

Family Advocacy Model Research

Prepared for: Family Advocacy NSW

October 2022

Sandra Gendera and Karen R. Fisher



Research Team

Prof Karen R. Fisher, Sandra Gendera, SPRC, UNSW

For further information:

karen.fisher@unsw.edu.au

Social Policy Research Centre

UNSW Sydney NSW 2052 Australia

T +61 2 9385 7800

F +61 2 9385 7838

E sprc@unsw.edu.au

W unsw.edu.au/sprc

© UNSW Sydney 2022

The Social Policy Research Centre is based in the Faculty of Arts, Design and Architecture at UNSW Sydney. This report is an output of the Family Advocacy Model Research project, funded by Family Advocacy NSW.

Suggested citation:

Gendera, S and Fisher, K. R. (2022). *Family Advocacy Model Research*. Sydney: UNSW Social Policy Research Centre.

Contents

Contents	i
Tables and figures	i
1 Introduction	1
2 Family Advocacy model	3
3 Impact of the advocacy model	7
3.1 Impact on person with disability	7
3.2 Impact on the family level	13
3.3 Impact on leadership development	16
3.4 Impact on the rights of people with disability	19
3.5 Impact on community and systems	21
4 Mechanisms for social change in the model	24
4.1 Advocacy support, resources and skills development	24
4.2 Leadership development and changes in leadership	26
4.3 Progression of rights, people with disability realising their goals	29
5 Conclusion	32
Appendix A: Program logic and methods	34

Tables and figures

Table 1: Family Advocacy program logic	34
Figure 1: Model of Family Advocacy	4

1 Introduction

Background

Family Advocacy is a community based, state-wide disability advocacy agency, funded by state and federal funding programs to promote the rights and interests of people with developmental disability across NSW.

The work undertaken by Family Advocacy NSW falls into three main areas:

- Statewide advocacy-advice and advocacy information for individuals and families
- Leadership development for family members.
- Systemic Advocacy

The main objective of Family Advocacy is to support families to advocate with or at times on behalf of the person with disability, with the goal to support people with disability to realise their goals, hold valued roles and lead lives embedded in the community to experience the same things that most Australians take for granted: an education alongside their same aged peer, a job and a home of their own.

Purpose of the research

Family Advocacy NSW commissioned the Social Policy Research Centre (SPRC) at UNSW, Sydney to undertake independent research to explore the impact of the advocacy model at the person, family and community/systems levels, and to identify mechanisms of social change within the model.

The research aims to inform current operations and provide an overview of the Family Advocacy model. The research methods were interviews, case studies and document reviews about the activities in Family Advocacy. Any name in the report is an alias to protect confidentiality.

Key findings from the research

The Family Advocacy model supports people with developmental disability to achieve their preferences and full potential with the support from their families. Family members gain capacity and leadership skills and connection to other families with similar values and drive social change. Other key findings from the research include:

- Families' expectations for equal rights for local social inclusion that are responsive to the person's preferences.
- Using the power of lived experience (stories, workshops, peer-to-peer family education) to activate higher expectations and vision.
- Families with specific knowledge and experience are identified and supported to become "subject matter experts" and peer leaders to influence change beyond their own family and local community.
- Advocacy with a personal and collective voice, which requires capacity for advocacy, language to articulate the vision and entitlements, and capacity to argue for change in the community and services (e.g., local services, schools, workplaces) to meet the person and family's expectations for inclusion.
- Collective strength is harnessed by bringing families and people together who have shared expectations about social inclusion particular to a person's preferences and the vision to create change in the community and services.
- The model fosters opportunities to engage with diverse people, families and communities to share that individual and collective vision for social inclusion, promotion of rights and justice for people with disability.

2 Family Advocacy model

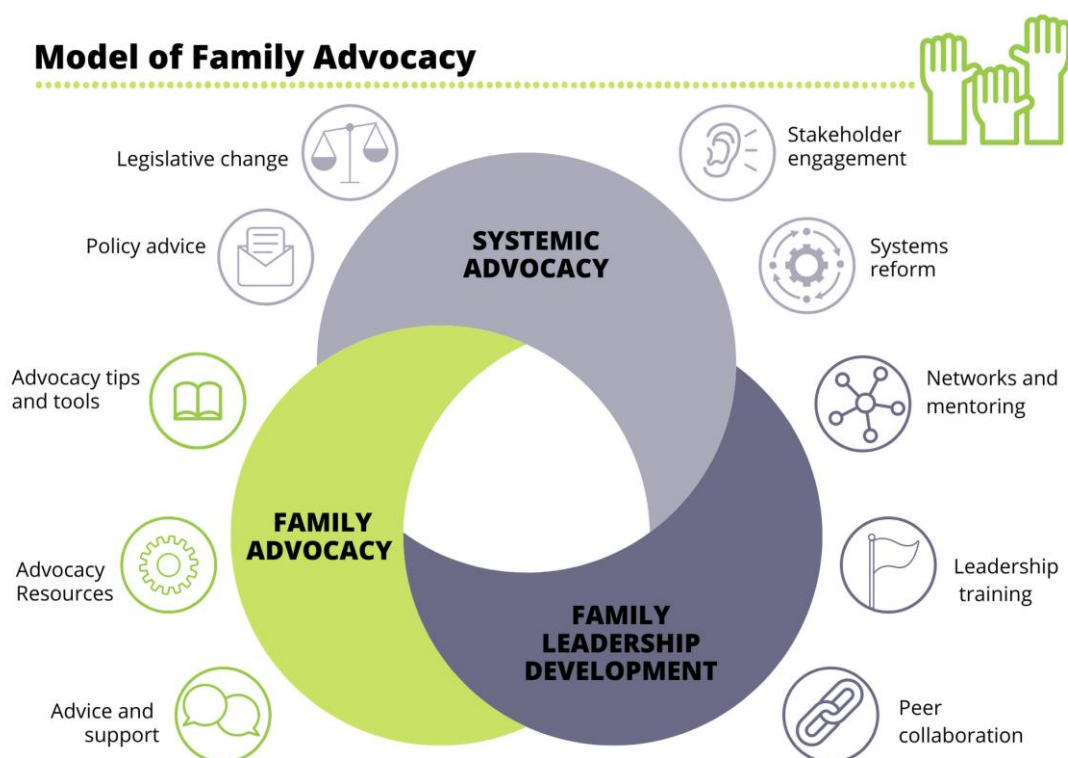
The Family Advocacy model is designed to protect and progress the rights and interests of people with developmental disability through equipping families to advocate with or at times on behalf of their family member with disability.

In the model, families are positioned as and supported to become agents of social change. Working alongside a family member with developmental disability and within the broader community, families are seen as key to progressing rights and facilitating valued roles for people with disability, and central to safeguarding against harmful experiences. The wellbeing of their family member at heart, families play an important role in negotiating and counteracting power imbalances with services, social institutions (schools, education), the employment sector and community at large.

