Strengthening Parent Support Program

Practice Framework

Supplementary Information

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Association for Children with a Disability

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Contents

Introduction

The Supplementary Information in this document provides a description of the information learnt from parents[1] and professionals to provide the necessary information to develop the Strengthening Parent Support Program (SPSP) Practice Framework. Information was gathered through:

- **Semi-structured phone interviews with parents**

Parents were invited by local SPSP Coordinators to participate in an ‘interview’ or discussion through an emailed flyer. The interviews aimed to learn about parents’ experiences with the SPSP, challenges, outcomes, opportunities, and barriers to each of the three elements of the program. Thirty-five mothers participated with representatives from 10 SPSP service providers. Their children with disabilities ranged in age from early childhood to teenagers with a variety of diagnoses including autism, intellectual disability, developmental delay, cerebral palsy, down syndrome, vision impairment and rare genetic conditions.

- **Semi-structured phone interviews with parent leaders of peer support groups, SPSP Coordinators, managers and the ACD community education facilitator.**

Parent leaders of peer support groups, SPSP Coordinators and managers, and the ACD community education facilitator were invited to participate in an online semi-structured interview. Five parent leaders, eleven Coordinators, and five managers across Victoria participated. The interview sought to hear about their experiences with the SPSP, an overview and description of the evolution of their programs, benefits, successes and challenges, professional development activities and recommendations about what they would like to see in this Practice Framework. The Coordinators had a broad range of undergraduate qualifications from disciplines such as mental health, counselling, paediatric nursing, community development, education, health promotion and behavioural science amongst others. Most of the Coordinators had lived experience of parenting a child with disability. All parent leaders of peer support groups were mothers of a child with disability.

- **Consultation with national and international program leaders**

Information was also sought through consultation with national and international program leaders including P2P USA, The ARK Northern Virginia USA, Plumtree NSW, Kindred NSW and KIIND WA.

- **Scan of the literature**

A scan of current literature on parent support groups was conducted to provide a broad overview of the research evidence.

- **Advisory groups**

Finally, meetings were held with an expert advisory, management and reading group in order to provide feedback on the content and structure of the framework.

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[1] The term ‘parent’ or ‘parents’ will now be used to refer to both parents and carers.

1. Peer support groups

What was learned about peer support groups is best described in six interconnected areas:

a) Participation and engagement
b) Social-emotional support
c) Information, resources, and navigation of the service system
d) Effective facilitation
e) Peer leaders
f) Focused groups

a. Participation and engagement

Parents indicated in the interviews that they attended a SPSP peer support group because it provided them with social connection, emotional support, parenting resources, and information about how to navigate the service system. Interestingly, these elements are all reported as opportunities for peer support in a recent research study commissioned by the Department of Social Services (ARACY, 2022). Some parents also indicated that as their children became older, they continued to attend the group so they could contribute to their community, support younger parents, and learn new information as they needed it. They felt a close connection to the group and found that their information needs changed over time.

Parents and Coordinators discussed the barriers to parent participation in SPSP peer support groups such as poor publicity about the SPSP, lack of public transport, travel costs and time, hours that didn't suit family life, and lack of affordable childcare/respite. These structural barriers to participation in community programs have all been identified in the literature (CCCH, 2010). For many parents, it was important that the SPSP was a place "with a nice vibe" or "just where all parents go because we want to be where everybody else is." Coordinators also noted that many parents wanted peer support groups to be out in the community, at a casual place like a cafe, park, or golf club. It's interesting to consider the parallels for children with disabilities where research indicates that intervention works best when it's provided in 'natural environments' – for example in family homes, the park, and kindergartens (Workgroup on Principles and Practices in Natural Environments, 2008).

Several parents talked about the venue being a "deal-breaker" not just because it needed to be community based, but it needed to be wheelchair accessible, pram friendly, have safe access to a car park, and accessible by public transport. Coordinators also noted the importance of these accessibility requirements. These structural barriers to participation have been reported in the literature on other peer programs such as supported playgroups (Berthelsen et al., 2012; Commerford & Robinson, 2016).

