

Side By Side – Complementing and sustaining the benefits of professional positive behaviour support interventions by building connection

A strengths-based peer support program building resilience amongst families supporting a person with a disability who has behaviour that can sometimes be challenging

An Initiative of the Positive Behaviour Support Guiding Committee

Pilot Program – April 2012 – October 2013

1. Introduction

The Side by Side peer support program is a pilot initiative specifically targeted at families who are supporting a family member with behaviour that can at times be seen as challenging. It is supported by the Disability Services Commission through the Positive Behaviour Support Guiding Committee. The Committee was formed to oversee the implementation of recommendations from the ***Towards Responsive Services For All*** report on the capacity of WA's disability sector to support people with 'challenging behaviours'.

As members of the Committee, Developmental Disability WA had consistently identified the need for family support strategies that would increase the capacity of families to support their family member, as well as the important role of families and carers in supporting the implementation of change in the disability sector. This was also supported by the operational planning of the Committee which identified family support as a strategy for the implementation of the Positive Behaviour Support framework.

The Committee's identification of family support as a priority reflected its deep understanding of the impact on family life of what is often referred to as challenging behaviour. Families who are supporting family members who have behaviour that can sometimes be challenging are widely acknowledged to be some of the most isolated family carers of people with disabilities. The nature of challenging behaviour means that families often find it harder to access respite services and education because services and schools are unable to manage those behaviours. This means that families supporting people with challenging behaviours find it difficult to have respite from their caring roles, and to be able to pursue paid employment. These families also tend to find it more difficult to participate in family and community life because of the difficulties of managing challenging behaviour in public spaces and sometimes the fear of people's reactions. These families often find it difficult to maintain friendships and social connections because they feel that others simply do not understand.

Family carers of people with disabilities who have behaviour that can be challenging also experience very high levels of stress. Many families struggle to understand their family member's behaviours, what it means and how best to support them to avoid those behaviours and improve their communication with others. Without good support to understand their family member's behaviours, families sometimes use behaviour management strategies that originate in early childhood but which become less effective over time. Sometimes the behaviours can result in physical injury to families and sleep deprivation, and they can have significant impacts on family dynamics.

The impacts of isolation and stress on families of supporting someone with behaviour that can be challenging can have a significant impact on the capacity of families to advocate for their son or daughter. They can also have implications for the ability of families to continue to care for their family member at home, potentially resulting in poorly planned and managed decisions and transitions that can have a devastating effect on the person with a disability and their family.

DDC formed a small working group and developed an Expression of Interest for a peer mentoring project which was aimed at building the resilience of families supporting a person with a disability exhibiting challenging behaviours, and in July 2012 was successful in securing a twelve-month grant of \$150,000 from the Disability Services Commission (DSC).

2. Peer-Support Approaches to Reducing Isolation and Building Resilience Amongst Family Carers Supporting a Family Member with “Challenging Behaviour”

In response to the effect of isolation and stress on this group of families, DDC was interested in how these approaches might benefit this group specifically and increase their resilience in managing the impacts of challenging behaviour. Peer mentoring and family leadership approaches have a long history in supporting the families of people with disabilities, and DDC believed that families who are experiencing particularly high levels of isolation could experience significant benefit from such an approach.

The first stage of the project was to review existing models of family mentoring and leadership and their effectiveness for this group. A project steering committee was appointed to oversee the project development and DDC employed a project coordinator to undertake the work. In addition to the steering committee a network of mentors with specific expertise and experience in positive behaviour support, family mentoring and support, and project development and management was formed to support the project coordinator.

An extensive review of family mentoring, leadership and support models was conducted. This included a desk-top literature review of published evidence as well as conversations with local, national and international networks with successful expertise in this work. The review found that while there are many successful examples of family support models, there was no evidence of such models targeting families caring for a person with 'challenging behaviours' or including specific strategies to connect with such families.

The review identified and described four key models of family peer mentoring and support and considered them in the context of working with this population of families. Jaquie Mills of Vela Microboards Australia, and chair of the Positive Behaviour Support Guiding Committee, provided guidance and input through this review as a family member with significant expertise and experience in family leadership and peer support.

Model One - Skills Development

A skills development approach provides families with the opportunity to come together to learn new skills. The environment needs to be welcoming, intimate and provide a safe and secure setting for people to feel comfortable. The aim of the workshops is to develop networks and connections through a shared learning experience. Particular care is required to build trust amongst the participants so that they can feel able to share their experiences. Regular skills development opportunities would be provided over a period of time and could cover topics such as self-advocacy and communication skills, positive behaviour support strategies, community connecting and person centred thinking. The aim of the workshops is to consolidate through a shared learning experience.

This model reflects a preventative approach, and would probably best suit families who are not experiencing crisis. It was felt that it would likely be particularly useful to parents of school age children in order to build strategies to prevent challenging behaviours escalating.

Model Two: Social Media

Peer support models utilising social media provide an opportunity for people to come together for mutual support and sharing of information no matter what time of the day or night it is or where they live.

This would be a model that would likely appeal to people who are especially isolated either through family circumstances and/or their locality, particularly important in a Western Australian context in supporting families who are living outside of the metropolitan area. Particular conversation topics could be facilitated as well as families having the opportunity to drive the topics depending on what it is they want to get out of it.

Model Three: 1:1 Family Mentoring – ‘I got your back’

This is based on the typical model of mentoring, and is the format used by the Alberta Association for Community Living (AACL), an international leader in family mentoring and leadership development. This type of mentoring was considered most relevant to support families who are struggling, are in crisis and have lost hope. This approach requires mentors to have access to training and support, to have clear roles and responsibilities in their mentor role, and be able to provide or link the family to practical strategies. The role of the mentor includes providing moral and emotional support. They need to be able to carry hope for the family at a time that the family isn't able to. The project would require resources to provide mentors with the appropriate training. We considered the question of whether the mentors would be remunerated for their work. There needs to be an on-going commitment to the mentees. A great deal of thought needs to go into the matching process (location, ability to commit for a period of time, what form of contact will be required e.g. Email, face to face, phone etc) and how far the responsibility of the mentor goes.

Model Four: Social Interactions

This model uses informal gatherings of people over a shared common interest e.g. book club, movie club. It is most effective when targeted at people who live in the same local community where there is a possibility of mutual friendships and support forming and developing.

