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Centre for Disability Studies

The Role of Peer Facilitators in the Now & Next Program

Report prepared for:

Plumtree

9th February, 2018

Centre for Disability Studies,

University of Sydney

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DISCLAIMER

This report is supported by a grant offered under the Innovative Workforce Fund, administered by National Disability Services (NDS) with funding from the Australian Government Department of Social Services.

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INTRODUCTION & BACKGROUND

In 2017, the Australian Government established the Innovative Workforce Fund (IWF) to help to develop, expand and communicate innovations in workforce practices in the disability sector in order to support the Australia-wide rollout of the National Disability Insurance Scheme (NDIS). The NDIS is a national initiative that provides individualised funding packages to assist individuals with disabilities in Australia. The IWF was allocated AU$4million to fund projects that would explore innovative workforce practices to answer the need in the disability sector to re-examine existing workforce structures and practices in response to the NDIS rollout and its impact on the sector.

The IWF funded 29 organisations throughout Australia to undertake workforce related projects. Plumtree Children's Services, Inc. (Plumtree) secured funding from the IWF to research and document the use of paid peer work in the Early Childhood Intervention (ECI) sector. Plumtree undertook to analyse its own experiences with paid peer facilitators to understand more fully the benefits of peer work to the ECI sector and its stakeholders, and to use those experiences to interrogate the conditions for success when utilising a peer workforce to complement and supplement traditional allied health, educator and professional ECI staff.

Servicing the communities of the Inner West and South East of Sydney, Plumtree has been providing support for young children (aged 0 to 8 years) with a developmental delay or disability, and their families, for over thirty years. Since 2015, Plumtree has been employing paid peer workers. Initially, Plumtree employed peer workers to develop and facilitate its unique family capacity building program, Now and Next. More recently, however, Plumtree has recognised the broader potential for a peer workforce in the ECI sector, and has employed peer workers in a variety of roles to complement and supplement its allied health and ECI workforce. Its IWF project thus committed both to researching and to documenting Plumtree's experiences employing peer workers in ECI.

This report by the Centre for Disability Studies was commissioned by Plumtree as one component of that IWF research and documentation. The report is complemented by an extensive literature review (primarily considering the mental health sector research) and a summary literature review situating mental health research findings within the ECI and disability contexts completed by Plumtree. The conclusions and recommendations in this report have informed other deliverables arising from the project, including a toolkit for ECI organisations of guidelines and resources to support the integration of a peer workforce.

SUMMARY OF REPORT

This report provides a compilation of the data obtained from a series of focus groups run at Plumtree by a team of researchers from the Centre for Disability Studies concerning the integration of Peer Facilitators into the services at Plumtree. Responses to each question have been categorised by the individual focus group and then ranked from highest to lowest based on the tally of the preferential vote given by each participant of a given category. A compilation of all of the individual responses that were placed into each of the categories can be found in the Appendix 1.

The report concludes with some comments on, and analysis of, responses overall followed with a list of recommendations arising from the findings.

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ABBREVIATIONS

AHP – Allied Health Professionals

PF – Peer Facilitators

FGA – Family Group A

FGB – Family Group B

CDS – Centre for Disability Studies

NDIS – National Disability Insurance Scheme

GLOSSARY

Peer Facilitators are parents of children with disabilities who work at Plumtree with families of children with disabilities.

Allied Health Professionals are clinical staff who work for Plumtree in a paid capacity[1].

Family members are the service users of Plumtree have experienced the work of both the allied health professionals and peer facilitators.

Focus Group is where a group of people come together to discuss **a series of questions** that relate to the aims of the project.

AIMS OF THIS PROJECT

The Centre for Disability Studies was contracted by Plumtree in order to assess the efficacy of the use of peer facilitators in aiding service provision at Plumtree. This study provides feedback to the organization based on the expressed perspectives of each key stakeholder group including, allied health professionals, peer facilitators, and family members of children with disabilities who access Plumtree services. Plumtree has been utilising peer facilitators for over two years and so offers a unique opportunity to assess the use of peer facilitators within disability support services. Data was obtained through focus groups facilitated by a team of researchers from the Centre of Disability Studies using a nominal group technique. Common questions were asked across all groups with questions more targeted to the defined experience of the group.

METHOD

Nominal Group Technique

Participants were asked a question (which was also written on butcher's paper) and invited to spend thirty seconds reflecting on the question before writing a response on a post it size piece of paper. Once each participant had written one or more response/s all responses were collected and placed onto the sheet on which the question was written. The facilitator then asked the participants to help group the responses into 'categories.' Once these categories were made the group was then asked to write a score that would rank

[1] Although one staff member who participated in the focus group with the allied health professionals was employed in a related administrative role.

how well they felt the category of response answered the question posed (i.e. if there were 4 groups of responses the participants would rank the categories of responses 1-4). The scores assigned by individual participants were then tallied, meaning that the responses with the highest numerical value were the least strongly endorsed by the group, and conversely, the responses with the lowest numerical value were the most highly endorsed.

QUESTION 1: WHAT DO YOU UNDERSTAND THE ROLE OF PLUMTREE'S PEER FACILITATORS TO BE?