As families gain advocacy skills, knowledge and confidence, they become better prepared to promote a family member's interests and to support them to live a rich and meaningful life in the community, with access to expected opportunities (education, employment, training with same aged peers, within the local neighbourhood).

The Family Advocacy model is underpinned by the vision and value of inclusion of all people with disability, irrespective of a persons' ability, supporting people to identify and fulfil their potential and obtain the many offerings in the community, thereby creating a more just and inclusive society. To realise this vision, the model invests in families to support change at the individual and family level and at the community/societal level.

Figure 1: Model of Family Advocacy



Family advocacy – individual and family level

People with developmental disability experience many barriers in the community. Family Advocacy provide guidance, support and resources so families can effectively advocate at the local level. An important component of the advocacy approach is that it invests in developing the advocacy capacity of families over the lifecourse. The advocacy role of families is not a once off occurrence. The continuous advocacy role is often due to the significant barriers experienced by people with disability and due to the significant support required by their family member in everyday life and throughout their lives. In this model, families are seen as well placed to provide ongoing advocacy and safeguarding with their family member, due to their affective and enduring relationship.

Family leadership development

Leadership development with families is a core function of the Family Advocacy model. Potential family leaders are identified through the advocacy advice and support provided. Some families are approached and offered the opportunity to attend relevant internal and external training. For example, a family may already advocate at their local school to have their child authentically included and be experiencing pushback and barriers from the school. In this case, Family Advocacy

may suggest the family attend one of their education related advocacy workshops. Gaining access to training and skills on inclusive education supports and informs the family and empowers them to work with the school and teachers to achieve change. By helping to create and advocate for an education environment and appropriate support, families support their child with disability to have the opportunity for a successful school experience.

The model works with families who are focused on their family member with disability achieving experiences of the good things in life and to have similar opportunities as their same aged peers without disability. The model invests in family leaders whose values and vision for their family member align with those of Family Advocacy.

Central to the model is for families to drive social change with their own efforts, communities and networks. Families who have taken part in leadership development, and have grown their knowledge on a particular topic, are then provided opportunities to support other families to do the same (peer to peer education). Another part of the leadership development focuses on families having opportunities to present at advocacy related events. Initially this step involves the family presenting their story of how they achieved a good life alongside their family member and how they overcame the many barriers along the way. The lived experience guest speakers share their life experiences, tips and tools with their peers, other families who are aspiring to achieve similar outcomes alongside their family member. As families grow the model expands to other opportunities and support for some leaders to become more strongly involved, for example, deliver content at advocacy workshops, webinars and present at conferences and lead peer networks.

Systemic advocacy

The third pillar of the Family Advocacy model is to undertake a range of activities to promote and protect the human rights and interests of people with developmental disability as well as their families. Family Advocacy, for example, collect data on diverse advocacy issues, undertake stakeholder consultations on select topics, seek feedback and input from families across the state, provide policy advice, and argue for policy and legislative change for systems reform. In the interviews one staff explained the need for systems reform,

As a society we've taken a whole group of people, for whatever reason, out of that rich fabric of society. All our work [of Family Advocacy] is not rocket science, it is about supporting people back into the typical schools, jobs,

homes, communities and thinking about structures and supports that are needed to make it happen.

Family leaders and the experiences of families with disability have direct input into the systemic advocacy work. For example, they are invited to provide case studies for submission to government and other reviews, asked to complete surveys on specific issues, family leaders are invited to attend meetings with relevant decision makers or participate on relevant committees, roundtables and advisory boards.

3 Impact of the advocacy model

3.1 Impact on person with disability

People with developmental disability living lives embedded in the community, holding valued roles, realising their interests through the support and advocacy of their families were visible throughout the stories shared in the research.

The families who took part in interviews were strong advocates of people with disability living a rich and included life in the community. Their advocacy supported their family member to achieve experiences and opportunities like that of their other children. Families said that crafting a positively framed vision of their child's life early on was key. They were building on their child and young person's strengths and the families' vision of an included life, which were central to them "remaining on track", and to seeking and creating opportunities that were "included rather than segregated". Any name in a story of change is an alias.

A vision for an included and connected life

Tom's mother Betty told Tom's story of living a rich life in the community.

At the Family Advocacy workshops and meetings very early on, we learnt the importance of having a vision. We learnt that if we families don't have a positive and aspirational vision for our child with disabilities, somebody else will have a vision for them.

And the services that have a vision for people won't necessarily be in the best interests of the person. Instead, it could be in the interests of the service or the provider or the NDIA for the person becoming a lifelong 'client'.

I strongly believe, because we had a clear vision for Tom's life when he was very young, that he would grow up together with his siblings, in his local community, doing the things that were available for all children his age. After a while, professionals, teachers, and others, they stopped approaching our family only with ideas that segregated him. They knew already, Tom was not going to a sheltered workshop, school or other program; it was not something we would agree to.

Tom is in his mid-20s and to this day he has never been into a day program or a segregated service of any sort. Anything like that, he's just never done it! We advocated for him to have the necessary teacher support to attend the local public school and learn with his peers his own age.

Tom does activities in the community, horse-riding, he loves being around animals and working at the local farm and stables. Where he goes, he makes friends and builds connections, he is happy when he gets to do the things he loves.

People with disability in the stories expressed themselves, their preferences, likes and dislikes, with their families. The families advocated for opportunities so their children could explore their interests, have a range of experiences and develop their preferences for future choices and opportunities. The families said that empowering them to advocate and hold a vision for their family member, and to enable a young person's interests and growth had a positive impact.

The stories showed that children and young adults participated in local activities (community groups, events, sports), they were supported to create diverse connections and contribute to their local communities (getting involved in activities with a friend or neighbour like sporting events, volunteering at a local community centre or walking a neighbour's dog).

Families often decided early that their child with disability would attend mainstream schooling. In the interviews they said that while children and families experienced many barriers and gatekeeping to attend local schools they were mostly successful because of their intensive advocacy, and their campaigning and networking with other parents.

Participation in post school education and obtaining paid work (in open employment) was another hurdle experienced by people with disability and their families. Families spoke of low expectations by teachers, employers and the community, little flexibility to adapt and adjust processes or support requirements.

Families who persisted and supported their family member to overcome such barriers found that advocacy resulted in young people with developmental having the opportunity to try out what they enjoyed and try something new. When this happened, the experiences often exceeded their expectations, and in the process they discovered their potential, gaining confidence and skills, and learning about what they were more and less interested in.

Creating opportunities for exploration and learning

Melinda's mother Christina told the family's story of exploring Melinda's work and career options.