Along with structural barriers to participation and engagement, the literature also highlights interpersonal barriers such as the professional's cultural sensitivity and awareness of trauma informed practices. Parent's lack of trust in services, misperceptions of what programs offer, and a lack of confidence to engage in a program have also been noted (CCCH, 2010). Parents talked about these interpersonal barriers in relation to other peer programs they had tried, but not persisted with, because they felt judged and unwelcome. They also indicated they needed a "calm place" that catered for the "sensory and neurodiverse needs of families."

Some parents also talked about the comfort of being with parents from the same culture or with parents of children who had the same diagnosis. Coordinators indicated they had previously supported specific peer support groups (e.g., mothers of home-schooled children with disabilities, kinship carers) for that reason, and there were certainly many examples of specific groups currently meeting for parents of children with autism, pre-school children, and culturally specific groups. There is some research that suggests that offering groups for people with similar experiences of their child's condition and/or with similar social backgrounds may be beneficial (Sartore et al., 2021).

"It gets lonely. I don't have family to give me support so I saw this group in a brochure. I feel better going to group."

Many Coordinators spoke of the challenge of establishing and sustaining groups for fathers, but there were some examples of dads participating in evening online groups on topics they choose (e.g., understanding challenging behaviour), meeting at the pub for dinner, and one-off events such as a bus trip to the footy where they could bring a mate. One Coordinator indicated that they engage fathers through participation on their committee of management, but this has a very different purpose than providing support and building their capacity in being a dad. It's important to note these efforts to engage fathers given that research that demonstrates evidence of fathers' potential to positively influence their children's health, social success, and academic achievements (Fletcher et al., 2014). Approaches to supporting father's engagement in Australian child and family services are reported to remain mother-focussed, however recommendations to support father inclusive practices have been proposed. These include: approaches and resources to support practitioners' knowledge, attitudes, and skills with a focus on self-reflection; understanding the historical discourse of father involvement; and, cultural sensitivity towards men (Fletcher et al., 2014). Currently in Victoria, a research project by the Murdoch Children's Research Institute and Tweddle Child and Family Health Service is underway. The aim of the 'Working Out Dads' project is to gather data on whether fathers of children with additional needs or disability find the program acceptable and explore fathers' satisfaction with the program.

Parents and SPSP Coordinators talked about "enhancing" regular peer support groups with an event over the holiday period, an education seminar in the evening, or a respite weekend. Many Coordinators partnered with other local organisations or secured philanthropic funding to support these additional programs.

"It's good to go somewhere over the holidays with the kids so we can get to know each other's family. Just a picnic in the park."

Interestingly, several parent support programs interstate and in the USA, report that they have attempted to facilitate peer support groups but have had difficulty maintaining them with high dropout rates and "burn out over time". They highlighted the significant funding and resources required to implement the program well using volunteer facilitators, and the induction and professional development requirements to support a skilled team of facilitators. They have generally reverted to an information, resources, and referral model because of these barriers.

Parents and Coordinators talked about the importance of developing the program *with* parents, rather than *for* them. This is in line with the literature on co-designing services.

> *"By involving parents in the design, implementation and delivery of the program, it ensures that the intervention addresses the real and current concerns of families and delivers programs in a friendly, accessible manner."* (CCCH, 2011)

"It was hard at playgroup. It felt judgey. But when I go to our group and things aren't going well, someone will give me a cup of tea and say "I was like that yesterday. It's a positive experience."

They also discussed the need for healthy and respectful relationships between each other. The relationship between parents and the Coordinator was seen as a critical factor in parent participation and engagement in the program. This is supported by the literature that suggests strong supportive relationships with professionals can help parents overcome barriers to participation (CCCH, 2021). Research indicates that supportive relationships begin with an understanding that families know their circumstances and child best and this can be supported through the complementary expertise that can be offered by professionals. When this premise is acknowledged, then professionals can begin to develop relationships that respond to the families' individual priorities, culture, circumstances, and values by building on their strengths. (CCCH, 2021; Dunst & Espe-Sherwindt, 2016; Kennedy, 2017; Trute, 2013).

The quality of the relationship between the parent and the service provider is seen as one of the 'threshold' factors that are essential for effective engagement of families (Barnes, 2003; CCCH, 2010).

b. Social-emotional support

Most interviewed parents indicated there were there were key reasons for their continued involvement in the group. They needed the group to be a "welcoming" and "safe space" where they could be comfortable with other parents "who just get it". They expressed relief at finding somewhere where they could "laugh and cry" with people who were "non-judgmental", "respectful", "caring", "warm" and "validated feelings". When the group felt safe, parents were then open to providing and receiving social and emotional support from each other.