It was agreed by the project steering committee and the DSC that a model that combines skills development and 1:1 family mentoring would be the best approach in this context. It is a clear intention of this project to intervene with families who are experiencing isolation and for whom there are many real barriers to participation. A traditional 1:1 family mentoring approach is able to be targeted to those families in need of support, and is also flexible in terms of the method of delivery and the timing of delivery. This is particularly important given the significant demands on time that these families face and the often very unpredictable nature of family life. The incorporation of a skills development component to the model was seen as useful in educating families about 'challenging behaviours' as a form of communication and providing families with some of the practical tools that might be of assistance in responding to 'challenging behaviours' and that could complement some of the clinical and sector developments being supported through the work of the Positive Behaviour Support Guiding Committee.

The choice of a model for the project also involved an important conversation about language and finding the right language to describe the intent of the relationships between the families in this project. In particular, there were concerns about the term 'mentoring' and its implication of one party having superior knowledge and experience that they are imparting to another. Drawing on the experiences of a family peer support project in South Australia, Family by Family, the project steering

committee agree to proceed with a working terminology of “sharing” and “seeking” families as a way of acknowledging that families are wishing to learn from each other but without implying a difference in power, knowledge, value and expertise which people felt the other terminology did.

3. Side-by-Side - Co-producing a strengths-based peer support program building resilience amongst families supporting a person with a disability who has behaviour that can sometimes be challenging

As an initiative of the Positive Behaviour Support Guiding Committee, the project had a very specific target – family carers who are supporting a family member with a disability who has behaviour that can sometimes be challenging, or a person with “challenging behaviours”. Consistent with the positive behaviour support framework, the project drew directly on Emerson’s definition of challenging behaviours.

As described, the immediate aim of the project was to test the effectiveness of family leadership peer support approaches in overcoming the particular isolation, stress and loss of hope often experienced by family carers supporting people with disabilities who have “challenging behaviours”. DDC believed that these families had a particularly strong capacity to benefit from these types of approaches due to the impacts of “challenging behaviour”, and that it was possible that a targeted approach was important for this group.

DDC also believed that the particular isolation, stress and loss of hope experienced by these families had flow on impacts for formal support services and systems, and that responses that addressed these issues for families would have flow on benefits including:

- Better planned decisions and better managed transitions;
- Reduced exclusion from social and community life and services;
- More effective interactions with professional support services;
- Improved policy development and service provision in both mainstream and specialist services for people whose behaviour might sometimes be seen as challenging;
- Quality feedback on service delivery and outcomes about how well our specialist support services are responding to people with behaviour which can sometimes be challenging, what the service gaps are and what might be a relevant framework for evaluating service delivery and outcomes in this area; and
- Better access for family carers to information with which to critically evaluate services thereby giving them greater choice and control over their service provision.

This initial review identified the broad range family leadership and support approaches, evaluated their applicability to this group of families and recommended a model that combined a family-to-family 'mentoring' approach with a skills development component that would assist families to develop practical skills in responding to their child's "challenging behaviour".

Once a broad approach had been defined, DDC wanted to ensure that families themselves shaped the way in which the project worked so that it would be successful for them. This co-production approach is widely recognised as being fundamentally important to the legitimacy of family leadership and peer support approaches. This of course required that DDC connect with a number of families who both had a child with "challenging behaviours", who had a positive approach and mindset to supporting their son or daughter, and who would be willing to be part of such an initiative.

From the outset of the project, there was a particular awareness that families who are supporting someone with challenging behaviour can be very vulnerable and isolated, and that they are very often time poor. The project reference group felt that in order to minimise the risks that families might be disappointed and might disengage, it was agreed that we should not target potential "seeking" families until the project was established and there was a network of support for them to tap into. So the initial focus was on recruiting potential "sharing" families and engaging them in a co-production process to more clearly define the project model.

Accordingly, and with the input of the project reference group, the project team used a targeted communication approach to identify potential "sharing" families, tapping into existing relationships and networks. Networks that were used included Local Area Coordinators, the Positive Behaviour Teams, service providers, schools and families that members of the project team and the reference group were aware of. Through these relationships and networks we extended a broad invitation to be part of a conversation about families' experience of challenging behaviour and the relevance of connecting with other families.

This approach was not as effective as quickly as we had expected it to be. Issues included misunderstandings of the target group for the project, and some unexpected hesitation around extending the invitation to families. The latter was found to be attributed to concerns by professionals that expectations on "sharing" families would be too high. It should be noted that concerns around expectations had been specifically identified by the project team from the outset and that we had gone to great lengths to be clear with project partners that this invitation was very broad, that it would not commit families to anything, and that families would define the boundaries for their roles.

After some weeks, it became clear that this targeted approach was not effective, and the project team embarked on a broader communication strategy. A flyer was prepared and distributed through a much wider network: all DDC members and stakeholders, all Local Area Coordinators, more service providers, and other parent and support groups. The focus on this approach was to maximise our direct contact with families so that they themselves could decide whether or not they were interested. The previous targeted approach had relied on professionals to identify families that they felt would be suited and/or interested.

In response to this broader communication, 21 families contacted the project coordinator and indicated their interest in being part of a conversation about the project. Nearly all of the families who volunteered to be “sharing” families had a child with autism or Angelman's syndrome. The ages of their children ranged from 5 through to 25 years. They came from right across the metropolitan area. The families were a very diverse group in terms of their backgrounds and the age of their children, but they shared a mind-set about understanding their child. They all spoke very positively about their sons and daughters, despite the challenges they'd faced with regard to behaviours, and a sense of a personal journey of change in their own lives. All of the families indicated that they believed such a project would have benefit. Families were also very aware of the potential value of their experiences, information and skills and expressed a desire to share that with others.

Once an initial network of “sharing” families had been identified, the project coordinator engaged a small number of families in a co-production process to design the support model with a focus on the role of the sharing families. DDC worked collaboratively with Vela Micro Boards Australia. DDC and VMA co-facilitated four workshops between May and August 2012 with 9 families' involvement. The outcomes included the group coming to a shared understanding of its purpose, guiding principles, review of current models of Mentoring practice, drafted an introduction to family letter. Out of these workshops and through working through exercises, a first draft model (attached) evolved that included safeguards for mentors and mentees. Part of the process was for the sharing families to recall what good support had felt like and looked like for them in their journey. This included their reflections on what bad support had been like for them as parents.