Once Melinda was in Year 11, we knew that we wanted her to do as much work experience as possible. Sitting in class all day and learning was not her thing. She loved children, she was very happy and caring around our young family members, so we thought, child studies might be a great thing for Melinda to try out.

I rang up the person [at TAFE] that's meant to provide the support in the VET system in TAFE, she asked, "Why are you coming to see me"? I responded, "Well because my daughter is enrolled, and she needs support". The woman reluctantly agreed to a meeting with me and my husband. Once we arrived, she showed us what she called, the 'more appropriate options', taking us on a tour of the segregated retail class and cooking classes. We went back to the woman's office, and I asked firmly, "How will doing retail advance [Melinda's] career in childcare"? The woman almost fell off her chair. ...Melinda ended up studying childcare at TAFE and she did really well. The class teachers were fine and, you know, what we've found through the process, that students are capable of so much more than anyone thought they were because they had the opportunity to be exposed to it. Melinda actually passed half the competency course even though she was had low literacy at the time.

In the meantime, Melinda found work in another industry, hospitality, where she worked three days a week for five years. Once that work ended, she took a volunteering role at the local leisure centre. They had a creche and Melinda looked after the babies once a week. It turned out that she enjoyed being around babies, but she was not interested in toddlers [laughs]!

While Melinda didn't find her passion in childcare, she accumulated points to get one-to-one swimming lessons [at the leisure centre] and there she met another young woman her age. She is actually a very good swimmer now. And this experience brought her into company of women her own age, rather than just hanging around with her old parents. Also, she got involved and really helped her community!

For the last seven years Melinda lived in her own apartment in town. She loved living there, having her independence. Recently she moved back home with us due to some health issues and Covid, which was a very isolating and scary period for our family.

Choices about work and meaningful activities can be diverse depending on the person's preferences. A stakeholder commented that going into open employment was not straightforward for some young people with developmental disability. Family Advocacy peer workers and staff encourage families and people to remain open to different ideas, as individual journeys of 'work', achieving one's potential and contributing would look different for each person.

We really try and get young people into the open employment ... it's just a notion of avoiding that segregated model of putting people together just because they're disabled ... So, we don't prescribe to families or anybody, that this is what you must do, because that would be totally unrealistic. But we do prescribe the vision, and what we feel is a better life or a more meaningful life for the young person.

Family Advocacy aims to "empower families to think outside the box", to discover options offered and available in people's local communities. That could include, starting with a tailored and time limited work experience at a friends', family or neighbourhood business. Seeking out experiences or volunteering to identify a person's interest – likes and dislikes, thereby enabling a person to grow and learn through doing the things that other young people would in the community. When working with families, stakeholders emphasised that parents and allies needed to start with the young person with disability and their interests at the centre, without limiting a person's process of development by their disability.

Melinda's story demonstrates that for most young people, interest and capabilities change as they explore who they are, what they like, and how they can contribute. Through Melinda's volunteering experience she was supported to find out that she was more interested in caring for newborns than older children. In the process she became good swimmer, made new friends, and was actively involved in her community.

Finding out what a young person or family member with developmental disability wants and enjoys doing occurs through deliberate advocacy and planning, but also through new opportunities.

Enabling a meaningful and connected life in the community

Benjamin's father Matthew told the story of Ben finding work and volunteering in his community.

Benjamin is in his early 30s, he lives in his own home; he loves newspapers and goes to the newsagent whenever he can, he loves touching, smelling and collecting newspapers – he's got a huge stack at the back of his house! Benjamin needs support for most of his daily activities, also finding employment and making friendships. When he was young Ben had a brain injury, which meant that his eyesight is heavily affected, he has intellectual disability, and he struggles to filter his emotions, which causes him to behave unpredictably at times.

When Benjamin was school age, we first sent him to the local primary school. We were advised he should go to a special unit, and at first, we took that advice. But we discovered he wasn't learning much, and Benjamin's behaviours were getting worse. We started to research how you best educate a child with intellectual disability. We decided that special units and special schools are not the best way for children to learn. Once we found Family Advocacy, we learnt a lot of information and they have supported us by giving us strategies so Benjamin could keep attending the local mainstream school.

The local school were not always supportive of Benjamin attending. They kept promising things that were never delivered, but eventually he went to primary school and had support, and he seemed to be learning things. It became more difficult with high school.

We found out that rather than sitting in class he enjoyed doing things, so his last years of high school he mostly did work placements at the local Bunnings hardware shop and a gardening business. He loved going there.

One of these jobs continued a bit longer. It has been difficult over the years to find good employment opportunities for Ben, for him to genuinely do useful things out in the community, and for employers to be accepting and open to him and his differences. Ben also volunteers in his community and is contributing through unpaid work.

Families learned about their family member's preferences by listening to, noticing, making opportunities and supporting their family member/children's interests and strengths, as illustrated in these stories. They advocated for or facilitated opportunities for the person to explore these emerging interests.

The stories of Benjamin, Melinda and Tom demonstrate how parents took on greater decision making while their children were still young. As the young people grew older and were exposed to a wider range of experiences (through school, community, family/friends and home life) they had opportunities to express their wants and likes.

Family Advocacy emphasise the importance of supporting people with disability to establish, create and maintain a wide range of personal connections in their local communities. By creating routines, for example, getting a coffee every Wednesday at the same local café, it makes opportunities to be known and connected and functions as a safeguard for a person from harmful experiences. The goal is not only to enrich people's lives but also build safeguards which people with disability can rely on.

Community connections as a safeguard

Roger's mother Annie told Roger's story of working in the community, and how being known in the local community functions as a safeguard in Roger's life.

We attended a workshop run by Family Advocacy and our life changed. We listened to a story by another family and it was very powerful. Family Advocacy has supported us on the way, through connecting a group of like-minded families who share this vision of inclusion for people with disabilities. They helped us to form a vision of a good life and holding high expectations for our son. I really learned how to advocate for my son's interests and ensure he could achieve his best self in life.

Roger, my son, had a brain injury when he was 9 years old. That's how we got into the disability world. We always wanted him to lead a life that supported his strengths. Roger attended mainstream school. After leaving school he started work at the local supermarket.

I strongly believe that he would not have had the skills or the confidence to apply for a role in retail if he had not been educated together with his peers. Roger is so embedded in his community. He is much more known well known in his community than I.

That has also become a real safeguard for him. Because he attended the local school, works at the local supermarket, he is known and loved by many people it is a safeguard. I know that other people in the community will look out for him when Roger is on his way to work, or he is at work, and when Roger attends sporting events with his friends.

In the Family Advocacy Model there are opportunities for people with developmental disability to present their stories alongside their family members for example at conferences and other events.

3.2 Impact on the family level

Families involved with Family Advocacy reported that being part of and connected to the organisation had a positive impact on them and their family members.