FINDINGS

The strongest theme present in responses to this question, across all groups, was that the role of the peer facilitator provided 'support', along with 'shared experience' (though this second theme was stronger among peer facilitators and families than allied health professionals). The theme of 'support' is pervasive throughout the focus group discussion. Terms like 'safety net' and 'support network' were at the forefront of discussion in this regard. All groups also recognized the peer facilitators as being uniquely positioned to offer emotional support, encouragement and empathy due to their ability to relate to parent's experiences. For Family Group A this ability of peer facilitators to offer emotional support was expressed in regards to the support offered by peer facilitators in helping to combat loneliness/isolation. In comparison Family Group B commented on gaining support with service delivery and specifically NDIS preparation. (See Table 1, and Appendix 1 for the nominal group technique responses to Question 1 from participant groups).

TABLE 1: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	PF	AHP	FGA	FGB
1. Support	3	10	-	7
2. Shared lived experience	11	-	5	-
3. Empowering	-	-	7	-
4. Aiding loneliness	-	-	5	-
5. Mentoring	-	-	3	-
6. NDIS support	-	-	-	15
7. Service delivery	-	11	-	8
8. Community building	10	-	-	
9. Linking parents with service providers	6	-	-	-

QUESTION 2: HOW DOES THE ROLE OF A PEER FACILITATOR DIFFER FROM THAT OF A THERAPIST (ALLIED HEALTH PROFESSIONAL)?

FINDINGS

As in the responses to Question 1, the capacity of peer facilitators to bring their lived experience to their support of parents was predominant in the distinction participants make between the role of the peer facilitators and that of the allied health professionals. This emphasis on lived experience also expressed itself in the category 'empathy' where peer facilitators made comments such as '*The empathy only another parent with a shared experience can know.*'

While allied health professionals also emphasized the significance of lived experience in differentiating the roles, there was also a strong emphasis for the allied health professionals on the non-clinical role of the peer facilitators. Allied health professionals tended to emphasize more than other groups that it was the differing levels of clinical expertise, ethics, and 'mindset' that differentiated the peer facilitators from allied health professionals in the support offered to families. Family members commented on friendship as well as peer facilitators being experts by experience. (See Table 2, and Appendix 1 for the nominal group technique responses to Question 2 from participant groups).

TABLE 2: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	PF	AHP	FGA	FGB
1. Shared Lived Experience	4	17	4	-
2. Non-clinical	-	14	-	-
3. Different Mindset	-	13	-	-
4. Understanding/ Empathy	8	-	-	-
5. Ability to Disagree	16	-	-	-
6. Family Support	-	-	7	-
7. Friendship	-	-	2	-
8. Mentoring	-	-	7	
9. Advice	-	-	-	9
10. Experts by Experience	12	-	-	6

QUESTION 3: WHAT SPECIFIC BENEFITS CAN A PEER FACILITATOR OFFER TO PLUMTREE'S SERVICE USERS, FOR WHICH AN ALLIED HEALTH PROFFESIONAL DOES NOT HAVE A CAPACITY?

FINDINGS

In describing the benefits a peer facilitator can offer to Plumtree service users, as in response to questions 1 & 2 there was a strong emphasis from within both groups on the significance of lived experience and empathy. This was summarized by allied health staff as *"to speak from a personal rather than professional POV (inappropriate for a professional to speak from a personal view)"* and put simply by the peer facilitators as *"shared lived experience and understanding."*

Additionally, there was also a strong emphasis by peer facilitators on the social bonds and community building arising from their role. The allied health professionals spoke explicitly about the peer facilitators being well positioned to provide advice and guidance around accessing services. Both groups also emphasized the peer facilitator role as fulfilling social and friendship needs, such as providing "a listening ear", and "facilitating play dates". Of interest was that NDIS advice was only raised by the peer facilitators and was not highly ranked. (See Table 3, and Appendix 1 for the nominal group technique responses to Question 3 from participant groups).

TABLE 3: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	AHP	PF
1. Support/Friendship	17	-
2. Shared Lived Experience	14	4
3. Role Modelling	13	-
4. Feedback to Services	-	-
5. Understanding/Empathy	-	8
6. Advice from Experience	12	-
7. NDIS Advice	-	20
8. Social	-	16

QUESTION 4: HAVE PEER FACILITATORS BEEN ABLE TO ALEVIATE THE CASELOAD OF ALLIED HEALTH PROFESSIONALS WITHIN PLUMTREE?

FINDINGS

In terms of perception as to whether peer facilitators had been able to relieve the work load of the allied health professionals, there was a significant disparity between allied health professionals and peer facilitators. The allied health professionals were divided between stating that there had been positive outcomes while others categorized 'no' and 'unsure' as their highest ranking. Where there was impact recognized it covered administrative support in preparing resources and NDIS plans, as well providing emotional support for families leading to stress reduction. Goal setting was identified as an area that allied health personnel appreciated the support of the peer facilitators in working with families. Peer facilitators on the other hand, saw themselves as helping with the allied health professionals caseloads in many different ways inclusive of working in collaboration and bringing an authentic perspective to discussion between one another based upon the credibility of the lived experience of being a family member. They saw that they could assist families to understand the working relationship between family members and allied health professionals which in turn could lead to allied health professionals working with happier families. However, for some allied health professionals they felt that emotional support given by peer facilitators to families where the children had high and complex needs did not transfer into relieving stress for the families within the context of their professional relationship. (See Table 4, Appendix 1 for the nominal group technique responses to Question 4 from participant groups).