The next focus was to identify specific training that would assist the sharing families in their role and what type of support they may require. DDC connected to CLAN WA to develop a tailored strengths-based approach training model which included a ‘train the trainer’ component (this supports the sustainability of the program and we had 3 families and the project coordinator participate as potential trainers). The training was offered to Mentors with the Angelman Syndrome Association of WA. This not only strengthened the existing Side by Side families but also provided an opportunity to partner, learn and share with another family led peer support program. The Side by Side families also attended a Communication & Supporting Skills workshop. Each

sharing family received support not only from the larger group but also regular, formal supervision with the project coordinator.

The project deliberately took a developmental approach so that it could respond to and change accordingly to the particular needs of families as they emerged. Many families who were involved had not been a part of a project such as this before.

Once the draft model was ready, the focus shifted to engaging seeking families. The project was advertised using the previous strategy – through existing networks, service providers, LAC's, PBT and schools. This time it was taken one step further and included attending team meetings of LAC's, PBT and Therapy teams. The Side by Side families were very proactive in spreading the word directly to families they were in contact with through other support groups, forums they attended and workshops. The project coordinator also connected with Positive Partnerships and were able to use their follow up forums to promote the project and share our stories. We always had a sharing family present with the project coordinator when attending these events/meetings. It was a true partnership between families and Developmental Disability WA. It was very apparent that this was a program designed by families for families with the necessary support of an organisation.

We began the matching process. We aimed to where ever possible match sharing and seeking families by location and age of their son or daughter. Ideally we wanted to be able to match two sharing families with one seeking family to act as a safeguard. We recognised that all families continue to deal with day to day life of supporting a son or daughter whose behaviour can be challenging and families continue to experience times when they were less available to provide support and in fact may need support themselves.

As families began their work, it became apparent that the program required formal documentation to record information, track progress such as outcomes achieved and to keep track of their hours of support. The aim was still to try to keep the program as flexible and as informal as possible. Families and the coordinator also discussed the idea of a self-assessment tool to track changes in behaviour, moods, confidence, relationships, and feelings of isolation.

From the outset, there was a commitment to recognising the value of the expertise, experience, contribution and time of the sharing families in this project. To do this, the decision was made to reimburse families for their time, petrol and phone calls. This kind of approach was also used in the Family by Family peer support project in South Australia which DDC identified during the early stages of reviewing family peer support models. This approach enabled families' costs of contribution to be recognised in some financial way without paying an income.

4. Evaluation Methods –Action Based Research, Reflection, and Story Mapping

The aim of the Side-by-Side project is to build the resilience, confidence and hopefulness of family carers that are supporting people with disabilities who have “challenging behaviours”. It is a small project, working directly with a discreet number of families who have regular contact with the project coordinator, who has also invested significant time building connections and relationships with a range of professionals who also work with the target families particularly Local Area Coordinators, Positive Behaviour Support teams.

Given the small scale of the project, there was limited scope or budget for a sophisticated evaluation approach. From the outset, the project hoped to use an action research approach to reflect the specific intention of the project to engage the participants in its design and implementation. While this wasn’t used as a strict methodology, it provided scope to draw on a range of qualitative methods such as the participant’s reflections, mapping of the personal stories of participant’s through the project, collecting qualitative feedback from stakeholders and adapting the approach in response as we went. The project also used pre and post surveys to try and give some form of quantitative measure to the impact of the project.

The evaluation framework identified a range of evaluation questions for the project:

- What impact has a peer-support approach had for the families who participated in the project?
- Are families of kids with ‘challenging behaviours’ different to other families of children with disabilities?
- What does it take to work with this particular target group?
- What has been most effective about the project in responding to the target group?
- What have been the barriers to the model?
- Do we think that there is an ongoing role for a peer-support approach targeted at families of children with ‘challenging behaviour’?
- What would it take to sustain such a project over time?

Given the developmental nature of the project and the stated desire of the families not to make it too formal or structured, it proved difficult to provide a structured process for gathering information. This was also DDC’s first attempt at building a family peer network, and so it was also a developmental exercise for the organisation. Now that a working model has evolved and DDC is familiar in working with this model we believe that there is scope to utilise a more comprehensive and structured approach that could collect good quality information throughout the process.

Pre & Post Surveys

In order to try and provide some form of quantitative measure of the impact of the project for families, the original intention was to complete pre and post surveys of families.

In the early stages of the project, the intention was to gather self-assessments from families as they entered the project, with a similar self-assessment being completed at the end of the project. It proved a challenge to get families to undertake the initial self-assessment, and this was a specific topic that was addressed as part of a project reflection exercise with families in March 2013. During this exercise, the project considered two potential self-assessment tools – one a questionnaire asking families to rate themselves on measures of stress, hopefulness, anxiety and social connections; and the other a 'Wheel of Life' covering multiple domains. Families were reluctant to use measures that pre-defined their outcomes, and there was a strong view from families that they wanted the assessment to be as individualised as possible. Families were comfortable with the framework of life domains, but they wanted to select the domains that were most relevant to them. Some families have retrospectively completed the self-assessment of where they felt they were at the beginning of the project.

Five out of 13 families have completed a self-assessment. While the self-assessment captures some sense of where the families felt at the outset of the projects, we are not confident in its value as an evidence base in assessing the specific impact of the project as many factors in a family's life could be contributing to how they feel at a particular point in time. A more direct and specific way of exploring how the project is impacting on people would appear to be necessary.

One very clear message from families was that they did not want participation in the project to involve paperwork, and so we recommend using other techniques that work for individual families to gather information.

Group Reflection Day

On 5th March 2013 Vela Microboards Australia facilitated a reflection day for families who had participated in the project as either sharing or seeking families. The purpose of the reflection day was to provide participants with the opportunity to reflect on their involvement in the project to date, to share its strengths and identify areas of improvement, and to identify ideas for further development. Six families were part of the reflection day. More families hoped to be part of the day, but were unable to participate due to challenges which arose for them on the day. This is not uncommon for families in this target group. The draft findings of the day were shared with those families who were then able to respond as to whether these were representative of their own experiences.

A more detailed report on the findings of the reflection day is attached, but an overview of the key themes is provided here.

What works?