Receiving information, guidance, skills building, leadership development and networking with like-minded families strengthened their resolve and capacity to support their family member and reduced their sense of isolation. Becoming part of a community, a 'social movement to promote the rights of people with disability', meant that families felt connected and validated in their beliefs, hopes and vision for the future of their family member.

Peer support through Family Advocacy

Sam's mother Prima tells the story of becoming part of Family Advocacy

I've been connected to Family Advocacy for about 25 years. When my son was quite young, I was looking for people that had the same values as we did, as a family.

We wanted our son to have the same opportunities as our other children, even though he has a very high level of need. I wasn't happy to accept that his life would be different; although we knew there would be challenges.

When I found Family Advocacy I knew, I had found my tribe, basically, like-minded people who believed in total inclusion, and we felt validated as a family!

So, being connected to Family Advocacy gave me a lot of confidence and I met some really fantastic people, and it changed our lives. I know we would have pushed what I got for Sam anyway, but it would have been a lot harder because I would have felt a lot more isolated, and without a clear direction how to go about it.

I wouldn't have had that support of the people behind me, who I knew, you know, many families were doing the same thing, they had the same values and vision of inclusion.

Being part of Family Advocacy also provided families with tools and empowerment to make a difference to the inclusion of their family member in their local community. Families said they were supported in their efforts to advocate with or at times on behalf of their family member to achieve an included valued life in the community, in their schooling, and more broadly to advocate for inclusion on a societal level.

Becoming more proactive and confident also had a positive effect on families themselves. Annie, Roger's mother, explains how she learned to be more outspoken and confident over time.

Family members growing in confidence and skills to speak up

Roger's mother Annie told her story of her growing advocacy skills and confidence.

We have five children; Roger is my fifth and youngest. When he was 9 years old, he acquired a brain injury, that's how our family got into the disability world. Family Advocacy showed me and gave me the tools to advocate and speak out on behalf of my son Roger.

I became a different person! I wasn't like that when Roger was born.

I learned that there was a lot of pushbacks, a lot of negativity towards families with disability. Family Advocacy was a light for us, they gave us a different perspective and hope, connection with other families and helped me grow and become the person I am today.

Examples of some practical empowerment tools and guidance around inclusive education, were about how to work well and communicate with local schools and creating personalised portfolios with their child, highlighting their strengths and interests.

Parents valued a wide range of information about using signs and images to communicate with children, that they could also share with teachers; tips on how families, teachers and school aides can work well together; and how to build the best possible support around a child with disability in mainstream school.

Impact on families from Family Advocacy

“Since my daughter finished studying and started working 2 years ago, it was a big change in our life. It had an effective impact on all of us”.

“Family Advocacy has been critical in keeping the relationship with our son's school amiable and we would feel lost and helpless without their support and guidance”.

“Families care for their children as a priority, we need advice and support with managing relationships with schools. With so many priorities on families and education system, it's the children who bear the brunt of low expectations, prejudice and discrimination”.

“We need Family Advocacy to help us raise our disabled child. Every stage of his life is a new chapter, with new challenges, and we need help. We value that we have people we can call on to guide us, particularly with respect to education”.

“Family Advocacy informed me of my child's rights to access mainstream education. I was provided with written information and over the phone guidance and help in organising a meeting with our school. It really helped our family to turn around the situation”.

“Working with Family Advocacy has not only enabled us to achieve fairness it has also had a stabilising effect on our family. They know their stuff and when I ring them with an issue they can advise me straight away what our entitlements are, how to achieve them through positive interactions with the school”.

Source: Family Advocacy survey

Family Advocacy guidance, inspiration and information is wide ranging across children and young people's transitions. Families and people with disability said they valued that Family Advocacy provided a range of information and guidance, focusing on key transitions in a person's life, entering education to leaving school, finding open employment, and building community connections and friendships.

Managing diverse expectations of families is an aspect of the work of Family Advocacy. While the survey responses were overwhelmingly positive, one respondent felt that the approach and messaging around inclusive education was too narrow and excluded families, who were choosing special education for their child with disability.

This organisation actively promotes exclusively inclusive education, which I do not agree with. Special schooling options are a valid choice, and their demise should not be promoted by any organisation purporting to represent all people with a disability.

Source: Family Advocacy survey

Family Advocacy advice and resources support people to navigate the service system. Families and people with disability valued having access to information and resources on general advocacy, information on self-management of NDIS funding and plan reviews, communicating with planners, and navigating diverse social and complex medical systems and social service contexts.

“Our young people with no way of speaking up for themselves risk being left behind, only those with the financial means, skills and resources to negotiate the maze of health systems and policy will receive the help they need. Access for young people with disabilities to help themselves benefits us all.”

“The NDIS system has been very unreliable so far, and it would be good to know there is backup, if difficulties arise again in the future.”

Source: Family Advocacy survey

3.3 Impact on leadership development

The Family Advocacy model is designed to promote leadership by families who advocate alongside with or at times on behalf of the person with disability in their family. The model was achieving strong impact on family leadership on multiple levels, families leading within their own family to advocate for change in the persons' life and on a community or broader social level.

Some impact is also noticeable on the leadership of people with disability. Although the data was limited, some people with disability in the survey said they used Family Advocacy services independently or in combination with their family's support. They said advocacy was 'essential' to gain information about their rights and options, build independent advocacy competencies, feel empowered and lead decisions and navigate situations in their own lives (e.g., have an advocate at a NDIS meeting).

Impact on leadership development

“I need support at NDIS meetings to advocate for my needs. Not the service needs, to access the community, to be seen as an individual, not a service recipient.”

“I rely on advocacy services for information and advice. If they [Family Advocacy] are not available, I have no idea where to seek help and not enough time to search.”

“Who will I turn to, who can provide help, answers, guidance and referrals?” [is how I use Family Advocacy]

“Essential [Family Advocacy] reduce stress and increase confidence that advocacy will remain available... [I am] feeling insecure, knowing that this certain services/assistance is no longer there for a person with special needs like me.”

Source: Family Advocacy survey

Families and stakeholders involved with Family Advocacy underlined the importance of the model for building and enabling family leadership and creating diverse leadership opportunities.

The stories with parents demonstrated that families, who felt strongly connected and aligned with the approach and values-proposition of Family Advocacy, wanted to lead by “example” within their own communities and “give back” by educating other families, or advocating for wider social change.

Families who had achieved gains for their family member were sometimes asked or wanted to share their knowledge, expertise and story through the model. Families shared their lived experience with other families at conferences, leading peer meetings or peer groups, and indirectly, through leading by example in everyday life. These experiences increased families’ confidence and development of their leadership skills and potential.

