the capacity of siblings to manage their experiences and to strengthen their relationship with their brother/sister.

Recognition & Prevention

Siblings are provided with support early to enable better health outcomes

The first step in ensuring that siblings are provided with support is to ensure their needs and contributions are recognised. They are often overlooked when the needs of a child with disability, understandably, is the focus and siblings are rarely included in or referenced in domestic policy within disability, health, education, family services or child protection.

The support that families are able to access in the early stages after diagnosis of disability has a large bearing on how the family functions as a whole in the short and long term. It is important for services to take a preventative approach to identifying mental health protective and risk factors in children.

There is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health challenges. If left unaddressed, the challenges which siblings face can increase their risk of developing longer term mental health concerns, at considerable cost to them, governments, and the community.'

There has been little research and investment into the experiences of siblings, however the evidence that does exist internationally is strong in its findings.

- Siblings of people with disability have a significantly increased risk of depression, regardless of any caring role and have increased rates of physical health problems.[5]
- Parents and caregivers are reported to more likely experience depression, which can have an impact on all children.[6]
- Parents do not access services for themselves or their other children as the focus is on the child with disability.[7]

[5] Hogan, D., Park, J., & GoldschECIder, F. (2003). Using Survey Data to Study Disability: Results From the National Health Interview Survey on Disability. Research in Social Science and Disability, 3, 185-205.
[6] Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., Kingston, M. (2008). The nature and impact of caring for family members with a disability in Australia. *Australian Institute of Family Studies, 2008.Research Report, no. 16*
[7] Ibid.

- Some siblings are both physically and emotionally harmed by a brother or sister with disability, and this is often not reported by parents as they are fearful of what outcomes might ensue. [8]
- Teasing or bullying from peers; feeling the stigma.
- Growing up with the needs of someone else always taking priority; they learn to put their own needs second which can also have implications for relationships over the lifespan.[9]
- Education outcomes may be affected by anxiety, tiredness, depression, social stigma and worry for parents.[10]

Sibling Relationship First

Sibling relationships are usually the longest of any and are complex and ever-changing. Siblings are crucial to the long-term wellbeing, social inclusion and safety of people with disability

The sibling relationship is of utmost importance regardless of any caregiving role that may or may not be played.

Often, in both policy and practice, sibling support is framed as young carer or carer support. This pillar of practice promotes sibling first language which acknowledges people as a sibling first before the assumption or labelling as a 'carer'. It is crucial that siblings are recognised as an important part of the lifelong social support system for a person with disability regardless of whether they are playing a direct caregiving role or not.

There can be benefits for both siblings and the person with disability if there is more focus on the relationship than caregiving. If siblings continue to be included under the 'young carer/carer' policy umbrella, we may miss the support needs of many siblings, who are not providing caregiving but nevertheless may have other challenges that create stress. If siblings do provide caregiving, and this is kept in balance, it can be an enriching experience for them.

However, it can be detrimental if siblings are labelled as 'carers' especially in the early years. Many siblings already have a heightened sense of responsibility and this term can add to their anxiety about the role they might be expected to play, even from a young age. It can also add to the difficulty in developing an identity that is not totally focussed on being a 'helper' and putting the needs of others first.

In addition, over the long term, such terminology does not add to the dignity of children and young people with disability, for example a 12-year-old boy would most likely feel uncomfortable with his 10-year-old sister being known as his 'carer'. Again, it is important to focus on the relationship between the siblings and not assign specific roles that might

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[8] Siblings Australia Adult Sibling Project 2017 Creating Capacity – Support for Adult Siblings.pdf (siblingsaustralia.org.au)

[9] Young, S. (2007). The forgotten siblings. Australian and New Zealand Journal of Family Therapy, 28 (1), 21-27.

[10] Shivers CM, McGregor C, Hough A (2019) Self-reported stress among adolescent siblings of individuals with autism spectrum disorder and Down syndrome. Autism, 23(1):112-122

hinder that natural relationship. All family members need support from time to time, regardless of the roles they may play.