During the reflection process, families were asked to document aspects which are working for them and to provide detailed information about a theme that was particularly strong for them.

Six main themes emerged from the reflection:

- Fostering hope through connection with others who have had similar experiences;
- Validation of me and my decisions;
- Strength based approach;
- The unique role of the project co-ordinator;
- Building relationship and connection; and
- Flexibility.

What could be better?

Families were asked to document aspects which were not working well or which could be improved. They were again asked to provide detailed information about a theme that was especially significant to them.

- Engaging the disability system in the project (this referred to challenges in getting professionals to engage with the project and to refer families to it);
- Describing the mentoring role (this referred to discomfort with the language of “mentoring”);
- Who is the program for? (this referred to families who were grappling with behaviour challenges that didn’t fit the definition of challenging behaviour used for the project);
- Getting in early before the damage is done;
- I hate paperwork!;
- Getting to know each other’s families and children;
- Finding more ways to connect with each other;
- Making sure the boundaries are clear; and
- Opportunities to practice what we have learned (this referred to practicing and coaching in the use of the strengths based approach).

How do we measure our work?

The project tested a self-assessment tool with “sharing” and “seeking” families which focussed on levels of stress and anxiety and signifiers of depression to measure the impact of the project. The conclusion of an extensive reflective discussion was that families decided that they wanted to describe a range of life areas from which

“seeking” families could select the areas in which they wanted to make change. Goals within these life areas could be developed and the impact of the project in supporting “seeking” families to achieve them could be measured.

It was also important to the families that these goals and desired outcomes be able to be expressed in a range of formats so that families could choose a format that best suited them.

The areas that were identified by the families were:

- Family;
- Relationships;
- Career;
- Friends and Social;
- Emotion and Spirituality;
- Finances;
- Personal Growth;
- Health;
- Community Contribution; and
- Fitness.

A range of other indicators that could be measured were also identified by the families during this reflection:

- How would you rate your ability to be resilient/bounce back?
- How hopeful do you feel about your future?
- How satisfied are you with your achievements?
- How often are you able to take time out for yourself or to exercise?
- Questions about diet and sleep.
- How would you rate your levels of self-confidence?
- How confident are you in your relationship with professionals and services?
- How would you describe your relationship with your son/daughter?
- What differences in your son/daughter would you like to see in the future?

Where to from here?

The reflection day explored a number of other issues about the future development of the project including: finding an appropriate language for the project, promoting the project, and maintaining and supporting the connections.

As discussed earlier in this report, there was significant discomfort amongst families with the language of mentoring. Families wanted a language for the project that was more equitable, and they also wanted a name for the project which reflected this and which also made it easy for them to talk to others about the project. The overarching theme that families identified for the relationship between “seeking” and “sharing” families was one of partnership, and so it was important to the participants that this

be reflected in the roles. A number of possible names for the project were identified, the most popular of which was “Side by Side”, and so this has become the working title for the project.

Mapping Family Stories and the Project Journey

The most effective way to explore the impacts of the project has been to map the individual family stories of both sharing and seeking families, and also the story of the development of the project.

Here, the Project Coordinator and families used a mind-mapping approach to journal the stories of both seeking and sharing families from their introduction to the project and what was happening in their life at the time, their experiences throughout the project, and their current state at the time of the evaluation. These maps were then analysed for themes, and commonalities and contrasts between the stories were identified.

A similar approach was used to journey the story of the development of the project itself, and again a number of themes were identified. This included gathering some feedback from professionals who have been in contact with the project.

The themes were then mapped against the evaluation questions, and the results are described in the next section.

5. Results

The themes that emerged from the analysis of the various evaluation sources were mapped against key evaluation questions for the project:

- What impact has a peer-support approach had for the families who participated in the project?
- Are families of people with ‘challenging behaviours’ different to other families of children with disabilities?
- What does it take to work with this particular target group?
- What has been most effective about the project in responding to the target group?
- Have there been any barriers to the development or implementation of the model?
- Do we think that there is an ongoing role for a peer-support approach targeted at families of children with ‘challenging behaviour’?
- What would it take to sustain such a project over time?

5.1 Impact of peer-support for families

The benefits of the project for individual families have been different for each family member who has participated in the project reflecting where families are at on their engagement with the project and what their key priorities were. For some families there have been very specific and practical outcomes of the project and for others the development of skills and confidence have been the key outcomes. For all of the families who have participated, the development of new connections and a sense of hopefulness has been a consistent theme. Furthermore, the benefits have been shared across seeking and sharing families alike, and it is clear that for 'sharing' families this experience has also had a positive impact.

While growth in skills and confidence have been a general benefit of the project, it is clear that for some families this has been a particularly significant increase. This appears to be particularly pertinent for those families whose participation has created meaningful and supportive friendships that are now being sustained independently. For two mothers who participated in the project as sharing families, the growth in confidence and the opportunity to develop new connections and to engage in the disability and education sectors has resulted in paid employment opportunities where their skills and experiences as parents and their previous employment skills are being utilised.

For some families, participation to the project led to the establishment of structures and strategies to support a family who was already actively supporting other families. Through their LAC, one Side by Side sharing family had been connected with some other families in their area to provide support. However structures and supports had not been put in place to support them in this role and to support the other families to develop their resilience. The Side by Side project was able to assist this family to clarify their relationship with other families in a way that set boundaries and required the families they were supporting to put strategies in place rather than rely on that support. This experience confirmed for the project that it is critical to have clear boundaries and expectations of the relationships between families in a support context, and to actively nurture 'sharing' families. It also raised the question of how many families are playing a 'sharing' role in the community at the encouragement of professionals without the right supports.

Another key practical outcome for several families has been a focus on goal setting, and the development of strategies and supports to pursue those goals. For one family the decision and support to apply for Family Living Initiative support emerged as an outcome. The application for assistance was successful and has had a significant practical impact for this family. Before their participation in the project, the family had not been aware of the opportunities to access this kind of support – without which their family situation might have deteriorated into crisis. In another example, a sharing family's professional experience as a speech therapist was able to be shared with a seeking family to directly assist them in developing schedules to assist with their child's therapy. It was through the establishment of trusting and positive relationships amongst families that 'seeking'

families felt able to identify practical goals to assist them in supporting their family members and to draw on the experiences and expertise of 'sharing' families and their support to actively implement strategies and supports towards this end.