Families learning from each other and educating the community

Roger's mother Annie told her story of becoming an advocate, making a contribution to empower other parents, also advocating for system changes.

I wanted to give back and show other families that there was another way, that it was not all negative and that people with disability can lead a full and rich life in the community, achieve their potential. I have been at many workshops as a parent, to tell our story. You could see how that is important to families. They don't just want to read things in a book, but hear from another family, what their story is and how they did it.

Over the years I have also spoken to many politicians, I will also speak to the builder who was fixing our house about the challenges for people with disability and their families. I try to bring more awareness to the community.

When I went to speak to my local parliamentarian about changes and cutbacks at schools for example, hopefully, every time you speak to someone, they will take it seriously they will understand and add their weight when it comes to making funding decisions or new legislation.

Over the years, you become the expert on the situation of your family member. So, when politics discuss or legislate certain politics, you get to advocate for your family. Politicians do like to hear from family members, they like to hear what the experience is on the ground.

Family Advocacy are great, they always try to link in a particular family with expertise in an area to the public hearing or policy review that politicians are trying to address or resolve.

Family Advocacy staff emphasised that they approach family leaders who represented and aligned closely with the values and vision of the organisation. They were offered further leadership development and skills building, such as weekend courses or development over a few months. Often it was these family leaders who invested their time and effort to promote the rights people with disability further and advocate for social changes more broadly.

3.4 Impact on the rights of people with disability

Families held diverse roles in promoting the rights of people with disability as evidenced in the interviews.

Many of the examples were about building systems, support and inclusion in mainstream education. Some families were also involved in a broader range of rights initiatives, independent funding and living options. They said that building family's advocacy skills and vision of inclusion were a way to grow the pool of families in the community who can advocate for their and other children and adults with disability, for broader social change.

Advocating for changes to education

Tom's mother Betty explained how she became a peer leader for other families to help them develop a stronger voice in their school communities.

After my son left school, I was close to retirement, I had more time. I wanted to pay it forward. An opportunity came up to lead some workshops that Family Advocacy were running with newer families. So, they asked me if I wanted to get involved and I said yes. I've done a workshop to learn about facilitation of groups and leadership. I'm doing some systemic work too. I am currently leading a peer network, generally these are four Zoom sessions, two weeks apart to assist newer families to develop a vision for their sons or daughters; the Developing of Vision workshop, is all about helping parents to understand why it's important to have a vision.

Together with another family leader, we assist 17 or 18 or so participants to become leaders within their own communities, as far as advocacy goes. That could be taking on a stronger role in your local school, neighbourhood, educating others. So, that's a really exciting initiative.

A lot of the leadership development, we do with other families, is to get to as many people as possible, systemically involved in the cause within New South Wales, to change how people with disability are mostly excluded. And those family leaders, they come from all different parts of the state. So, I'm involved in that as well.

I just see it there is such a huge need out there. I also get really disappointed because I can just see these special schools and special units still being built and developed. Here in our community, I can just see parents being coaxed into that special education area, which is something that I want to try and change.

More broadly, family leaders also promoted the rights of people with disability by educating other families about the human rights of children and people with disability, and how family members can act as a safeguard.

Families also protected a family member's rights by acting on their preferences. Learning how to notice and act on preferences is part of forming the vision.

Acting on a young person's preference and dignity of risk

Benjamin's father Matthew told the story of Ben living in his own home.

With the NDIS, we started self-managing our funding from day one. The information we had through Family Advocacy. As a family we wanted more control over the resources available to Ben and how to enable him the best life he could live. Many years ago, our family bought a small house nearby, and together we decided that it was a good time for Ben to move out of home, enabling him to do the things that are satisfying for him, some are a bit eccentric but that's just how he likes to spend his time.

Benjamin started living in his own home when he was about 22 years old. When he was still living at home, we had support workers coming in to assist him with most his daily living. Then I had to go away for two and half weeks. Interestingly, when I got back home, Ben said to me, "What are you doing here? Go away, go to your home." That's when we knew or realised for the first time that Ben may be happier to be on his own, it had not even occurred to us before. But he seemed to enjoy having more control of the place he lived. So, shortly after, that's when we started planning Ben's move into his own home, where he still lives today.

During the night he doesn't have any paid support. Then, I agreed with Ben, if he stays in his bed until the morning, when his support worker arrives, he can keep living in his own home. So, far that's worked!

Also, I am confident that if he were to wander the streets because he attended the local school, many people in our community know Ben. They know where he lives, who to call if there was an emergency. Those school connections are now his additional safeguards to living a good life in the community.

Beyond the individual and their family, Family Advocacy were demonstrating how families, communities and systems can work together to act on the preferences of the person. To protect a persons' rights, family members were introduced to concepts of balancing rights, choice, and dignity of risk; including how to support a family member with disability to make decisions that reflect their preferences rather than being in their 'best interest'. Family Advocacy underlined that while children were young, advocacy was mostly undertaken on behalf of the child (substitute decision making), for example, when dealing with the NDIS parents were the child's nominee. As children become young people/adults, family members developed skills to 'respectfully [advocate] alongside' their family member.

In regard to a person with developmental disability, it is most important to have a family member involved and present in any meeting [with NDIS], using supported decision making, as in many cases, a tremendous amount of support will be needed in a delicate and respectful way.

The advocacy by family leaders on the systems and policy level, together with Family Advocacy, was seen as another major contribution to protecting and advancing the rights of people with disability.

3.5 Impact on community and systems

Family Advocacy, as a grassroots organisation, also advocates for broader policy changes. These efforts are carried out and driven together with families on the ground, who are experiencing the discrimination and devaluing of their family member with disability and the disjointed service system in their everyday lives.

Family leaders in the interviews recounted numerous campaigns and broader systems and policy changes they were involved in. For example, for the right for people with disability to live, be educated and work in the community; support for individualised and self-directed funding to enable individualised living options. Other policy involvement was around the use of restrictive practices and behaviour management, input into policy development (representation on boards and committees), and reviews at state and federal levels, like the Disability Royal Commission in 2019.

People's right to individualised funding and living options

Melinda's mother Christina tells her story of their involvement in policy change

Family Advocacy helped us to connect to other families who were experiencing similar systemic issues [within their school communities] and who were fighting for the same rights for their children to be educated with their aged peers, regardless of disability. We started a campaign around children with disabilities rights to take part in mainstream education. It was powerful to work alongside other parents.

A few years later we started campaigning for changes for post school life, to be around individualised options, not day programmes and segregation. Another campaign we were involved in, that was much before the NDIS started, was around individualised funding, people with disability and their families being in charge of and directing the supports, enabling people to live in their communities, with the support they need.

As a family member and leader, I was involved in different meetings with politicians and the community, and other things like that. The aim was to get the message and policy over the line, to get it agreed to.