For adult siblings, formal planning for the future and the open discussion of expectations on siblings has been reported as uncommon in families.[11] These can be difficult discussions to have. Sometimes the expectations of siblings (both their own contributions and the goals for the person with disability) can be quite different from parents and primary caregivers. It can be particularly fraught when the person with disability has limited capacity to contribute to these discussions. Currently there is little recognition of the roles or needs of siblings and there is no imperative for agencies to address those needs or support the sibling relationship. Adult siblings report to Siblings Australia that the system does not often recognise their role or their unique knowledge and understanding about their brother/ sister with disability. [12]

Inclusive Practice

Meaningful and sustainable support for children with disability begins within the home context. It is important for services to consider placing more effort and resources into families in these early years to ensure strong family functioning and capability. Fundamental to sibling inclusive services is that siblings' experiences are acknowledged, valued and embedded into the organisation.

The driver for meaningful participation and inclusion rests on the attitudes, beliefs and actions of communities: Families have shared common experiences of feeling excluded from their local community, as well as the erosion of their family, kinship and informal networks.[13] Siblings can also be restricted in their involvement in the community due to the impacts of a brother or sister's disability.

Rather than caring being shared across networks or kinship, especially in times of added stress, in most families it is centralised on the family unit and it is a common experience for this to fall onto the shoulders of siblings.

Inclusive Goal Setting

Service delivery approaches often work with families to establish goals around connection and relationships, especially since the introduction of the NDIS. These conversations however seem to place greater emphasis on strengthening relationships external to the family, whilst overlooking the crucial relationships in the home.

Siblings might also wear the hats of mentors, prompters, teachers and playmates. A suitable goal for a child and/or adult with disability might be to focus on strengthening the relationships with siblings. Another might be around learning to interact and communicate with siblings to develop skills that strengthen relationships within the

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[11] Siblings Australia Mapping Project 2017 FINAL-Siblings-ILC-Mapping-Project-Report.pdf (siblingsaustralia.org.au)

[12] Ibid.

[13] The National Action Plan for Children with disability and their families 2020-2030, Reimagine Australia

family. These skills may then be transferable to build on relationships with other people within the community.

Goals will depend on the individual needs of the child and the family. Approaches to meet these goals might include peer support from other siblings of children and/or adults with disability, capacity building supports to strengthen siblings' understanding and confidence in managing not only the way they interact with their brother or sister but also how to manage others' reactions. All of these will not only strengthen the relationship but also improve the sibling's capacity to support their brother or sister.

Services need to work within all the settings in which a child operates – family (immediate and extended), friends, peers, school and community.
Inclusive practice centres the child's right to participate in their family and community as other children would. As services have started to evolve toward a social model of disability, more of the focus of services is in the everyday environments of children, where they learn best and where they have the strongest relationships.

This pillar acknowledges the emphasis on family and building capability of others. Often, the focus is very much on the parents and primary caregivers in a child's life and overlooks the important contributions and needs of siblings. Approaches such as 'team around the child' need to include the other children in the family.

Further, this pillar encourages services to look beyond the responsibilities of what parents and/or caregivers hold. This might include working alongside families to understand who is in their circle of supports, who else can support care responsibilities for their children or provide emotional or physical support to the family. These conversations work to expand the relationships and connections beyond the nuclear family unit to the broader kinship and community network.

Four Pillars in Practice

Case Study for Early Childhood

Lucy is an 8-year-old sibling to her older brother, Tom who is 10 and has autism. They live in a caring family and have two sets of grandparents involved in their lives. However, the parents are finding it hard to cope.

Tom's behaviour is becoming more difficult to manage – he finds communication a challenge and has multiple 'meltdowns', possibly related to being over-stimulated and/or frustrated. Mornings are trying for the whole family as they aim to get ready for work and school, but inevitably they are always late, as it takes some time to help Tom get ready. Everyone starts the day with stress.