5.2 Engaging specifically with families supporting a family member with behaviour that can be seen as challenging

The Side by Side project explicitly sought to test a family peer-support model targeted to families supporting a family member with behaviour that can be seen as challenging on the basis that the experience of these families is different to other families living with disability. This was based on the assumption that because of the very nature of 'challenging behaviour' it has particular impacts on families. These assumptions are outlined earlier in the report but key themes include increased risk of social isolation, feelings of shame that can be associated with 'challenging behaviour', and particular impacts on family dynamics. Communication and negotiation skills within these families are often undermined by stress and families often face additional financial pressure particularly where families are limited to one income. These exacerbated stressors on families can often amplify the impact of further events such as relationship breakdown and health issues. These factors were certainly present in the lives of the families who participated in the project, and feedback consistently reinforced that a targeted project created a safe space where families knew that other families would understand their experiences.

The Side by Side project confirms the benefit of targeting these families, and this then leads us to examine what it takes to work successfully with these families.

For families to be supported in this kind of personal development work either as 'seeking' or 'sharing' families it is clear that there need to be trusting relationships in place that families know will be there when they are ready and when they need them and that offer consistency, confidence and stability. This is a key rationale for the value of the coordinator role – a person who can be consistent and stable and a sustained contact point no matter what is happening in the lives of families. Families' patterns of engagement with the project were not necessarily consistent according to what was happening in their lives, but the knowledge that the coordinator would be there provided confidence and stability and a consistent presence. The fact that the coordinator was able to take the lead role in knowing each of the sharing and seeking families, and to take responsibility for keeping the momentum of the project going and following up on things was critical to the success of the project. The coordinator also played a critical role in maintaining relationships between the project and each individual family despite what else might be happening – particularly where a 'sharing' or 'seeking' family had been referred to the project but a match was not yet available. This meant that families who were referred to the project but were not able to participate immediately either because of their circumstances or because a match wasn't available didn't lose the opportunity. In this regard the project found that timing of engagement was very important – that it

was critical to engage with families as soon as possible after an initial contact to build momentum and engagement at the point where there is a sense of urgency because that is often a critical opportunity for personal change. Sometimes, families will reach out in a moment of crisis but disengage when that immediate crisis is over. By keeping connected to those families it was possible for the coordinator to re-engage with those families when they were interested in further involvement.

Flexibility and being able to respond to families' needs in terms of time availability and methods of communication is also critical. Communication with families would sometimes be intermittent according to the demands on families. For some families additional pressures such as health issues both increased the need for connection and support while also making it harder to keep in contact so using whatever form of communication and engagement works for a particular family at any point in time is critical. Some families preferred to engage face to face while for others e-mail proved a more effective communication tool. This applies equally to seeking and sharing families. In this regard, it emerged in the project that there is value in having more than one 'sharing' family for seeking families if possible to compensate for the fact that sharing families might not always be available when needed due to their own commitments. This was not practical across the project due to the limited number of 'sharing' families, but it did occur in some particular geographic locations with positive effect. In other examples developments in the lives of 'sharing' families, such as health issues and new paid employment opportunities, meant that their ability to support their 'seeking' families became challenging and it was not possible within the constraints of the project to engage new 'sharing' families to fill that gap.

Striking a successful balance between establishing a level of commitment from families to participate without putting too much pressure on them was also important. Given the intention of the project to build resilience and hopefulness and to support positive change in the lives of families through peer-support, there was a sense from families that a willingness to develop and explore positive change was an important ingredient. With this in mind, from the outset the project was very intentional about taking a strengths based approach. This is reflected in the emergence of hopefulness and goal setting as key outcomes. In this context, both seeking and sharing families had to come to the project with some level of commitment to engage but it was clear that there should not be pressure put on families to engage at a pace that they were not comfortable with. This can be particularly challenging for families who want to be connected but who are in the midst of a crisis or experiencing highly complex issues.

In these situations it is clear that a highly intentional focus is needed to overcome these challenges and keep families engaged. This leads to reflections on at what stage in a family's development journey peer-support might be most pertinent. While the benefits of peer support might be useful in helping to maintain the benefits of clinical interventions such as Positive Behaviour Support Teams, the experience of some of the Side by Side families would suggest that in fact this intervention would

be relevant as a preparation for that intervention. Some of the Side by Side families who had participated in Positive Behaviour Support reflected on their dependence on the Teams as a key connection and relationship, so perhaps building good connections before clinical intervention would be more effective in not only preparing families for what is expected of them during that intervention but also in establishing other connections to mitigate against dependence on professionals who will ultimately not be sustained.

Relationships are at the heart of this work, both at the individual family level as well as with professionals and services, and from a project development point of view it must be acknowledged that building those relationships takes time. This is especially so when we understand that people are juggling other demands and expectations both as families and as professionals. In this particular instance, just building relationships with professionals that would encourage them to connect families with the project took time and that hadn't been factored into the time originally allocated to the grant. As has been discussed earlier, nature of families' availability also means that working to strict time-frames is difficult. From a contracting point of view, flexibility in managing timeframes was important to this project. The connection of the project to the Positive Behaviour Support Implementation Guiding Committee provided regular opportunities to report to the Commission updated on the progress of the committee, but is it worth noting that this same level of engagement wasn't present with the contract managers who weren't as cognisant of the progress of the project.

5.3 What are the potential barriers to this work

Getting the word out

A key barrier in the early stages of the project was simply getting in contact with families. As indicated earlier in the report, the group overseeing the development of the project felt that it was important to identify a network of 'sharing' families before connecting with potential 'seeking' families. It was agreed that this was important to minimise the risk that 'seeking' families who identified a need for support would be disappointed or let down by there being no-one to connect them with. Accordingly, the project coordinator invested a significant amount of time in building relationships with Positive Behaviour Support Teams, Local Area Coordinators and service provider organisations to identify families who they thought might be in a position to contribute. This approach did not prove successful however, and it was not until a broader communication approach was utilised that families began to engage with the project.

It is also worth acknowledging that many of these professionals probably had not had a working relationship with DDC previously, and certainly were not likely to have seen DDC working with families in this kind of way. Accordingly, it is possible that

the organisation and project needed to establish a track record and credibility, and that professionals wanted to see the project working before they were confident to connect families with it.