Now, we have the NDIS, but at the time this was still blue sky thinking – you know, there was no guarantees our family members were going to be successfully gaining that funding, but it just needed to be an option....this change needed to happen!

Another example from the interviews, about how families advanced the rights of people with disability and impacted on their communities, was about a father from a regional town, who together with other families started an inclusion subcommittee at his child's school (after a suggestion from the principal).

The committee was seen as a useful platform for parents with children with disability to come together, support and learn from each other about navigating the mainstream school system and supporting children with disability. The initiator of the P&C subcommittee was recently invited to lead the inclusion subcommittees for an entire region, with close to 260 schools involved. The purpose was to build positive relationships within school communities around inclusive practice, to support the advocacy of other families and to enact change at a grassroots level.

The initiative continues to be supported by Family Advocacy as it grows, led by family leaders seeking change.

This “format” of connecting families around a particular interest and topic issue was later developed into a workshop series by Family Advocacy to assist other families across NSW, and in other states, to be inspired and empowered to establish and run similar initiatives, whether at their local schools or community level.

4 Mechanisms for social change in the model

This section of the research looks at the mechanisms for social change within the Family Advocacy model, what the effective mechanisms are, how and why change occurs or not within the model. The project logic is in Appendix A.

4.1 Advocacy support, resources and skills development

Families are empowered to strive high and learn about the rights of people with disability. Family supporters develop skills, vision and confidence to speak up with and for their family member with disability, they seek out and create opportunities for them to lead valued and inclusive lives.

Source: Family Advocacy Program Logic 2022

Accessible, competent advocacy support

Family Advocacy aims to provide easily accessible, responsive, timely, competent advocacy services and support over their phone helpline. Families said that they “relied on” and “trusted” the guidance, advocacy tips and strategies provided, the advice was helpful to guide their next steps, or resolve issues they were facing (survey comments).

Family Advocacy also provides a wide range of resources, tailored information and tools on their website and embedded within workshops and other learning formats, such as weekend courses. Families said that they valued that the content was focused on key issues and around life transition points (advocacy skills, self-management, dealing with NDIS, inclusive education, finding and customising work, setting up a home, supporting people to make decisions e.g., through circles of support). A staff member commented on the way support and advocacy development were provided:

It’s a bit of a buffet, family members pick and choose what they need at any given time. People have access to things at a time in their life that it’s relevant to them.

Online peer networks, seminars and other resources have been part of the Family Advocacy model for many years, and other online have been added over the last two

years in response to COVID restrictions. Staff have mixed views about the effectiveness of online strategies. Some staff argued online options made advocacy development more accessible to more families across the state. Other staff emphasised that certain types of leadership development and skills building were more effective when face to face settings were possible.

Overall, providing accessible, competent advocacy support and development of competencies is an effective mechanism in the model, as it enables families and people with disability to engage with information, resources and support that they need, when they need it.

Respectful approach with a firm vision

Family Advocacy engagement and support adhere to a vision of full inclusion of people with disability according to the stakeholders. Staff acknowledged that full inclusion was “the harder path for families to take.” Staff said they were therefore mindful and respectful in the way they present their advocacy approach:

Supporting families at whatever stage they are on that journey, [we] slowly try and build their confidence in their advocacy skills, we never make it sound easy.

Rather than being “too prescriptive” staff said they worked in an encouraging way, making sure families had opportunities to think through alternative options for their child or family member with disability.

Staff reflected that working with respectful practice was a powerful tool to engage families who were still at the beginning ‘of their journey’, newer to the Family Advocacy empowerment approach or did not yet fully align with a vision of full inclusion. Staff emphasised that they were also uncompromising in their advocacy position, for example, on inclusive education in mainstream schools. Children and young people with disability, regardless of their situation, having the same opportunities to be successful and included with their aged peers, was described as a core foundation of the Family Advocacy vision.

Regardless of the initial topic the family brings, they are provided with assistance. A common reason families make first contact is about group homes, to seek advocacy advice for problems associated with many of these services. As the families are receiving support to navigate this issue, if it is a constant problem, Family Advocacy may ask if their family member has considered individualised living arrangements.

They might discuss that, “Some families report that [individualised living] can often remove many of the barriers that you are currently attempting to navigate.”

Reach and engagement

Family Advocacy provide advocacy advice, workshops and information sessions to any family who ask for guidance and advice. Family Advocacy staff reported they successfully engaged with a range of demographic and diverse families from across the state. For example, they said 30 per cent of families were from culturally and linguistically diverse backgrounds and across socio-economic groups.

Stakeholders emphasised that “going a path of full inclusion” was much harder for families due to barriers, investment and strong advocacy skills. It is unclear the extent that economically disadvantaged and time poor families currently approach Family Advocacy. Family Advocacy could review how it is reaching families who do not have personal, community or local service capacity to be aware of fully inclusive options before their children enter segregated support.

4.2 Leadership development and changes in leadership

Families are supported to participate in leadership training and mentoring. Family members connect with one another in leadership development opportunities, through peer networks and advocacy related events. Over time, the strengthening of vision, capabilities and connections help families to influence change at broader community and systems levels.

Source: Family Advocacy Program Logic 2022

Lived experience and subject expertise

Developing family leadership is a central mechanism for social change in the model. Evidence from the interviews and survey demonstrated that families learned from and appreciated lived experience stories. The stories were perceived as genuine, providing insights into successes and challenges to achieve an included life. The stories created opportunities for families to connect and ask questions. Building and investing in family leadership also meant that the model was sustainable, as leadership resourced families who were already involved so they could deliver and drive the advocacy work of the future. Family leadership contributed to driving social

change and raising awareness within their local communities, supporting newer families (peer work), and advancing the rights of people with disability through systemic policy work and government reviews.

Family Advocacy works with families from diverse locations who advocate for family members with a range of needs and preferences, which meant that families had a diverse wealth of knowledge and experience. Investing in leaders and supporting some families to attend advocacy skills and training over time, meant Family Advocacy has a growing pool of subject experts who can become involved in different leadership roles within Family Advocacy and externally. Families said they often “dipped in and out” of leadership roles, such as representation on boards and committees. Their role depended on their life commitments and their changing subject expertise as their family member’s life changed over time. The changes within a family meant the family leaders were available to share their story according to the specific time and context.

Developing family leadership in the model was a deliberate and planned process. Family Advocacy developed specific training opportunities for the range of skills and leadership roles needed for advocacy. They support attendance at capacity building events by funding accommodation and travel so that families from a range of locations to attend. Potential family leaders are selected according to internal systems to identify prospective family leaders. These processes ensure that limited resources for leadership development are effectively used to support leaders who share the model’s value proposition. For example, staff noted, when they selected potential leaders, as a team they would consider key questions and criteria before sending out invitations,

Does the family relate to the importance of inclusion? What does this look like currently for their loved one? Are they motivated to learn more to support their family member to achieve a good life? Does the family want the same things for their child with disability as for their other children, or do they treat them differently?