Lucy often feels like her brother doesn't love her as he cannot respond much to her attempts to connect. She also feels left out sometimes as her mum is always taking Tom out from school for therapy appointments. Her schoolmates have started to mock her brother and she doesn't know what to say. She feels embarrassed but also feels badly for her brother and wishes she could stop them saying those things. She has

started to say she doesn't want to go to school. She has started to switch off trying to engage with her brother.

She sometimes wishes she had a brother like her friend's brother, and then she feels guilty for feeling that way.

Lucy's parents feel overwhelmed trying to manage their family and their work, alongside getting as much therapy for Tom as they can. They have a Plan Manager involved in assisting them with the NDIS, but it still feels so hard getting what they feel they need for Tom to reach his potential. They feel pressure to get as much therapy as they can for their son. They feel no-one talks to them about their family and what all of their needs might be, everything is focused on Tom. Over time, Lucy feels more and more isolated and resentful. It is not difficult to predict the trajectory as she moves into teen and adult years, where family relationships might be strained or even break down.

Support on the other hand, in these early years, might lead to a very different outcome, where family relationships are strong, and Lucy takes a keen interest in her brother and his life. She doesn't always realise it, but she is often acting as a coach or mentor to her brother. With support, they have learned how to share fun activities together, even if just for short periods, and she knows that the relationship with her brother will always be an important one for them both. There are still some rocky periods, but the family feels united in managing these times – they are there for each other and Lucy knows she can talk about her challenges with her family and with others.

Support for the family might come through the NDIS or through mainstream services. NDIS supported capacity building supports might include assisting Lucy's parents to support her. These supports might also include helping Lucy to identify her own needs, to understand herself better but also how to understand and engage with Tom more effectively. These supports could help Lucy to respond to friends who may then respond in a kinder way to her brother and other children with disability. Getting together with other siblings in a peer support program will help her feel less alone and give her tools to manage the various challenges. Suitable goals for a young child in their NDIS Plan might be 'to strengthen my relationship with my sibling', or 'to build the capacity of my sibling and me to enjoy a strong relationship', or 'to learn ways to interact and communicate with my sibling, to help me to enjoy better relationships in my family and to extend these skills to relationships outside my family'. Goals will depend on the individual needs of the family.

Mainstream supports can include intervention through the health system – GPs, therapists etc, or the education sector.

Four Pillars Applied

The 4 pillars below demonstrate the approaches that can be taken through a SIBAWARE lens. The changes in the service delivery approaches may be more about tweaking the questions asked within whole families, rather than a radical overhaul of service delivery.

These approaches ensure that Lucy can manage her stresses, interact more positively with her brother which supports the confidence in the caregivers for their parenting role for both children.

The SIBAWARE approaches do not eradicate stress for families, but they support more opportunities for families to work together to ensure they can function as best they can. Both children have the support they need to reach their potential and to enjoy their sibling relationship.

Pillar	Pre SibAware	Post SibAware
Whole Family approach	Providers talk with parents about the needs of Tom and how he can get the therapy he needs. Lucy is overlooked and she feels isolated.	Providers talk with parents about the needs of Tom alongside their own needs and also the needs of Lucy. Does the parent relationship need support? They focus on family strengths and the importance of all the family relationships in Tom's life. How can Lucy's needs be met and how can we consider her contribution to Tom? Providers are aware of services for siblings and use referral pathways to these, e.g., the Siblings Australia website and the services it provides.
Recognition/prevention	Focus on Tom and parents. Lucy's wellbeing and possible contribution is not recognised. Her mental health is increasingly impacted.	Recognise Lucy, find out about her anxiety. What does she need to manage that? What supports are in place for her? What resourcing does she have and need?
Sibling Relationship First	Siblings not involved in therapies. Focus on Tom's relationships in the community with sibling relationship largely overlooked. Lucy feels more and more removed from her brother and her resentment towards him grows. Her parents don't have the tools to support the relationship. They worry about Lucy and the relationship with her	Support the relationship between the two siblings, find activities they can share, ask Lucy for her input (she may have unique insights), assist the siblings to have fun together. Include sibling in behaviour support therapies if applicable, to improve her capacity to engage with Tom. Build parent capacity to provide Lucy with tools to interact with Tom.