TABLE 4: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	AHP	PF
1. Yes	16	-
2. Conditional/Unsure	13	-
3. No	13	-
4. Collaboration	-	5
5. Emotional/Peer Support	-	12
6. Perspective/Credibility	-	7
7. NDIS Support	-	22
8. Alternative Service Recommendation	-	19
9. Bridging Gaps	-	19

QUESTION 5: WHAT LIMITATIONS SHOULD PEER FACILITATORS HAVE (I.E. ARE THERE AREAS OF SUPPORT IN WHICH PEER FACILITATORS SHOULD NOT BE INVOLVED)?

FINDINGS

Both allied health professionals and peer facilitators were strongly in agreement that their respective roles were differentiated by their level of clinical expertise, and that boundaries as well as guidelines need to exist in this regard.

Allied health professionals were more specific in their comments about the factors that distinguished clinical from non-clinical roles. The allied health professionals indicated that there '*should not be any clinical decisions such as diagnosis or treatment*' on the part of peer facilitators, and that peer facilitators should not be involved in '*roles that require clinical training/clinical reasoning*' or '*give specific recommendations on goals, treatments or reports.*' The allied health professionals also conveyed a firm belief that limitations should be placed on the handling of '*confidential documents for scanning, uploading or entering reports*' by peer facilitators. Commentary from the peer facilitators was targeted more at the need for limitations associated with complicated developmental advice, where families were very distressed (e.g. suicidal), direct therapy advice, as well as specific therapeutic advice that related to medical conditions. It was summed up by one peer facilitator who said, '*We are not therapists and to be careful with the advice we share and how we share it.*'

Privacy issues were raised by both groups. From the allied health professionals it related to peer facilitators being in the same office space when they were being supervised while for peer facilitators conflict of interest was raised by insight gained into the issues associated with other Plumtree families that they were peers to.

Another issue raised by the allied health professionals was the implications of peer facilitators having easy access in work time to their child's therapists if unexpected issues occurred. (See Table 5, Appendix 1 for the nominal group technique responses to Question 5 from participant groups).

TABLE 5: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	AHP	PF
1. Clinical Advice	7	5
2. Non-Plumtree Work (during work hours)	21	-
3. Attending AHP's Debriefing/Supervision	14	-
4. Areas Requiring Clinical Expertise	-	8
5. People Who Are at Direct Risk of Harm	-	13
6. Privacy Issues	-	14

QUESTION 6: WHAT DISADVANTAGES (POTENTIAL OR EXPERIENCED) DO YOU SEE IN INTERGRATING PEER FACILITATORS INTO PLUMTREE'S SUPPORT STAFF?

FINDINGS

Allied health professionals offered a number of possible challenges in integrating the peer facilitators into Plumtree's support staff (though none of the allied health professionals stated that this integration should not happen). The highest ranked category of response to this question for allied health professionals was 'professionalism', which encompassed conflict of interest arising from being both a peer facilitator and family member receiving services from the same organisation; different viewpoints on therapy approaches between the two groups; and lack of clarity between the roles of the two groups. Lack of clarity around roles was the highest ranked category for Family Group A. Family members commented that this had led to misunderstandings which in turn was expressed by allied health professionals as lack of trust. The categories of 'professionalism' and lack of 'clarity around roles' in integrating the two groups together also related to boundary issues. Allied health professionals indicated that the boundary between being a peer facilitator and parent was hard to maintain for both groups. Peer facilitators were exposed to confidential information about other family members who they had meet through Plumtree activities. Allied health professionals additionally indicated that boundaries were easy to cross where peer facilitators took the opportunity to seek information about their child's needs from the therapists outside of appointment times. Other lesser challenges expressed by family members included financial and lifestyle balance matters. If the peer facilitators role was integrated into the support structures of Plumtree the questions was asked as to how salary cost would be covered without resorting to a system of cheap labour. (See Table 6 and Appendix 1 for the nominal group technique responses to Question 6 from participant groups).

TABLE 6: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	AHP	FGA	FGB
1. Boundaries	17	4	-
2. Professionalism	12	6	-
3. Clarity around roles	13	3	-
4. Financial	-	4	-
5. Balance	-	7	-
6. None/Few	-	-	5
7. Group Work	-	-	10

QUESTION 7: WHAT COULD PLUMTREE MANAGEMENT DO BETTER TO SUPPORT THE INTERGRATION OF PEER FACILITATORS?