Whatever the reason, it is certainly true that as the profile of the project grew that the number of referrals increased, and indeed new families have made contact with the project even after it has ceased.

This experience highlighted some of the barriers that organisations like DDC face in connecting directly with families as non-direct service provision agencies. Organisations such as DDC rely in part on others such as LAC's, service providers, schools and other professionals to pass on information to families that enables them to connect with specific projects such as Side by Side or to organisations more generally. DDC recognises that there are many factors that contribute to this. LAC's and other key professionals in families lives in particular are a main conduit of information to families and so are naturally receiving a significant amount of information from across the sector and community and are then having to decide how to most effectively target that information to families. There might be many factors that determine how a professional targets that information, and it is important to acknowledge that this can include their own perception of families' circumstance or on their relationship with families. In relation to Side by Side specifically, this might include for example a professionals perception of a family's willingness to make changes or be involved in self-development. Furthermore, it is possible that some professionals lack the confidence and skills in identifying when families need support and how to have the kind of conversations with families that will elicit those issues. For example, one LAC spoke of identifying a family who they thought could benefit from the initiative but not feeling confident about presenting the idea to them for fear of offending them by suggesting that they might need support.

Understanding Challenging Behaviours

Another barrier that was faced early in the project was inconsistent understandings and interpretations of what challenging behaviour is. This occurred both amongst professionals and also some families who were seeking support. The project specifically drew on Eric Emerson's definition of challenging behaviour, and on challenging behaviour that results from a developmental impairment.

Some early referrals were for people who were seen to face particular challenges, but who were certainly not facing behavioural challenges. The project was also contacted by a number of families whose children experienced some behavioural issues associated with their impairment but which certainly did not meet the threshold of Emerson's definition. This indicates that perhaps families' understanding of challenging is relative to their own experience of it rather than any particular definition of challenging behaviour. This is consistent with feedback gathered through the *Is There a Better Way* training where people were invited to

develop their own definitions of challenging behaviour and then to compare these with Emerson's definition. From that it is clear that experience of behaviour as challenging differ between families and that different families will have different thresholds of challenging behaviour and that in part this is dependent on family capacity.

This represents a challenge when seeking to target an initiative such as Side by Side – how do we target the support to those families with the greatest need in terms of the impact of their family member's behaviour without leaving people who would benefit from informal supports stranded?

Practicalities of family engagement

There are some key practical matters that shape the engagement with families in this kind of work that are important to be aware of.

The first and foremost challenge of working in this space has been managing the expectations of a project against the realities of working with families. Families are busy juggling family commitments, and in order to keep the momentum going on a project like this it is clear that coordinator role is critical. The coordinator provided consistency, continuity, and ongoing engagement in a way that was respectful and responsive to the lives and needs of families. Without someone in that key role whose responsibility it is to keep the project going in a day-to-day way projects like Side by Side would not succeed. It is also important to recognise that because of the juggling in families' lives that this kind of work is not consistent with rigid timeframes and that it can take considerable leg work and lag time to build engagement and trust before progress can begin to be seen.

A second challenge was how to effectively support families that might not be geographically close to each other. While some particular local connections and networks emerged through the project, particularly in Mandurah, Side by Side did not operate in a targeted geographic location. This meant that families were spread across the metropolitan region, with expressions of interest also being received from regional locations. From the outset of the project design it was clear that in order for relationships between sharing and seeking families to be successful there was going to be a need to be some kind of way of connecting families who had things in common or developed a natural affinity rather than because they lived in the same geographic location. That said, it also emerged from the project that if there is too great a geographical distance that this can compromise engagement with distance a factor in some arrangements not being sustained. From a project management point of view it is important to recognise that working in this way has practical implications such as travel time for the coordinator. There is also the added challenge of how to engage with families who are living in regional Western Australia and how for example new technologies might be useful in supporting those families. From the point of view of scaling up an initiative like this though, it is useful to reflect on how to

bring a focus to the work that can allow it to be effectively scaled up. In other projects, this would tend to lead to a geographic focus but in this area some other kind of focus would be necessary. In light of the engagement of Side by Side with the Positive Behaviour Support teams, perhaps that might be a point of focus – either in connecting with families who have exited the program to assist them to maintain the benefits of the professional intervention or with people who might have been identified as potential participants in Positive Behaviour Support to help prepare them for the personal demands of that process.

Building on these points, it is also important to recognise that there will be limits to how many families can be supported at a time by one particular person. The Side by Side coordinator plays a critical role in identifying and engaging with potential sharing and seeking families, facilitating the matching of those families, and providing support to sharing families in their role. While individual families play the lead role in maintaining their ongoing connections, the coordinator continues to be a source of contact, support and development as required. The requirement for ongoing engagement and connection cannot be underestimated in this kind of work and it is important that there not be unrealistic expectations about how the coordinator works and how many families can be supported at a time. It is also important to acknowledge that there is not necessarily a consistent pattern to the work of the coordinator and that there can be peaks and troughs of activity according to what is happening in families' lives. This needs to be acknowledged in managing and supporting the role of the coordinator.

Finally, family demands and capacities in relation to data collection for this kind of work must also be factored in. Data collection methods that are not onerous and are not 'just more paperwork' must be utilised, and wherever possible data collection should add value to the experiences of families. Data collection methods should also reflect the principles of co-production on which the project was based. Qualitative mechanisms have proved particularly effective here, and mechanisms such as the reflective exercise facilitated during the course of the project not only gave feedback on the progress of the project but also contributed to the development of the initiative in a positive way.

5.4 What would it take to sustain it over time

The experience to date of the Side by Side project has confirmed that families who are supporting a family member with 'challenging behaviour' have significant capacity to benefit from a family peer-support approach, and that a targeted approach to working with these families that respects the particular impacts that 'challenging behaviour' can have on family life is necessary. It has also confirmed that peer-support has not only social and emotional impacts for families, but that it can also lead to practical and tangible outcomes that also have a positive impact in the lives of families. It is also clear from the feedback via professionals working with these families that the positive outcomes from family peer-support models play a

complementary role to the professional interventions for individuals and families in relation to 'challenging behaviour'. The shift towards a positive behaviour support model clearly relies on families being able to successfully sustain the benefits of clinical interventions, and that the capacity of families to do this is influenced by environmental factors. Good peer-support for families that successfully address these factors in a way that is meaningful for families is a sustainable way of providing that support.