	brother but lack confidence to bring about change	
Inclusive Practice	No real consideration given to Lucy and the different settings in which she operates.	Consider how to improve relationships in the family, also explore how the different settings in which Lucy operates can support her – eg extended family/friends, especially grandparents, school, community. Consider other avenues for support for Lucy outside of family both formal and informal. In addition links to: ● GP ● Teachers ● Psychologists ● SibWorks ● Peer support program

Self Assessment for Services Working with Children

Reviewing an organisations policy, practice and service delivery through a SibAware lens can offer a guide to where there are strengths and identified gaps.

This self-assessment is intended to support organisations to check their own practice in relation to family and sibling support, and can be the basis for strategic planning in this area.

Four Pillars Embedded in Policy, Procedures & Governance

To be able to support families effectively, organisations need to be committed to providing a whole family approach. This requires organisations to adopt policies and procedures that encourage true family-centred practice, provide support to all family members and focus on early intervention and prevention of longer-term impacts.

These policies provide the context for family and sibling support and advocacy for greater resources.

Organisational Policy, Procedure & Governance	What this could look like
Develop organisational policies that acknowledge the importance of the whole family. Ensure policies and procedures reflect a commitment to a whole-family approach, early intervention and prevention.	Include in strategic documents the term 'whole family'. Develop procedures for including siblings in documentation and databases.
Where appropriate, encourage adult siblings to be involved in consultation groups, board of management and in the workforce.	Actively encourage siblings to engage with organisation from governance through to recruitment.
Review terminology in policies, procedures, communication materials to ensure terminology is sibling inclusive.	Review application and/or interpretation of family to ensure it is inclusive of siblings. Refer to 'family members' rather than 'parents' where appropriate.
Review assessment, support provided and case closure processes to ensure the inclusion of siblings and ways of working recognise and acknowledge siblings and take a prevention approach.	Appropriate documentation needs to be developed; for example, intake forms can more appropriately (than current practice) reflect the whole family structure.

Service Delivery and Ways of Working	What this could look like
The development and provisions of programs that focus on maintaining and strengthening the sibling bond.	Where possible, acknowledge and show interest in siblings. Provide programs that promote sibling connection. Encourage staff to undertake training in the needs of siblings. Ensure therapists include siblings in approaches that involve. behaviour support for a brother or sister with disability.
Promote and celebrate the role of siblings as key members of families who are valued and respected.	Display the SibAware Principles at the service and provide them in materials given to families. Ask siblings if they have information they would like to contribute to 'Personal Profiles' or 'Life Journals' for their brother or sister. They often have a unique perspective, even from a relatively

	young age.
Ensure family centred goals are sibling inclusive.	Recognise that siblings might also have knowledge which may be useful (this might be repetitive of above point).
Review ways of working with families which considers the possible role of all settings which includes family/home environments, school, peers, community.	Ensure staff know about community sources of sibling support, e.g., relevant therapists, school approaches.
Develop pathways of support for the whole family through referrals, community links and information.	Provide information to families about sibling and whole family supports in the community Explore sharing resources in order to run sibling support programs such as groups or camps.
Develop procedures to ensure that there is an annual review of sibling well-being. This could be aligned with any annual review of the child with disability.	Ask parents to give feedback on how the child is impacted at home, school etc and explore how they might contribute to the review of the child with disability but also what supports are available to the sibling.
Develop partnerships with other agencies that support families with disability. Share resources in running sibling programs. Encourage staff involvement in sibling support networks.	Reach out to other organisations in the area to map how the local community is supporting siblings and work together on perhaps building a network of resources for families.