FINDINGS

The allied health professionals also saw clarity around roles and a code of conduct around the maintenance of professional boundaries by peer facilitators as the most significant way that management could support the integration of peer facilitators into Plumtree services. Indeed, responses categorised by allied professionals under different titles (than clarity of roles, or boundaries) were at least partially concerned with these central concerns. For example, comments around space such as '*better physical facilities (rooms) to allow more private conversations*', '*Separate spaces*', '*Different space to work/casual mingle in open space*' were as much tied to differentiating the roles as they were concerns about facilities, particularly in regards to issues of confidentially. The issues of boundaries also emerged in comments from the peer facilitators under the category of '*communication*' with comments such as '*Create clear boundaries regards communications*', '*Define the roles of peer facilitators with current Plumtree staff*', and '*Clarify roles and responsibilities. Training.*' However, peer facilitators also expressed a desire for increased collaboration between themselves and allied health professionals. (See Table 7 , Appendix 1 for the nominal group technique responses to Question 7 from participant groups).

TABLE 7: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	AHP	PF
1. Space	16	-
2. Roles and Responsibilities	10	-
3. Training	19	-
4. Recruitment	21	-
5. Promotion	-	14
6. Integration/Collaboration	-	7
7. Communication	-	5
8. Planning	-	14

QUESTION 8: WHAT SPECIFIC BENEFITS (PERSONAL OR PROFESSIONAL) HAVE YOU EXPERIENCED AS A PEER FACILITATOR?

FINDINGS

Peer facilitators were highly positive in their discussion of the benefits of their role with Plumtree. In particular, peer facilitators saw the benefits of their role at Plumtree as falling under the categories of '*meaning*' and '*learning*.' The peer facilitators saw the ability to use the experiences they had gained by facing the challenges of being the parent of a child with a disability as offering them a sense of purpose, which in turn lifted their self-esteem. Indeed, it should be noted that the comment under the category '*self-esteem*' also fits very neatly with the category of '*meaning*'. The peer facilitators also saw both the learning that they gained from the training provided by Plumtree and the experience of interacting with parents as a peer facilitator as a direct benefit of participating in the program. (See Table 8, Appendix 1 for the nominal group technique responses to Question 8 from the participant group).

TABLE 8: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	PF
1. Money/Hours	13
2. Learning	7
3. Meaning	6
4. Self-Esteem	16
5. Support	18

QUESTION 9: WHAT SPECIFIC BENEFITS CAN A PEER FACILITATOR OFFER TO YOU PERSONALLY AS A PARENT?

FINDINGS

The family groups were highly positive in their discussion of the benefits that they experienced through the implementation of peer facilitation at Plumtree. Both groups discussed the social connections that peer facilitators enabled, and the capacity of peer facilitators to alleviate feelings of isolation. Family members also discussed this social aspect of peer facilitators as having a positive impact on their general outlook on life. Family members also mentioned the 'compassion' and 'support' provided by peer facilitators as a highly significant benefit of the peer facilitator's contribution to Plumtree services. (See Table 9, Appendix 1 for the nominal group technique responses to Question 9 from the participant group).

TABLE 9: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	FGA	FGB
1. Connection	2	-
2. Shaping Attitude	4	-
3. Guidance	6	-
4. Mentoring	8	-
5. Compassion	-	6
6. Advice	-	9

QUESTION 10: HOW DO YOU THINK THAT PEER FACILITATORS HAVE IMPACTED ON SERVICES AT PLUMTREE?

FINDINGS

Family Group A saw the peer facilitators as fostering increased trust between parents and Plumtree services. This was the most significant way that this group saw peer facilitators as having impacted services at Plumtree. Additionally family members discussed having an alternative to a clinical focus as a key contribution of peer facilitators to Plumtree services. The second group of family members emphasized that the peer facilitators brought a level of personal experience to the service, though many of the comments under this category can also be understood as being related to increased trust. For example one of the comments under the category '*experts by experience*' was '*More credibility/weight*' (i.e. the life experience of the PF's brought a level of credibility). (See Table 10 and Appendix 1 for the nominal group technique responses to Question 4 from participant groups).

TABLE 10: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	FGA	FGB
1. Trust	**3**	**-**
2. Service Delivery	**6**	**-**
3. Overall Positive	**6**	**-**
4. Less Clinical Focus	**4**	**-**
5. Expert by Experience	**-**	**5**
6. Advocacy	**-**	**13**
7.Community	**-**	**12**

QUESTION 11: HAVE YOU EXPERIENCED ANY DIFFERENCES SINCE THE INTEGRATION OF PEER FACILITATORS IN 2016-17?

FINDINGS

When asked about their views concerning the differences that peer facilitators have brought to the Plumtree service, responses from family members were overwhelmingly positive. The strongest theme for both family groups was the positive impact peer facilitators have had on service user's mindset/outlook. Additionally, family members were highly positive about the social bonds that peer facilitators enabled. Family members described the peer facilitators as providing 'a safety net', 'friendship', and 'community' as some of the key differences that they had experienced at Plumtree due to the implementation of the peer facilitator program. (See Table 11 and Appendix 1 for the nominal group technique responses to Question 11 from participant groups).

TABLE 11: RESPONSES TO QUESTION CATEGORIZED AND RANKED BY FOCUS GROUP

Categories	FGA	FGB
1. Change in Mindset	**3**	**6**
2. Goal Setting	**7**	**-**
3. Community	**5**	**9**
4. Friendship	**5**	**-**

CONCLUSION

Overall, the Peer Facilitator and Family Groups were highly positive about the implementation of peer facilitators within the Plumtree service. In particular, families and Peer Facilitators saw the shared life experience of Peer Facilitators as enabling a level of empathy and trust that helped to improve the outlook and attitude of parents and, furthermore, provided an alternative for families to a purely clinical approach to supporting the needs of children with disabilities and their families. Families also frequently reported appreciating the community building aspect of the use of Peer Facilitators and were appreciative of the social bonds that were formed between themselves and the peer facilitators.