A main criterion for families to become more engaged with the leadership approach was that they had to “relate to the work” of Family Advocacy. Family leadership, such as presenting at conferences or involvement at systemic levels or in policy work, was open to families who had chosen “a path of full inclusion.” The commitment to inclusive education means that Family Advocacy leadership development was focused on families who “strongly feel aligned” with these core values.

The effect was to not include families for leadership roles who had a family member attending full- or part-time segregated, disability specialist settings (education/ work/ housing/ recreation). While there was little data, some family comments suggested that families who wanted to support their family member to achieve a meaningful life but had previous or ongoing connection with segregated settings, may feel excluded from leadership opportunities.

The staff gave examples of mechanisms of support that made family leadership sustainable. One example is from the peer network coordination. Family leaders were trained to deliver and run peer network meetings, workshops or coordinate local level community meetings. Administrative organisation and tasks were managed at a central level by Family Advocacy. They said they would collate and invite participants to peer meetings, put together and send out additional information and resources, record the meetings and where applicable share the recordings etc. This process ensured that peer network facilitators (here a family leader) could focus on delivering their subject expertise.

Governance and representation

Family leadership was also visible at governance levels. Stakeholders emphasised that having families with lived experience represented and involved on various levels of the organisation was central to credibility and remaining “true and connected” to the issues faced by families on the ground.

The management committee has a four-year rotation to have a mix of families with experience and a fifth year for the chair to mentor the incoming chair. Stakeholders commented that they regularly reviewed the representation of the Family Advocacy board. This helped to ensure that families in regional and urban locations, with family members of different ages, levels and types of disability were represented. Family Advocacy were currently trying to engage families with young children with disability to become leaders or be part of the board to ensure the model remained effective for families who had no previous connection to Family Advocacy.

We need a wide demographic; we need young families as well, who can relate to our work ... And we tried to get that in the committee, so we have wide variety of age groups; families who have younger children today.

The staff said that leadership from families was crucial for strategic alignment. The voices of people with disability are currently not directly represented in the Family Advocacy governance. Their voices are harnessed at the family level and brought to the forefront by the families represented in the organisation.

The Family Advocacy model was established over 30 years ago, when the voices of families and people with disability were highly marginalised. The model could review its policies and procedures to identify if there are opportunities to involve the voices of people with disability within the organisation and its governance.

4.3 Progression of rights, people with disability realising their goals

People with disability realise their goals, contribute socially and economically and lead inclusive lives through the support of families identify.

The rights and interests of people are protected and safeguarded through the advocacy leadership development of families.

Source: Family Advocacy Program Logic 2022

The rights of people with disability, their preferences and interests are advanced and safeguarded in the model at different levels. People's rights are advanced at a family level when family member's expectations about the person's current and future contributions, their preferences and interests are promoted and supported, listened to and actioned on by creating typical opportunities for a person to grow, learn and have experiences (diverse, embedded in the community, with the right levels of support and some dignity of risk).

The stories of change included Section 3 demonstrated how parents and families listened to and promoted the preferences and interests of their children. Families facilitated opportunities for their children to explore their interests and have different experiences, including understand what they did not enjoy or want to continue.

The Family Advocacy model provides for resources and tools to assist families with processes for finding preferences, making choices and supporting decision making of people with disability and developmental disability. Stakeholders and staff commented that "prioritising the voice of the person with disability" and "everyone in the family unit being on the same page" was not always easy. It was not uncommon for there to be dissonance and difference of opinion within the same family (e.g., the person with disability wanting to move out of home, one parent being supportive and the other not).

Family Advocacy staff said they encouraged families to create circles of support, where the person, their strengths and interests stood at the centre, a variety of people in their life (including family members) supported the person to realise their potential and advocated for them to live their best life. Staff emphasised that all their advocacy skills development for family members was built on this premise of the person at the centre, emphasising the person's rights, strengths and interests. However, they noted that it was out of the organisation's control what happened in the home, and how effective families were at shifting decision making and agency toward their family member with disability.

The protection and promotion of rights occurred by families advocating for and demanding "more inclusive things from the system". Developing and investing in family leadership meant that a growing number of families were skilled and advocating in the community and alongside Family Advocacy. They were advocating for the rights of people with disability at different levels policy levels on topics of education, early childhood education and work/employment. They were also advocating on general areas such as community participation and recreation, housing, human rights, thereby promoting social change. Families and staff gave examples of these advocacy actions.

The more people, families are demanding inclusive stuff from the systems, then we can have systemic change. The whole idea is that individuals can only do so much, so we need a mass of individuals in order to change the systems ... Early childhood education and employment, that's our strategic focus, particularly around things that we want to look at changing systemically, we have a stronger focus of these.

Education and work are fundamental to lifting people on a pathway of living an embedded life in the community.

[Family voices are included] in the writing of submissions to all levels, whether it's state or federal government levels on all the topics that are part of our strategic plan, which are early education, education, and employment.

We also comment on other topics ... the NDIS, supported decision making, you know, there's issues with guardianship sometime ... So, broadly our job is to challenge restrictive and discriminative laws, policies and practises that keep people with disability segregated, limited or devalued, and excluded from society.

So, they understand what their rights are, and they understand how to navigate various system, and give family members them that confidence about that they are the best authority when it comes to their own child.

Developing family leadership is a core component of the Family Advocacy model. Families become advocates for change in their family life. They advocate for change alongside their family member with developmental disability and advocate to promote social change in various levels of their community and social life (systemic advocacy).

5 Conclusion

The model in brief

The Family Advocacy model promotes the rights and interests of people with developmental disability and builds family leadership across NSW. Through enhancing leadership and empowering them through guidance, advice, tools and resources. Families learn to advocate with or at times on behalf of the person with developmental disability, so people are supported to realise their goals, hold valued roles and lead full lives embedded in the community.

Impact findings

People with developmental disability living a life embedded in the community and holding valued roles was visible throughout the research. Families crafted a positively framed vision of their child's life early on, which they said was central to building a rich and connected life for their family member. In the stories, people with developmental disability participated in a wide range of local activities, community groups, sport and mainstream education. Being part of their neighborhoods and community had a positive impact on the person's social connections – they 'were known' and 'got to know people', creating friendships and a sense of belonging as part of their experience.

These outcomes were possible because families learnt about rights, acting on a person's preferences and how to balance rights, choice and dignity of risk. Family members were attuned to the strengths and interests of their family member and supported them to make decisions about starting or changing studies, courses and employment, or seeking out other ways to contribute through volunteering and helping neighbours.