Four Pillars Embedded in Workforce Development	What this could look like
Support staff to access up-to-date research material and resources related to family experience of disability (identification of risk and protective factors) and strengths-based approaches.	Keep a library of books, articles that cover the whole family experience, and specifically, sibling experience.
Provide education to staff regarding the impact of disability on the whole family, as well as best practice family/sibling support.	Connect staff to relevant training, have family members present to staff about their experiences.

Invest resources into the development of sibling support, with a key person to take portfolio responsibility. Encourage parent/sibling involvement.	A key person or team with portfolio responsibility to focus on the development of sibling support and the review of best practice in family and sibling support. This team could include family members from time to time. Ensure staff are equipped with the knowledge and skills to include siblings in therapeutic approaches when appropriate.
Provide training to staff about the experiences and needs of siblings from early childhood focusing on the importance of the role they can play in the life of their brother or sister, if the sibling relationship is strengthened.	Staff could be encouraged to join existing networks of sibling support providers.

Research	What this could look like
Evaluate own services, encourage research into what helps strengthen families/siblings.	Promote the inclusion of siblings in any research or service evaluation Include siblings in feedback on services and their value

Adult Siblings

Considerations for Service Delivery

The sibling relationship is often the longest of all relationships in our lifetime. Professionals will not be in the life of a person living with disability throughout their lifetime like an adult sibling might be. Within Australia's ageing population it is adult siblings who represent the next generation of support people and/or advocates for people living with disability.

Disability Services should consider how to support families to plan for the transition of responsibilities and supports from ageing parents to adult siblings where adult siblings are willing and able to take this on. The focus should be on the sibling developing a 'good life' for themselves, whilst contributing to a 'good life' for the person with disability, rather than siblings replacing a parent role or becoming a primary carer. The sibling relationship is likely to be more mutually satisfying and affirming if they can be engaged as siblings, rather than carer/caree.

Responsibilities and supports could include financial, residential, emotional, leisure, practical or advocacy matters.

It is equally important, however, for governments and providers not to assume that siblings will take over the main support of a person living with disability. In most cases, siblings want to play the role of a supportive brother or sister, not a 'carer'. People living with disability often prefer this too.

Service providers can recognise and show respect to siblings by acknowledging:

- The importance of the support, care and companionship that many adult siblings provide to their brothers or sisters.
- The importance of the sibling 'relationship' regardless of any caregiving role the sibling might play.
- The varying roles that adult siblings play in the lives of their brothers or sisters, that there needs to be choice in the roles they play, and this may change as circumstances change.
- Not all siblings will be willing or able to accept high levels of commitment, and siblings should not be expected to 'take over' from parents.
- Siblings are 'holders of information' who have a unique view of their brother or sister. They may like to contribute to 'Personal Profiles' or 'Life Journals' for their brother or sister.
- Siblings can be powerful advocates for people living with disability.
- Adult siblings may need support to manage left over feelings related to their childhood experiences such as grief, guilt, pride, embarrassment, or confusion.
- Siblings benefit from connection with other siblings – no-one understands a sibling like another sibling.
- All sibling pairs have unique relationships which reflect levels of closeness in the family of origin, childhood experiences, personality traits, cultural issues and personal resources.