The allied health professionals took a more critical approach to their discussion of the role of peer facilitation within Plumtree. Although they were positive about the concept they also indicated that it had implications for professional practice. In particular they saw a need to define the distinct roles of peer facilitators and clinicians, especially in regards to the types of advice that the respective groups give to parents (i.e. peer facilitators should not give advice that depends on clinical expertise and training). In defining such roles it was also stressed that peer facilitation should strongly align with a clear set of professional ethics, especially around confidentiality and mitigation of conflict of interest. Peer facilitators also identified the need for such ethical practices if their role was to be sustained within Plumtree.

RECOMMENDATIONS

Arising from this report the following recommendations are made:

1. The role of peer facilitators be clearly defined.
2. The role of peer facilitators in relation to the role of allied health professionals be defined.
3. That management consider ways in which the allied health professionals and peer facilitators can come together to:
    a. gain a shared and mutual understanding of their distinct roles and respective codes of practice.
    b. problem solve differences of opinion and practice between the two groups.

c. build a community of practice for peer facilitators that is supported by allied health professionals.
d. develop a shared training programme for both peer facilitators and allied health professionals.
e. facilitate any unresolved issues that get in the way of allied health professionals and peer facilitators working as a team.

4. That the work at Plumtree involving both peer facilitators and allied health professionals be documented within the Australian and international early childhood literature.
5. That the model of peer facilitation be disseminated beyond Plumtree within both mainstream and disability sectors that involve children with disability.
6. That strategies be put in place to financially sustain the peer facilitation programme.
7. That the implications of the model of peer facilitation beyond the early childhood years be explored.
8. That the development of a community of practice for peer facilitators be considered.

APPENDIX: WRITTEN RESPONSES TO EACH QUESTION

QUESTION 1: WHAT DO YOU UNDERSTAND THE ROLE OF PLUMTREE'S PEER FACILITATORS TO BE?

Category 1: Support

AHP's

"Provision of support network."

"To support other families of children with additional needs from a way that the staff (non-peer facilitators) cannot."

"Something to do with facilitating peer/parent groups."

"To create a support network for parents of children with disabilities."

"Provision of parent-to-parent support related to mutual concerns and shared experiences."

Peer Facilitators

"Guide and support fellow parents."

"Provide the parent connection/support only we can offer."

Families Group B

"An understanding guide in your journey."

"To support Plumtree families on our journey with advice and feedback on their experiences."

"To share their experience regarding a particular disability/challenge."

Category 2: Service delivery

AHP's

"To develop services at Plumtree-for parents-including Now and Next, Pictability and others."

"Provision of feedback and influence on service provision within Plumtree."

"To deliver services at Plumtree for parents including NON, Pictability and others."

Families Group B

"To assist with putting together parent programs and provide support to participating parents."

"Provide parents coaching and personal experience and direction."

"To provide leadership knowledge and personal experience to the group."

Category 3: Community building

Peer Facilitators

"Facilitate community building."

Category 4: Linking parents and service providers

Peer Facilitators

"To be the link between professionals and parents with a child with a disability."

Category 5: Sharing lived experience

Peer Facilitators

"Share lived experience."

Families Group A

"Empathy."

"To relate (connect) to new parents with their own/experiences. Mutual benefits."

"Like-minded."

"Empathy."

"Relatable experience."

Category 6: Empowerment

Families Group A

"A way for parents to feel empowered by their circumstances."

"Strength."

"Empowering."

"Empowered."

Category 7: Aiding loneliness

Families Group A

"To help new parents to not feel alone."

"Not feel alone."

"Not feel alone."

Category 8: Mentoring

Families Group A

"Mentor."

"Social worker."

"Miracle Mama!"

"Relatable experience."

"Mentor."

"Share/mentor."

"Share their experiences."

Category 9: NDIS support

Families Group B

"Sharing new information e.g. NDIS rollout and experience."

QUESTION 2: HOW DOES THE ROLE OF A PEER FACILITATOR DIFFER FROM THAT OF A THERAPIST (ALLIED HEALTH PROFESSIONAL)?

Category 1: Shared lived experience

AHP's

"They have unique and personnel experiences to share with other parents who can relate to their situations."

"They provide peer-to-peer support."

"The peer facilitator brings the lived experience of having a child with a disability."

Peer Facilitators

"Advice from someone who gets the whole picture. Lived experience."

"The perspective of a lived experience."

"Insights from shared experience."

"Personal experiences to help."

Family Group A

"Lived experience."

"Lived experience."

Category 2: Non-clinical

AHP's

"There are no peer facilitators working in a clinical capacity. Most (if not all) do not have a professional background in allied health or education."

"They have a non-clinical role with a passion for the cause."

"My role is specific to behavior and not general issues related to families."

"My role involves having training and qualification in AAC and Feeding and Communications.