One mother from a culturally specific peer led group commented that "we have a culture of friendliness and respect. A sense of belonging that helps the bond." The importance of belonging was echoed by many parents and is reflected in the literature (Department of Education, Skills, and Employment, 2010; Law, King, Stewart, & King, 2002). Coordinators highlighted their role in bringing parents together in a way that supported them to develop good relationships or friendships. They felt that they "set the tone for a welcoming and safe space" through respect, openness and listening to each other.

In the interviews, some parents described previous experience with peer support groups where they felt unwelcome because of the "clicky" nature of the other parents, or because of feeling “exhausted and triggered” by parents sharing their experiences. This was thought of as a sticking point for several parents who wanted the group to be a place where they felt “hopeful and inspired” rather than “drained by the ongoing stories of other families”. The Parent to Parent program in New Zealnd suggests that peer groups that are focused on ‘venting frustration’ tend to have a high turnover of parents (Parent to Parent New Zealand, 2023). Coordinators suggested that when parents express significant frustration or burden they should be directed to individual support from themselves, or referred to another appropriate service.

> *“Some members have a positive spirit. Those on a new journey see that and it lifts them up. It helps a lot for the newcomer.”*

Several parents talked about the decision they made about continuing to attend in terms of a “cost-benefit analysis”. They asked themselves questions like: *Is it worth the travel? Will I feel good on my way home? Have I learnt something new? Is there someone I would like to see again?* If the cost was too high, they didn’t return. Parents highlighted the role facilitators had to play in managing the group dynamics, so everyone had appropriate support and could come away feeling listened to and uplifted.

> *“Validation is helpful. Judgement is everywhere and I feel powerless. It’s good to have other people to bounce off. Not shoving advice down your throat.”*

Coordinators highlighted the need to provide a welcoming environment and to manage the needs of all families by sharing their stories and supporting each other. Several also suggested that this was something they needed to support parent leaders of peer support groups with. Some facilitators had developed ‘group rules’ that attended to these issues, while several developed the rules or agreements collaboratively with the parents so they had greater ownership of how the group would run and how parents would interact together. Some Coordinators also provided a welcome pack for new families. Research has shown the potential for negative outcomes when peer-led support groups do not have clear rules and boundaries and confidentiality agreements for the group (Shilling et al. 2015).

> *“I’m doing it to update my knowledge and talk with other parents. I feel relaxed. I can look after my mental health. It feels fun. I still need to learn. Before I was isolated. They give me some hope.”*

The relationships between parents have been noted as a potential barrier to parent participation in the broader literature on parent support groups (Berthelsen et al., 2012; Commerford & Robinson, 2016). Evidence-informed strategies to encourage a culture of belonging and ensure safe and positive interactions between all those involved in support groups, including new members of the group, have also been proposed. These strategies, such as those developed through the Family Partnership Model can also

> *“It’s good to hear other people’s stories, but it needs to be managed so it’s not heavy on our shoulders.”*

"We may not know the answer, but we know where to go to get the answer."

support strong parent-professional partnerships (Davis, Day, Bidmead, MacGrath, & Ellis, 2007).
One Coordinator suggested that she preferred to be thought of as a 'connector' rather than a 'facilitator' or 'Coordinator'. She indicated that her role was focused on supporting healthy relationships between parents, with the knowledge that peer support was the strength of the SPSP. Coordinators and parents agreed that the SPSP peer support groups had an important role to play in reducing social isolation, providing a forum for emotional support and friendships to develop. Although research on peer support is limited, there is some evidence that it may decrease feelings of isolation; increase parental coping skills, social interaction, physical and psychological health and families' capacity and skill development (Ireys et al. 2001; Dew et al., 2019; Law et al. 2002; Henderson et al. 2014; Orima Research 2013, Sartore et al. 2013).

c. Information, resources navigation of the service system

Apart from providing a welcoming place where parents could share their experiences, some Coordinators spoke about their role in creating an environment where parents could openly share information, ideas, resources, and strategies together. They had an understanding that parents develop rich knowledge and wisdom over time and are great sources of information.