Service providers can increase awareness/knowledge of the value/needs of adult siblings

Organisation Policy & Procedures	- Develop organisational policies that acknowledge the importance of the whole family. - Collect and keep information about adult sibling contacts on file and in databases. - Where appropriate, encourage adult siblings to be involved in consultation groups, boards of management, etc.
Workforce Development	Provide training to staff about the experiences and needs of adult siblings as well as the importance of the role they can play in the life of their brother or sister.
Service Delivery & Ways of Working	- Review the involvement of adult siblings with their brother or sister living with disability at annual planning meetings. - Talk with parents about including the names of adult siblings as support/contact people. - Encourage parents to be aware of the importance of planning for the future – for themselves, for their child living with disability, and for the whole family. - Personally invite siblings to social events or planning

	meetings rather than always relying on parents to pass on the information. ● Encourage adult siblings to ask questions about services provided for their brother/ sister. ● Assist families to navigate difficult discussions about the future, especially if parents and siblings hold different views about goals/independence for the person with disability. ● Develop programs to help maintain the sibling bond. For siblings who live far way, there are a number of creative ways to do this, such as email, photos and skype ● Assist siblings to find sources of support to process any difficult experiences from childhood, e.g., peer support, therapeutic support. ● Connect siblings with other siblings, e.g. SibChat, the Siblings Australia closed Facebook group for adult siblings.
Changing Terminology & Development of Resources	● Specifically mention siblings in service delivery information. ● Refer to 'family members' rather than 'parents' where appropriate. ● Provide information about disability services to increase their capacity to contribute to a 'good life' for their brother or sister with disability. ● Develop resources and links with local services that can help families plan for the future.

Considerations for Adult Siblings - Case Study

Lucy is now 38 and living in regional NSW. Her older brother Tom who is 40 this year, and has autism, is living in Sydney with their parents.

With the support of her parents, Lucy graduated from high school, went to university and pursued a career. The family had accessed appropriate support from when the children were little, which meant the family were very mindful of each other's needs. Lucy's parents ensured she enjoyed her independence, and supported her travelling in her twenties. She has since moved to Batemans Bay in south NSW (3 hours from Sydney), where she has a young family of her own. From a young age, Lucy and Tom's parents have tried to ensure that Lucy does not take on the direct care needs of Tom.

On reflection as an adult, Lucy appreciates the well meaning intent of her parents, but can't help but feel that now she is settled, she would like to be more involved in her brother's life and support her parents when she can.

Through the NDIS, Tom has support workers who attend to his care needs and also take him out for social connection. This is helpful because Lucy and Tom's parents have stopped feeling comfortable taking Tom out of the house as they feel his noises impact on other people. Lucy is wanting to offer some support and be able to come up

and stay at the family home to understand how she can play a role in Tom's life as a sister however this is the first time in their lives this conversation has unfolded.

Lucy is also concerned that her parents are now in their late 70s. Her mum is quite unwell in terms of chronic aches and pains. For the first time recently, Lucy had a conversation with her parents about what the plans are for when they are no longer here. Her parents discussed the number of services they have involved and the regular meetings to plan Tom's care and Lucy was unaware of the extent of information and planning that goes into supporting Tom. Lucy asked her parents if the services knew about Lucy and her mum informed her that they had never asked as it doesn't seem relevant to talk about Tom having a sister.

Lucy hasn't spoken about this with anyone before, as her friends don't have the same experiences and she doesn't know any adult siblings. Lucy wished there was an option to have a chat with someone else who 'gets it' but feels like there really is nothing out there to help her navigate this. Lucy wished she was acknowledged as a key member of the family and feels left out in the family planning where it could be discussed what role she wants to play in Tom's life and what Tom wants also.

Lucy wants to know who she can talk to, to get information about the service system, esp the NDIS and the complexities of that, including:
- Legal issues
- Accommodation issues
- Financial issues
- Employment for Tom
- Recreation
- Circles of support and building up a network for both herself and Tom

She has decided that she is going to ask her parents to meet with the services in Tom's life and talk to them about the support in place for Tom but also how she fits into the picture. Lucy is going to ask for a family plan, which involves her own capacity and life plans as well, such as visits to Batemans Bay and planning for future accommodation options closer to her.

Ideally, the services that the family meets with will share resources and information for Lucy, especially about peer support options - such interactions with other siblings provide validation, relief in knowing others share similar experiences, and a wealth of knowledge from those who have been on the same path.

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