Category 3: Different mindset

Peer Facilitators

"Different skills, interests, attitudes."

"They can organize playgroups as a form of support whereas the staff can only recommend or run playgroups."

"The peer facilitator role differs from my role as it is in a group scenario more than in a one-on-one scenario."

"Different reasons for seeking the role."

"Less distinct boundary between home and work."

"Stronger advocacy for parents (as opposed to children)."

Category 4: Understanding/empathy

Peer Facilitators

"Understanding of parent challenges."

"Understanding of what's happening in their lives."

"The empathy only another parent with a shared experience can know."

"Empathy."

Category 5: Ability to disagree

Peer Facilitators

"Ability to disagree without bad feelings."

Category 6: Family Support

Family Group A

"Family support for [child's name]."

"Family support."

Category 7: Friendship

Family Group A

"Friendship."

"Friendship."

"Emotional support."

"Trust."

Category 8: Mentoring

Family Group A

"Mentor."

Category 9: Advice

Family Group B

"Can help us navigate the world of therapy and system generally."

"Unbiased advice."

Category 10: Expert by experience

Peer Facilitators

"Real experience with services- advice that is not biased by organisation- only real experiences."

"Offer advice from strategies, therapies, etc. we have tried."

Family Group B

"Personal experiences. They've walked in our shoes."

"They are real life knowledge experts."

"Advice based in personal experience."

"Give advice based on personal experience."

"Lived experience and know-how."

QUESTION 3: WHAT SPECIFIC BENEFITS CAN A PEER FACILITATOR OFFER TO PLUMTREE'S SERVICE USERS, FOR WHICH AN ALLIED HEALTH PROFFESIONAL DOES NOT HAVE A CAPACITY?

Category 1: Support/ Friendship

AHP's

"Providing some emotional support."

"A listening ear(without progress notes)."

"The friendship."

Category 2: Shared lived experience

AHP's

"To speak from a personal rather than professional POV (inappropriate for a professional to speak from a personal view)."

"The personal experience."

"Supports on evenings and public holidays."

Peer Facilitators

"Have the perspective of lived experience."

"A shared lived experience and understanding."

"Family strategies."

Category 3: Role modelling

AHP's

"They can be/are role models for other parents (because they are also parents with children with a disability)."

Category 4: Feedback to services

AHP's

"Provide feedback on the services that they have come across (from the consumer's perspective)."

"They have more knowledge and experience using services for children with special needs."

Category 5: Understanding/Empathy

Peer Facilitators

"*Understanding and empathy through services such as direct one-to-one support, Pictability.*"

"*Understanding/empathy.*"

"*Empathy in (better) understanding the struggle.*"

Category 6: Advice from experience

Peer Facilitators

"*Reviews of services based on lived experience. E.g. schools, therapists, doctors.*"

"*Advice and recommendations from personal experience.*"

"*Warts and all advice.*"

"*Resources from every area. Not just one area.*"

Category 7: NDIS Advice

Peer Facilitators

"*NDIS planning. Share own experience.*"

Category 8: Social

Peer Facilitators

"*Playdates and coffee.*"

QUESTION 4: HAVE PEER FACILITATORS BEEN ABLE TO ALEVIATE THE CASELOAD OF ALLIED HEALTH PROFESSIONALS WITHIN PLUMTREE?

Category 1: Yes

AHP's

"Yes. E.g. 1 administrative support in preparing NDIS plan. E.g. 2 family preparation NDIS planning."

"Yes, enhancing other parents' skills in setting goals."

"Relieves the emotional needs of the parents and lowers their stress levels."

"Yes, helping as an assistant to make visuals for a client."

Category 2: Conditional/Unsure

AHP's

"Parents sharing their positive experiences with strategies might be more willing to try them."

"Yes, but it is too early to tell yet. Potentially peer facilitators can provide each other's families with opportunities to practice communication."

Category 3: No

AHP's

"No, in some ways I have more work to do around communications etc. of peer led services."

"No, their capacity does not relieve the stress of working with complex clients/families."

"Kind of: can lead to lengthy in depth discussions."

"No, not in my role. (I don't have a caseload)."

Category 4: Collaboration

Peer Facilitators

"Helping engaging families into their responsibility and involvement to their child's development."

"Teach parent how best to work with professionals- saves them time- parents are more effective."

Category 5: Emotional/Peer support

Peer Facilitators

"Families are comfortable talking to us about some issues."

"Provide emotional support so professionals have happier clients."

"Parent support."

Category 6: Perspective/Credibility

Peer Facilitators

"Credibility with family."

"We can see things therapists can't."

Category 7: NDIS Support

Peer Facilitators

"We help with some prep for NDIS meetings."

Category 8: Alternative service recommendation

Peer Facilitators

"Encourage parents to take more responsibility for "natural therapy""

Category 9: Bridging gaps

Peer Facilitators

"Connection between professional and parent perspective we bring."

QUESTION 5: WHAT LIMITATIONS SHOULD PEER FACILITATORS HAVE (I.E. ARE THERE AREAS OF SUPPORT IN WHICH PEER FACILITATORS SHOULD NOT BE INVOLVED)?

Category 1: Clinical Advice

AHP's

"Giving clinical/ professional advice."