The next step is to reflect on what it would take to make this approach sustainable and effective on an ongoing basis.

The most obvious aspect is time and recognition of the significant investment in relationship development that is required to conduct this work successfully. The profile of the project is certainly much higher now than in its early days, and it has a successful reputation that would make building relationships with professionals in referring families much easier. But it is important to recognise that working with families, particularly with those who face the additional challenges of supporting a family member with challenging behaviour, means that things progress at a different pace and that this needs to be acknowledged and respected.

In terms of building relationships with families, it would be recommended that a more structured way of engaging families and matching 'seeking' and 'sharing' families be utilised. As indicated earlier, a key focus of the project is to build resilience and hopefulness amongst families and it is recommended that in future we could be more intentional in our engagement with families in this regard. Building resilience is not simply about 'fixing' things. It requires some degree of commitment to change, and bringing an explicit awareness of personal change to process could be useful in understanding where families are at in relation to potential change. Talking about change is difficult and challenging, and the value of this project has been about demonstrating through peer-support that change is possible. And having the right skills to talk to families about change as part of the engagement process is critical. It is important that this process not become a way of excluding families, but of getting a clearer picture of where families are at in their journey so that the peer-support experience can be as positive as possible. This also requires that we continue to build explicitly on the strengths based approach, particularly in terms of more specifically identifying and building on the strengths of 'sharing' families.

Consistent with the focus on resilience and hopefulness, introducing clearer expectations and checking progress as a way of keeping the peer-support relationships in place would also be valuable, including expectations of levels of involvement from both 'seeking' and 'sharing' families. For example, 'sharing' and 'seeking' families often had different expectations of the experience. Some 'sharing' families expected higher levels of engagement with the families they were supporting, but for many 'seeking' families there was significant value in the knowledge that a truly understanding support was there when they need it. This also

indicates that perhaps there are skill sets amongst 'sharing' families that were not being fully utilised. In this regard, it is also recommended that an exit strategy be put in place not to end the relationships that form in the project but to signal an end to the structured involvement of the project. The purpose of the project should explicitly be on creating connections, and creating a safe space where families can identify goals and strategies as families that will grow their resilience and hopefulness. When a family has reached its goals, then Side by Side can be said to have had its impact and their participation in the project can be completed. If Side by Side has been effective, then successful relationships will have emerged that can be sustained by families independently and families can continue to be connected informally. Hopefully during the course of their participation in the project 'seeking' families will be in a place where perhaps they can act as 'sharing' families to others – if and when they are ready and with support. The project must however continue to be available to families so that where families circumstances change they can reconnect to the benefits offered by the coordinator. This also requires recognition that 'sharing' families might at times also need support, and that they also face pressures and demands from family life. We would recommend that in future this approach include back up supports to ensure that where 'sharing' families might be less available that alternative support is available.

As part of the Side by Side project, there was an explicit commitment from the outset to value in a meaningful way the contribution of families through their contribution to the co-production of the project as well as the time and skills and expertise provided by families. This took the form of the provision of gift cards to families, rather than direct payment. We would continue to endorse such an approach into the future.

Finally, to assist in a better measurement of the impact of peer support for this group, we would recommend the introduction of some form of behaviour assessment that can be utilised in a way that is meaningful and practically useful for families.

6. Discussion

Side by Side – Intentionally Locating Family Leadership as a Strategy for Systemic Change

The Side by Side family peer-support project emerged through the Positive Behaviour Support Framework Implementation Guiding Committee as an explicit strategy to respond to the need for family support as a response to 'challenging behaviour', a key issue identified in the *Towards Responsive Services For All* and highlighted within the Committee. As is the case in many sector development initiatives, the focus of the Committee has been on how to support the paid services sector, particularly to respond to the implementation of the Voluntary Code of Practice. Several family representatives and advocates highlighted within the Committee the importance of seeing development of capacity amongst families as a

critical strategy in complementing and supporting change within the services sector. The Committee is to be commended for acknowledging this and for actively supporting the Side by Side project as a family leadership strategy within their model for systemic change.

Developmental Disability WA believes that family leadership has a critical and undervalued role to play in systemic change within service systems, and we reflect this in the change model which constitutes our systemic advocacy whereby Developmental Disability WA works to create lasting positive change by:

- supporting people with developmental disability and their families to have a strong voice;
- partnering with others to develop more connected and inclusive communities, and
- influencing government and other decision makers.

For Developmental Disability WA family leadership is a key strategy in supporting families to have a voice. Over the last several months in conversation with a number of family leadership organisations, Developmental Disability WA has been articulating a developmental model for family leadership:

- “I lead my family” – individual families recognising their responsibility and authority as leaders of their own families and they want that responsibility and authority to be recognised and valued by others;
- “We share with each other” – families coming together to connect with each other out of their shared experience as families living with disability to share their knowledge, experiences, or skills in a mutually supportive environment. This can be a social endeavour providing an opportunity for social connection and comradery, or it can have developmental focus, including the development of mentoring relationships; and
- “We change the system” – families coming together in a coordinated way to influence systemic change based on their knowledge and experiences. This could mean changing “the system” locally (such as at a local school), or at a larger scale (such as influencing policy).

This model posits that family leadership requires a developmental approach that recognises that we are working towards a certain outcome (families influencing systemic change) and that there are stages of family leadership that must be progressed through in order to reach that outcome. A developmental approach recognises that change is progressive and positive. A developmental model describes a number of changes that occur over a period of time. While describing family leadership as a developmental process, we also recognise that each form of family leadership is not just a stage in that development but is a valued form of family leadership in its own right.

The above model for family leadership is developmental in that it describes a staged progression of family leadership in a certain direction or towards a desired outcome (“We change the system”) and assumes that none of the stages or levels can be skipped or by-passed. Developmental Disability WA believes seeks to support the development of family leadership because families express a clear wish to influence positive systemic change that will contribute to better outcomes for their family members. However, we also value each of these stages as unique forms of family leadership in their own right for the direct benefits they have for families and consequently for the family members they support.

Side-by-Side works both at the level of “I lead my family” and “We share together”, in that its explicit focus is on strengthening individual families who are supporting family members with ‘challenging behaviours’ and that a key aspect of this strategy is through thoughtful, intentional and structured sharing amongst families via a strengths based approach.