Parents said that they sought information from other families and trusted their knowledge because of their experience. They typically shared information about child development, learning and wellbeing, their own wellbeing, services and support, and issues related to the NDIS such as how to manage plans. Research suggests that peer support is seen as a positive resource for families of children with disabilities (Sartore et al. 2021; Shilling et al. 2013). Coordinators felt they could 'value -add' by providing evidence-based parenting information and share details about reputable supports and services. Both parents and Coordinators described information sharing as a two-way process: learning from each other along the way. Coordinators who were well connected to the community and had a broad knowledge of information sources often referred families to other programs where appropriate. For example, they let parents know about Raising Children's Network, Siblings Australia, Playgroup Australia and the ACD amongst others.

Whilst parents talked about their participation and engagement in the SPSP peer support groups and the social-emotional and informational support it provided, they also talked about how the Coordinators they interacted with had fostered those positive outcomes.

d. Effective facilitation

SPSP peer support groups are led by an employed qualified Coordinator, or a volunteer parent leader who is supported by the SPSP Coordinator.

"Our facilitator is amazing. Good at what she does. She's got experience and knowledge about disability and mental health. She just listens. I can call her when I need guidance or suggestions of where I can get help".

Parents commented that the facilitation of the group was critical to the success of the group. Parents discussed this in terms of the need for "a highly skilled human" with the skills and qualities that enabled them to create an environment that is accepting of, and responsive to, their needs.

Their experience of an effective facilitator was someone who was "true", "authentic", "knowledgeable", and "respectful". The importance of the role of facilitators is reflected in the broader support group literature (Commerford & Robinson, 2016; Jackson, 2013; DEECD, 2012). The necessary skills and qualities of those working with parents is also discussed in the literature and includes skills such as active listening, and qualities that include respect, genuineness, empathy, integrity, humility, and quiet enthusiasm (Davis et al., 2007).

Research indicates that essential elements of facilitation for parent support groups, include:

- developing trust with families
- utilising family centred practices
- creating a space that meets parent needs for social and other forms of support, knowledge of the local service system and referral pathways
- facilitating peer support (Armstrong et al., 2019, 2021; Commerford & Robinson, 2016; Jackson, 2011; 2013).

Further to that, factors found to contribute to better attendance rates in support groups include having facilitators who are good at engaging parents (Commerford & Robinson, 2016; Berthelsen et al., 2012; Williams et al., 2015). Many parents commented on the benefit of having a facilitator with lived experience. This is interesting given the different models implemented by the Coordinators. That is, those that had lived experience tended to directly facilitate groups. Whereas those programs with Coordinators without lived experience, but with other highly valued capabilities, leant towards a capacity building model where they focused on supporting parent-led support groups. Although this appeared to be a trend, it was not always the case. It's important to note that Coordinators came with tertiary qualifications across disciplines including mental health, counselling, peadiatric nursing, community development, education, health promotion and behavioural science amongst others.

"I've gone from being a parent in a group to now facilitating a group with other mums. It's been great for me. Really built my confidence and skills".

"Our children miss out when we don't have information.
We miss out when we don't have each other for support."

Some parent support programs in other Australian states and in the USA report that they have attempted to lead peer support groups in the past but cite the skills of the facilitator as one of the barriers to success. In brief, parents, researchers, and the SPSP Coordinators tell us that high quality facilitation matters.

"She (SPSP Coordinator) was really into building capacity, so I had great support in starting a new group."

e. Peer led support groups

Most of the literature related to peer workers and voluntary peer leaders comes from decades of research and practice in the mental health sector (Repper & Carter, 2011). There is much more limited research in disability services. A recent systematic review of quantitative evidence from the past decade of the effectiveness of peer support programs found that peer support is effective for reducing distress and improving the well-being and QoL among parents of children with disabilities (Lancaster et al., 2021). Findings from interviews with SPSP Coordinators and parent leaders of support groups suggested that parent-led groups were highly valued by participating parents. They were also viewed positively by the parent leaders themselves, who described their role as "fulfilling", "empowering" and "rewarding". They were pleased to be "giving back" or "paying it forward".

"It's a craft – how to use your lived experience to support others".

Several parent leaders spoke with enthusiasm of their experience as young parents participating in a support group and their development into a leadership role.