"Limitation on clinical and technical support."

"Early career therapists should not be allocated to parent facilitator families."

"Should not handle any confidential documents (e.g. scanning, uploading, entering information/ reports)."

"Should not make any clinical decisions such as diagnosis or treatment. (can only share their experience)"

"Roles that require clinical training/ clinical reasoning. (non-evidence based therapy ideas)"

"Should not have access to notes and reports."

"Specific recommendation on goal, treatments, approaches."

"Setting child goals."

"Is Now and Next Facebook group monitored?"

"Recommending types of intervention."

Peer Facilitators

"Complicated developmental advice."

"Specific therapy advice."

"Give direct therapy advice."

"Give medical advice e.g. feeding tubes."

"We are not therapists and to be careful with the advice we share and how we share it."

Category 2: Non-Plumtree work (in work hours)

AHP's

"Using work time to have meetings about their child with a non-Plumtree employee."

Category 3: Attending clinician's debriefing/supervision

AHP's

"*In the presence of the staff's debrief, supervision or collegial support.*"

Category 4: Areas requiring clinical expertise

Peer Facilitators

"*We are not counsellors. We can offer support as parents but need to be careful.*"

"*Not professionals.*"

"*Need to stick to the program content not opinion.*"

Category 5: People who are at direct risk of harm

Peer Facilitators

"*Deal with very distressed parents. E.g. suicidal.*"

Category 6: privacy issues

Peer Facilitators

"*Potential privacy issues.*"

"*Privacy and conflict of interest.*"

QUESTION 6: WHAT DISADVANTAGES (POTENTIAL OR EXPERIENCED) DO YOU SEE IN INTERGRATING PEER FACILITATORS INTO PLUMTREE'S SUPPORT STAFF?

Category 1: Boundaries

AHP's

"Confidentiality. Debriefing with staff member session about peer facilitator's child."

"Boundary issues in communication."

"Boundaries. E.g. when to chat about your child (during the session not when seeing each other in the office)."

"Harder to maintain professional boundaries. 1 e.g. a peer facilitator who has also been your client. 2. E.g. non-professional access to client records."

"Confidentiality and unconscious bias from a peer facilitator's experience may influence the decisions that he/she makes."

"Confidentiality issues."

Category 2: Professionalism

AHP's

"Conflicting information and use of strategies that are not evidence based or clinically effective."

"Different levels of professionalism and ethics."

"Conflicting goals during therapy or set at Now and Next. Poor communication."

"Plumtree facilitator choosing different type of service than Plumtree offers for their child."

"Conflict of interest."

"There is a conflict between our role in supporting and encouraging parents to provide the experiences their children need to learn and grow and their role as peer facilitator takes their time and energy away from their families."

"Conflict of interest (an ethical issue?)."

"Conflict of interest. E.g. trainee peer facilitator making complaint about staff member."

"Lack of clarity between their roles and responsibilities and the rest of the staff."

Family Group A

"Lack of sufficient training (to deal with certain issues)."

"Wrong advice?"

"Wrong advice."

Category 3: Clarity Around Roles

AHP's

"Lack of trust and partnership between them and other staff (need to figure out how everyone's roles are complementary and communication is clear and ongoing."

"Lack of understanding of ethical guidelines and risk to pool of expertise in organization."

Family Group A

"Opportunity for misunderstanding their role (by parents)."

"Misunderstanding."

Category 4: financial

Family Group A

"Exploiting peer facilitator. Cheap labour."

"Budget (NDIS will cash out if peer facilitator cost)."

Category 5: Balance

Family Group A

"Balance therapist/support."

Category 6: None/Few

Family Group B

"None. But there should be equal weights on professional and peer facilitators."

"None."

"No disadvantages. Two different roles. Qualified professionals provide therapy. Peer facilitators provide additional support and knowledge workshops."

"Not involved in specific therapy."

Category 7: Group work

Family Group B

"Disadvantage if peer facilitators start working one at a time with groups. Team approach works well. Different families will bond with different facilitators. Team approach worked well in Now and Next."

QUESTION 7: WHAT COULD PLUMTREE MANAGEMENT DO BETTER TO SUPPORT THE INTERGRATION OF PEER FACILITATORS?

Category 1: Space

AHP's

"Better physical facilities (rooms) to allow more private conversations."

"Separate spaces."

"Different space to work/casual mingle in open space."

Category 2: Roles and Responsibilities

AHP's

"Regularly communicate updates, concerns, changes to programs with all staff- especially as it is a new and evolving program."

"Differentiate peer facilitator admin vs advocacy."

"Choose peer facilitators that work for Plumtree with defined expectations."

"Clarify roles and responsibilities. Training."

"Communication."

"Create clear boundaries regards communications."

"Better communication with parents, professionals, peer facilitators about the roles and responsibilities."

"Communication."

"Define the roles of peer facilitators with current Plumtree staff."

"Clarify roles and responsibilities of peer facilitators(and communicate to everyone)."

"Check/refer to existing guidelines on rights and responsibilities of the staff, organization and facilitators. If there is none, Plumtree should develop a hard copy."

"Set clear roles and responsibilities as well as lines of communication."

Category 3: Training

AHP's

"Provide training to peer facilitators in relevant areas."