The opportunity to identify Side by Side as a strategy to support development within the paid services sector provides a useful opportunity to examine the interaction between family peer-support as an intervention with broader service delivery and clinical interventions. Clear feedback for example from the Positive Behaviour Support Teams indicates that clinicians in particular who are working very closely and intensively with families can see a positive impact on families that is also having a positive impact on their engagement with clinical interventions. If family peer-support can have a complementary impact for clinical interventions, Developmental Disability WA believes that this is a connection that bears further exploration. We also believe that the impacts of family peer-support on the person with ‘challenging behaviour’ within the family, and in particular on mental health outcomes for this group, is also worthy of a more specific focus. This is particularly critical given that people with intellectual disabilities and ‘challenging behaviours’ are at higher risk of poor mental health outcomes, as maintained by Emerson himself.

Family Leadership as a Strategy for Improving Mental Health Outcomes for People with ‘Challenging Behaviour’s

In August 2013 the Centre for Research into Disability and Society hosted a symposium and seminar series on health and intellectual disability. At that event Eric Emerson highlighted the relationship between intellectual disability, ‘challenging behaviours’ and mental health outcomes. Of particular interest to Emerson was the limited access to effective professional support for this group. However he also noted that there are environmental factors that contribute to behaviour, and ultimately to mental health outcomes, that emerge early and are highly persistent and yet amenable to change – largely because they are environmental. Failure to respond to these factors has a high lifetime cost to the person, to their family and ultimately to society. We see this in our own Western Australian context where a lack of access to highly specialised behaviour support strategies historically has

meant that for many families 'challenging behaviour' escalates to a degree where families are no longer able to cope and their family member with a disability leading to a crisis situation where the family member with a disability is removed from the family environment without planning and preparation and into an alternative environment, often emergency accommodation, so that their behaviour can be stabilised and a longer term option found. This is often in a supported accommodation setting rather than returning to the family home.

Emerson argues that there are some key lessons within this knowledge and experience about how we can respond to this group better. Where unmet need is high, Emerson argues we have two options – we can ration our traditional clinical interventions, and/or we can scale-up low cost alternatives. Emerson also argues that by focussing on those factors which contribute to 'challenging behaviour' and are amenable to change, targeted primary and secondary prevention strategies might be viable in ameliorating these factors. Finally, he argued that targeted primary and secondary prevention strategies are potentially efficient in mitigating the high lifetime costs of 'challenging behaviour'. Here in Western Australia, we have developed the highly successful Positive Behaviour Support Teams – a highly targeted and rationed clinical intervention. The Side by Side project has demonstrated that family peer-support represents a lower cost intervention that with the right support could be scaled up as a complement to clinical interventions. Family peer-support also offers a potential preventative strategy by working sustainably with families, to support them to continue to manage environmental factors that are contributing to their family members' behaviour after clinical interventions have ceased. In this approach, a family peer-support model such as Side by Side could be highly targeted at families as a direct complement to a clinical intervention but it is also likely to add value by preparing families for clinical interventions.

But what about families with a capacity to benefit who won't access the highly rationalised clinical services? How can these families also be supported to better respond to environmental factors? Developmental Disability WA believes that a highly targeted family peer-support intervention such as Side by Side could be complemented with a further strategy to develop and share resources with a broader range of families about understanding 'challenging behaviour', and understanding, identifying and responding to potential environmental factors. Resources, information, skills and education opportunities for a broader range of families on some of the key factors impacting on 'challenging behaviour' and the development and facilitation of a network of informed and connected families sharing their experience and learning together has great potential and would also be relatively low cost compared to clinical and professional supports.

Developmental Disability WA believes that a much longer view of a family leadership approach to supporting people with challenging behaviours is required. While the initial project has provided the opportunity to test some ideas and affirm some

assumptions about the specific value of a family leadership approach for families supporting someone with challenging behaviour, we believe that the two-year timeframe for the project provided a limited opportunity for monitoring its medium to long-term impacts. Developmental Disability WA would support a medium to long term opportunity to further test this approach as a complement to other clinical interventions, and with a particular focus on the benefits of family leadership to the family member with disability, particularly in relation to their mental health outcomes and their transition into long-term support services such as accommodation.

7. Conclusion

In its investigation of the Western Australian disability support sector's preparedness for supporting people with behaviours that can be challenging, *Towards Responsive Services for All* specifically acknowledged access to family supports for this group as a critical gap in our system. It specifically recognised the preventative role of family supports in ensuring that people with 'challenging behaviours' remain with their family for as long as possible. Naturally, this must be safe for both the person with a disability and their family members. *Towards Responsive Services for All* also acknowledged the specific vulnerability of these families, and therefore of their family members, because behaviour often leads to exclusion from structured support services such as respite, and also school in many instances. It also noted the flow on effects across families with familial relationships coming under great pressure because of the focus on the needs of the family member with 'challenging behaviour'. The focus of the report was on formalised service delivery models, and highlighted some of the pragmatic challenges faced by specialist disability support services in meeting the needs from this group.

While families are able to understand some of the challenges service providers face in supporting them, this doesn't change the outcomes for families – with one family member referred to in the report reflecting on the sense of feeling abandoned by services. This sense of abandonment and a sense of isolation was what inspired the notion of a family peer-support model for families supporting someone with 'challenging behaviour'.

The Side-by-Side project was based on two key assumptions which have now been tested through this project. The first assumption was that families in this population have a significant capacity to benefit from a peer-support approach because of the particular impacts of 'challenging behaviour'. The second assumption was that because of those particular impacts a targeted peer-support approach would be necessary. While the initial focus of the project was to test those assumptions and to examine what it would take to make this happen, the project also speculated that a number of longer term impacts would flow where these families felt supported. In particular, there was from the outset an aspiration that this kind of family support

approach would not only strengthen and support individual families by better connecting them to people who shared and understood their experience but also better equip families to navigate the 'systems' that they interact with.

Over a two year period, the Side-by-Side pilot confirmed the key assumptions which it wanted to test. The families who participated in Side-by-Side, both the 'sharing' and 'seeking' families reported important benefits for their family of participating in the pilot. Furthermore, the experiences of these families have confirmed that families who support a family member with 'challenging behaviours' do benefit from a highly targeted approach that understands and is responsive to the particular impacts of 'challenging behaviour' on family life.