Some parents were "tapped on the shoulder" by the SPSP Coordinator who had observed their leadership skills and qualities such as good communications skills, positive contributions to discussions, and a respectful and non-judgmental attitude. Other parents had seen a need for a support group closer to home, or primarily for parents of young children at their school, or parents of children with a specific disability such as autism or Down Syndrome. They approached the SPSP Coordinator to seek advice about starting a new group. In each instance the parent leader had support and guidance from the SPSP Coordinator that they reported helped them in their new role.

The support included attending some sessions, arranging the venue and speakers, supporting with referral and communications about the group, providing resources as requested, and arranging a catch- up with all parent leaders in the broader community. Several parents had been supported with relevant training such as the Carer Victoria facilitator training. One of the parent leaders of the peer support group went on to an employed position as a support group facilitator and spoke enthusiastically about how the original peer group and the support of the SPSP Coordinator played an important role in her career trajectory.

Whilst some SPSP Coordinators expressed concerns about parent led groups because of their support requirements and the perceived risks about issues such as privacy and boundaries of the role, others highly valued parent leaders because of their influence and ties to the community and their capacity to engage parents in the groups. The lived experience of parent leaders was universally viewed as a strength of their role, offering their peers shared experiences, local resources, mutual support, and hope. Mead (2003) suggested that peer support provides "a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful." It appears that parent-led support groups are perceived by SPSP Coordinators, parents, and parent leaders themselves as founded on similar principles.

> *"The potential benefits of a self-aware, kind, networked, skilled and informed parent in the role of peer facilitator would be second to none. They can offer things a paid staff member can't in some ways because they are offering their life as a learning tool and a connection point. They can increase the reach of a program by bringing in other parents they have come to know in their everyday lives of caring, their presence in an organisation provides a sense of 'street cred' and they are likely to know 'who is who in the zoo' in terms of providers - those who are a gift and a trusted resource, and those who are a waste of time and money and should be avoided, so can be great at choosing guest speakers and offering warm referrals."* (Parent)

f. Focused groups

Some parents preferred to join a group of parents from their own cultural background, or with children of similar age, or with the same diagnosis. Their needs sometimes changed over time as they shifted to, or from, a more generic group. Parents, SPSP Coordinators, and parent leaders all spoke of the need for focused groups to help parents "feel like they belong" but also of the importance of promoting inclusion and diversity in all groups.

Several parents from culturally specific groups spoke about the importance of being able to speak in their mother tongue, even if they were proficient in English. They talked about the need to talk "freely" about matters that were important to them, and that was only possible in their first language.

> *"When I speak Chinese, I'm speaking from my heart. In English it's purely communicating what I need. It's easy to talk in my own language about important things."*

Parents and Coordinators had a shared understanding of some of the cultural barriers to accessing services and support for children and families. Many of these barriers are also highlighted in the literature including:

- cultural rules or obligations relating to how someone with a disability is cared for, who performs a caring role, and what it entails
- stigma associated with certain disabilities or health conditions
- concerns about the cultural appropriateness of services
- cultural opposition to the idea of carer support groups and discussing family business
- lack of awareness of services or inability to contact services due to limited English proficiency
- promotional, informational, and educational materials not available in different language;
- lack of services for small or emerging communities in regional, rural, and remote areas (Carers Victoria, 2023)

"I don't have time or the energy to go out and hear information that I could have got in other ways. I like reading that stuff in a newsletter, or at the group I go to. I'm only going to a workshop if it's a really good speaker that's really helping me learn more."

Some of these barriers are also described in the literature for Aboriginal and Torres Strait Islander children with disabilities and their families. These include remoteness, social marginalisation, cultural attitudes towards disability, and culturally inappropriate services (DiGiacomo, et al., 2013). Some Coordinators indicated that very few families who identified as Aboriginal or Torress Strait Islander participated in the SPSP.

There are a significant number of autism specific groups across the state – both SPSP and parent led groups. Several parents indicated that one of the important factors in them participating in the group was the growing understanding of the neurodiverse needs of parents and the adaptations that were made to the program and environment. Parents and Coordinators commented on the importance of recognising the individual needs of *all* parents and providing adaptations to the environment such as a "calm place with gentle lighting" to encourage participation.

"Telling and sharing success stories to show hope has been really powerful for the parents in our group".