"Better training of peer facilitators- boundaries and professional expectations."

"Provide training to peer support workers about boundaries and roles."

"Training of peer facilitators in relevant areas."

Category 4: Recruitment

AHP's

"Recruitment."

"Ask staff what skill set/expertise they would like to see in a peer facilitator and recruit accordingly."

Category 5: Promotion

Peer Facilitators

"More promotion of programs and groups (i.e. Facebook)"

Category 6: Integration/Collaboration

Peer Facilitators

"Induction as a general staff member."

"Bring both teams together. Build relationship."

"Collaboration between peers and professionals."

"Have a collective meeting to introduce the team together."

"More opportunities to work with other organisations."

Category 7: Communication

Peer Facilitators

"Communicate the benefits of peer facilitators to the non-peer/ professionals."

"More to ensure therapy team not intimidated."

"Explain better why peers are here."

"Communication. What management should be doing."

"Be more sensitive to issues that divide peers from professionals."

Category 8: Planning

Peer Facilitators

"More forward planning."

QUESTION 8: WHAT SPECIFIC BENEFITS (PERSONAL OR PROFESSIONAL) HAVE YOU EXPERIENCED AS A PEER FACILITATOR?

Category 1: Money/hours

Peer Facilitators

"Money, flexible hours."

Category 2: Learning

Peer Facilitators

"It has enriched and imbedded my own learnings."

"I am always learning from other parents/ parent groups/organizations. Helped on my journey."

"Learning new things and training."

Category 3: Meaning

Peer Facilitators

"Giving back to others."

"Using my hard earned skills in a meaningful and relevant way."

"Rewarding feeling supporting other parents and seeing them grow and shift in mindset."

Category 4: Self-esteem

Peer Facilitators

"It has lifted my own self-esteem through contribution."

Category 5: Support

Peer Facilitators

"Other people support me (team members)."

QUESTION 9: WHAT SPECIFIC BENEFITS CAN A PEER FACILITATOR OFFER TO YOU PERSONALLY AS A PARENT?

Category 1: Connection

Family Group A

"Friendship"

"Connection. Combat isolation."

"Support/counselling."

"Friendship."

"Approachable resource. Information. Experience."

Category 2: Shaping attitude

Family Group A

"Value/self- worth."

"Sense of new norm."

"New ways of looking at things."

"Value."

"Opportunity to contribute."

Category 3: Guidance

Family Group A

"A pathway."

"Recommendations."

"Pathway."

Category 4: Mentoring

Family Group A

"Mentor."

Category 5: Compassion

Family Group B

"Support. They get it. They understand how I am feeling."

'"Reassurance… "you're on the right track." "Tomorrow's a new day." "We can work this out together."'

"Understanding and compassion that only other special needs parents can give."

Category 6: Advice

Family Group B

"Practical advice."

"Give advice on what has worked and not worked for them on their journey."

"Personal experience and knowledge (being in the same shoes)."

QUESTION 10: HOW DO YOU THINK THAT PEER FACILITATORS HAVE IMPACTED ON SERVICES AT PLUMTREE?

Category 1: Trust

Family Group A

"Trust."

Category 2: Service delivery

Family Group A

"*Curated to be current/relevant.*"

"*Event relevant.*"

"*Differentiator.*"

"*More meaning W.O.M. when promoting it.*"

Category 3: Overall positive

Family Group A

"*Game changer.*"

"*Game changer.*"

"*To share their experience regardless of particular disability.*"

Category 4: Less clinical focus

Family Group A

"*Less like therapy or appointment.*"

"*Relatable.*"

"*Plumtree is for me, not* [child's name]."

"*For me not* [child's name]."

Category 5: Experts by experience

Family Group B

"They add an extra level of depth of understanding, caring and knowledge that you can only get through personal experience."

"More credibility/weight."

"Brought their experience into training/coaching."

"Knowledge experts of the parent's journey."

"Provide lived experience of the difficulties. Extra depth."

Category 6: Advocacy

Family Group B

"Given a louder voice for families on what we need and would like."

Category 7: Community

Family Group B

"Better sense of community."

"Further strengthened community feel for everyone involved at Plumtree."

"Resulted in spreading word in 'special needs community' about services available at Plumtree."

QUESTION 11: HAVE YOU EXPERIENCED ANY DIFFERENCES SINCE THE INTEGRATION OF PEER FACILITATORS IN 2016-17?

Category 1: Change in mindset

Family Group A

"Positive mindset."

"Positive outlook on circumstance."

"Positive mindset."

Family Group B

"I have learnt to set goals in a positive mindset. Goals for my child, for myself and for my family."

"A greater sense of being able to overcome stuff. Strength."

"More structured and organised advice."

Category 2: Goal setting

Family Group A

"Increased motivation to do therapy."

"Goal orientation."

"Goals."

Category 3: Community

Family Group A

"Sense of community"

"Safety net."

"Safety net."

Family Group B

"Community."

"Not just a transaction-i.e. paying for a service. They provide a sense of belonging and community."

"A refreshing and empowering community not provided by anyone else out there."

Category 4: Friendship

"Friendship. Not isolated."

"Friendships."

"Friendship."