Importantly, the research illustrated the choices about work and meaningful activities that were diverse depending on the person and their preferences. Families said they had learnt to 'think outside the box' and be guided by achieving a person's potential, seeking out new opportunities, test and trailing experiences, and not defining a person through or by their disability.

The rights of people with developmental disability were advanced at a family level through maintaining high expectations, fostering diverse opportunities for inclusion and contributions, but also family members becoming advocates for social change. The impact of the model was visible as empowering families to live and to drive the

social change they want to see beyond their own family. Family members actively supported newer families through peer education and sharing their stories; were involved or started community groups with other families with lived experience to advocate for change (e.g., at their local or regional school); and were involved in systems and policy change around inclusive education, individualised funding and living options.

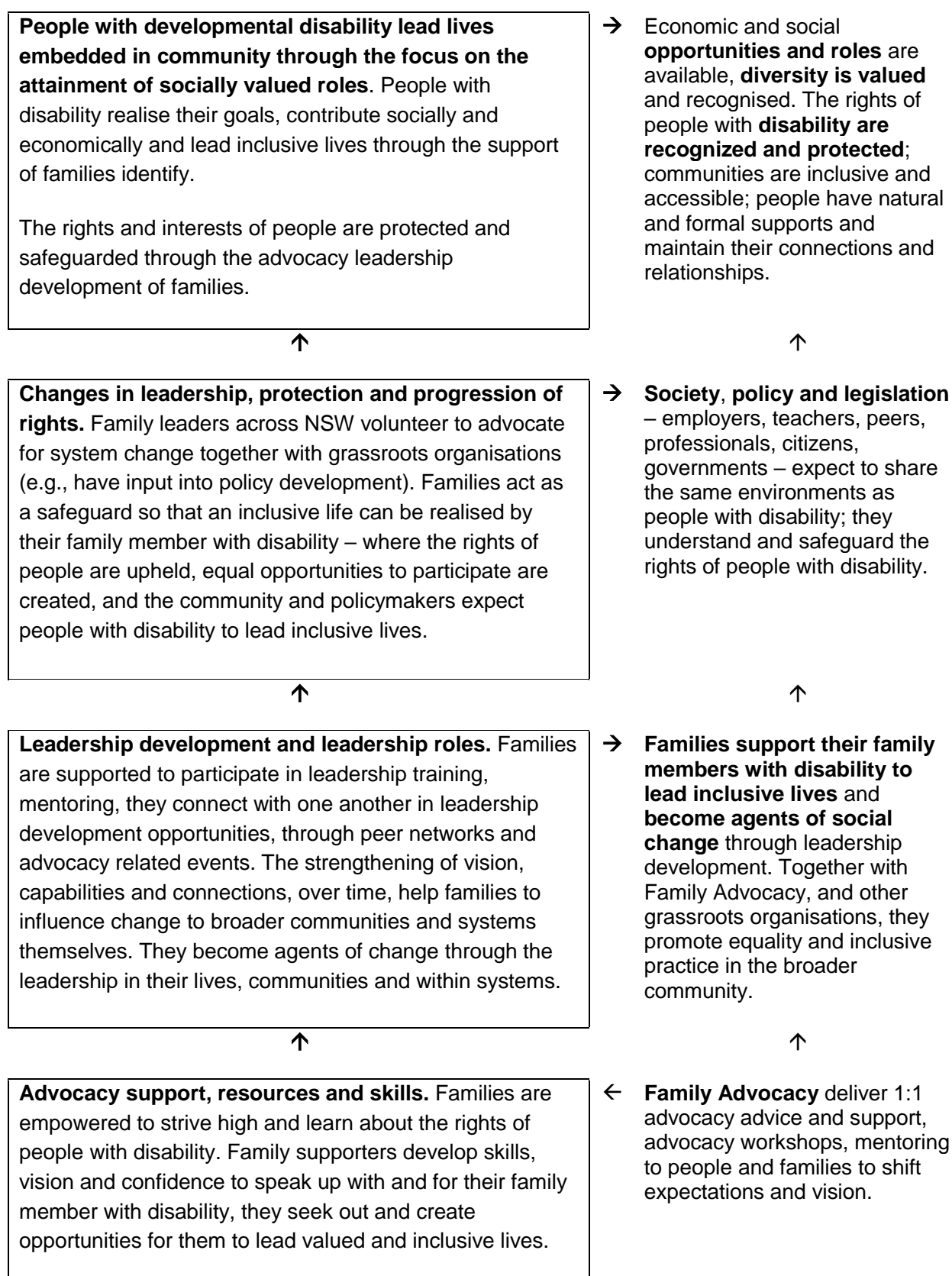
Process findings

Family Advocacy support families and the person by providing accessible, competent advocacy support (tailored guidance, online resources, tools, videos, decision making support including Circles of Support) and group and individual leadership development. The model starts from families advocating for change by envisioning a life embedded in the community that meets the particular preferences of a person with disability within their family and local community and service system. The steps in their advocacy include forming a vision, addressing challenges and sharing the families' experience with other families. The approach means the family can focus on the vision and local action needed to realise equal rights and entitlements of the person, in ways that can inform action for the rights other people and families in similar situations.

Family Advocacy engage a wide range of demographic and diverse families from across the state. Assisting families with similar advocacy goals to connect with each other and organise themselves, means that action and social change are decentralised and families with lived experience are involved in every part of the model – governance, delivery (peer to peer education, learning), leadership development and advocacy for systems and policy change.

Appendix A: Program logic and methods

Table 1: Family Advocacy program logic



Methods

Research objectives

1. Explore the impact of the family advocacy model on the person, family, and community and systems (what impacts can be observed over time)
2. Identify mechanisms of social change on an individual, community and systems level and factors that make the mechanisms effective.

Methods and samples

The research used a range of sources, existing and new information (data) to address the research objectives.

1. Review of program data and documents.

The research team reviewed relevant program documents provided by Family Advocacy. They included vision statements, grant proposals, policies and procedure manual. The review of program data included de-identified open ended survey responses. The survey was collected by Family Advocacy. 128 responses were relevant to the organisations' work and impact on families and people with disability.

2. Significant change stories with families

The researchers interviewed four families about their family members and their experience of being connected and empowered by Family Advocacy, the significant changes for the person with disability and the family.

3. Interviews with project staff

Three interviews with Family Advocacy staff focused on the vision, practices and procedures used in the model, and impacts observed as a result of the model.

Analysis and synthesis of findings

The data from the document review, interviews and stories of change, and survey responses were coded in Nvivo using a deductive coding framework and later synthesised for this report. The stories of change used in the report have been deidentified (names, places, other identifying information) have been changed.

Ethics approval

Ethics approval was from UNSW, Sydney. Number HC 220189.