Coordinators also talked about their role in modelling neuro-affirming language, and some spoke about their intentional approach to accommodating the needs of neurodiverse parents. This is in line with contemporary thinking about the importance of neuro-affirming approaches for autistic people (Trembath et al., 2022).

There are also several SPSP groups that are specifically for parents of preschool aged children. Some of these were formed by parents who identified a need for addressing the specific support needs of parents of younger children. These parents are adjusting to their child's learning and developmental needs and seeking specific social connection and emotional support, information about parenting, strategies, and access to services such as the NDIS. These early support needs of parents of young children with developmental delay or disabilities are identified in the literature (Guralnick, 2019).

2. Information and education sessions

Parents placed value on parent information and education sessions. These sessions were typically provided through annual or biannual seminars or workshops available to both parents and professionals throughout the broader community. Parents mentioned the value of these sessions when the topic and the speaker was "on point". Some of the topics mentioned included: ADHD, autism, neurodiversity, play, inclusion, guardianship, trusts, wills and estates, sexual health, respites, NDIS & Centrelink support, transition to employment, supported accommodation and parental self-care. Some parents suggested the education sessions on issues related to their child's transition to adulthood were valuable, whilst others bemoaned the lack of focus on issues that addressed their needs as their children became young adults. Others wanted more sessions relevant to young children. What parents most valued was education sessions that were responsive to their needs at the time.

Parents emphatically indicated that they didn't want to attend workshops or seminars for basic information that could be provided by other more accessible means such as newsletters, websites or through conversations at peer support groups.

Some SPSP Coordinators liaised with other services that provided parent education sessions. They indicated that for some parents, attending an education session was a 'soft entry' to the SPSP peer group as they moved into the peer support group with another parent they had met in the workshop. Some SPSPs had a referral pathway that 'fed' parents through weekly education sessions (e.g., Tuning into Kids, TRIPLE P, ASD sessions) into peer support groups. Sometimes the referral pathway worked the other way, whereby parents participating in the SPSP peer support group then accessed regular education sessions.

SPSP Coordinators indicated that education sessions provided them with a valuable opportunity to meet parents and talk with them about the other components of the SPSP. They were able to discuss the benefits of peer support groups and provide a 'warm referral' to a suitable group. This has been a successful strategy in some areas.

Coordinators reported that education sessions were largely provided by inviting a reputable guest speaker from the community to facilitate. They suggested that workshops and seminars were a good way for them to connect and interact with others in the community such as teachers and therapists if professionals were also attending. Events were face-to face, online or delivered as a hybrid model, although a hybrid approach was more complex for SPSP Coordinators and the guest speakers to manage and their perception was that it was less successful. There is some evidence that group education sessions for parents with a child with disabilities can be effective in addressing identified needs such as child behaviour (Sofronoff, Jahnel, & Sanders, 2011).

> *"Some parents do the online ADHD or autism program, then naturally move into the peer group. Or sometimes the other way around. It is a good way for families to get to know each other and choose what suits them."*

Parents talked about periodic SPSP education sessions as a valuable way to deepen their knowledge about a specific topic and gather information about services and support. They also talked about the significant impact of some parent education workshops provided by other services, or by the same organisation that auspices the SPSP. Research has found that some parenting programs for children with disabilities enhance functional skill development in the areas of communication, play and daily living skills. Parenting programs have also been shown to reduce behaviours of concern, increase community participation and enhance mental health and wellbeing in children and their parents (Hohlfeld, Harty, & Engel, 2018; Mazzucchelli et al., 2023).

There are several evidence-based parent education programs that are available in Victoria, including:
- TRIPLE P Stepping Stones
- Tuning into Kids

There are also some parent programs in Victoria with emerging evidence such as:
- Now and Next
- Envisage
- WeCare

3. Individual support

What we have learned about individual support is best described in four interconnected areas:

a) Fluctuating needs
b) Responding to emotions
c) Information and resource needs
d) Parent to parent support

a. Fluctuating needs

Some SPSP Coordinators indicated that whilst individual support is a critical component of their role, it has for many of them become an aspect of their work that has decreased over the past 12-18 months. Many reported that individual support was their primary focus during the peak period of the COVID pandemic when families were managing the worry and stress of lockdowns, schooling at home, and experiencing heightened anxiety. The requests for individual support decreased over time for many Coordinators. Many peer support groups resumed face-to-face contact and daily life returned to a more predictable routine for families.

Several SPSP Coordinators indicated that that period helped them to rethink how they managed their workload and the amount of time allocated to each area of their work. For some, that meant developing an approach to individual support that now includes efficient referral to more appropriate organisations and peak bodies such as ACD, AMAZE, or Carers Gateway. However, Coordinators continue to respond to periodic or intermittent requests for support with a focus on information and emotional support. It's important to note that this was not the case for all Coordinators, with at least one reporting an increase in individual support in recent times.

> *"My needs have changed over time. First, I needed emotional support, I needed hope. Now I need information, like about a new school. Now, I can share my story and help young mums with information and friendship. It's not just one-way".*

b. Responding to emotions

All the parents that were interviewed and had utilised individual support, also participated in a peer group, so had a relationship with the SPSP Coordinator. Because of that relationship they reported feeling very comfortable making periodic contact by phone or email.

They appreciated the support provided when they were "in crisis and not knowing where to go or what to do" and the referral to other services when appropriate. One parent referred to it as "just in time" support and that seemed to represent the thoughts of other parents.

"When parents call, they often just need someone to really listen and validate their feelings".

Coordinators reported that sporadic individual support was provided to families they knew, but phone calls and email support requests also came from parents that were new to them and that required "finessed' skills in responding to them appropriately because of the "urgency" of their support needs and strong emotions they were experiencing.

c. Information and resource needs

Parents talked about the value they placed on having reliable, current information on issues, but they often had difficulty sourcing it. This is supported by the literature that suggests that parents of children with disabilities report significant barriers to their information needs (Guralnick, 2019; Hussain, & Tait, 2015). Research has found that parents require information about their child's disability, available services, general child development and parenting, and strategies to use with their child (Jung, 2010).

"The hospital gave us a bunch of information. Where should I start? I need a year to understand. My mind blow up because I had to translate to understand and tell my parents. It was too much. We are not familiar with the system in Australia to know where to go."

Parents reported that they found the information provided to them by SPSP Coordinators when they phoned or emailed extremely helpful. Many parents also indicated that they valued information shared amongst themselves when they attended a peer support group. This is supported by the literature that suggests that parents prefer a broad range of informational supports (Santelli et al., 1996). Therefore, service providers need a multi-pronged approach to providing information.

It's important to note that many parents also valued the information provided in newsletters produced by some SPSP Coordinators and indicated that the newsletter was a primary source of information for them. In some instances, in areas where the SPSP newsletter was no longer being published, parents commented on the hole it had left. Coordinators who were continuing to produce a newsletter were aware of the value it held in the community but indicated that it was time consuming to produce and suggested it could be streamlined if the statewide material was produced centrally and local information added. Most saw that the value of producing the newsletter outweighed the effort required.

d. Parent to Parent support

Although it is not a component of the SPSP, one form that individual support has taken for several SPSP Coordinators is to carefully match parents in a novice and mentor arrangement. That is, a ‘novice’ parent seeking information and social connection is connected with an experienced ‘mentor’ family.

Several SPSP Coordinators have undertaken this parent-to-parent approach when a family member has contacted them for individual peer support. Whilst their approach differs slightly, in each instance the SPSP Coordinator has developed clear parameters and support around the matching arrangements. For example, the Coordinator attended the first meeting (online or face-to-face) with both parents and facilitated the initial discussion. Subsequent meetings are followed up with a phone call to both novice and mentor to check that everyone is comfortable with progress and to provide any information or support. The contact between families was short term (two to three contacts) and they had an agreed focus for each discussion. One parent who was matched with another family from the same cultural background indicated that this was a really significant support for her at a time when she was feeling very isolated.

There are specific programs such as this in some other Australian states (Kiind) , and internationally (P2P USA, & P2P NZ). They are often referred to as Parent-to-Parent, or P2P and they have typically formalised the novice/mentor role with a structured approach to induction and ongoing supports. The P2P USA program has 40 statewide alliances with a mission “to support a national network of Parent to Parent programs to ensure access to quality emotional support for families of individuals with disabilities and/or special health care needs”.

“It really helped to talk with another mum when he was little. I didn’t know anyone else with a baby like him. She helped me feel good about the future instead of worrying.”

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