Australian Chinese Disability Peer Support Groups in Sydney

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was Chinese tended to consider communicating with peers from the same culture in the same mother language as a condition of good peer support. People who were born in Australia were

CALD disability peer support groups are a valuable asset to inform the improvement of the NDIS because much of the support from peer support groups are related to goals of the NDIS at system level

Policy arrangements such as Ability Linker cultivate resource mobilisation across the disability and CALD communities to support the development and sustainability of grassroots peer support initiatives

Policies that foster grassroot peer support initiatives should include and respect the expertise of

1 Introduction

People from culturally and linguistically diverse (CALD) backgrounds in Australia have at least similar rates of disability to other Australians, if not higher (Zhou 2016). A lack of suitable disability support excludes many CALD people with disability from one of the most significant Australian social policy reforms of this century, the National Disability Insurance Scheme (NDIS) (Senerathna et al. 2018; Zhou, 2016). Earlier research has focused on barriers to culturally responsive disability support, such as a lack of information in other languages (Heneker et al 2017; Senaratna, et al 2018; Zhou, 2016). More information is needed about solutions to the problem.

Informal disability support, especially disability peer support, not only supplements formal supports but also assists people with disability and their families access and navigate the formal support systems (Purcal et al 2019; Walsh et al 2018). Empirical studies have confirmed that disability peer support run by and for people from CALD backgrounds is a good complement to formal disability support (Fang and Fisher, 2019; Wehbe et al 2019). In addition, working with CALD peer support groups has been empirically confirmed as a promising approach for disability organisations to improve their support quality (Fang et al 2021). New research is needed to better understand how to facilitate and support CALD disability peer support groups in culturally responsive ways.

This project examined how disability organisations supported and worked with CALD disability peer support groups in the context of the NDIS. The research answered three research questions.

1) What do Australian Chinese people with disability and their families perceive as good disability peer support?

2) What are the factors that contribute to the development and continuation of good disability peer support and how do the factors contribute?

3) What are the implications for culturally responsive support for grassroots disability peer support initiatives in CALD communities?

To answer these questions, we collaborated with four disability peer support groups

The research adopted a qualitative research methodology and used two types of data collected from June to September 2020. There were 40 semi-structured interviews with 46 participants, including peer members, group facilitators and organisation staff, and six group session observations.[3] The methods are summarised in Appendix 1.

The following sections present findings about the following aspects:

Perception of good peer support from the perspective of the Australian Chinese peer members

Factors for the development and continuation of the perceived good peer support

Implications for culturally responsive support for grassroot disability peer support initiatives in CALD communities.

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2. Good peer support: perspective of people with disability and families

Australian Chinese people with disability and their families said that good disability peer support was a way for them to meet people with shared experiences. The peer support groups gave them emotional support with each other, where they learnt new things from their peers. The participants' preferences of cultural responsiveness in good peer support varied between people who used Chinese as their primary language and others, such as young people with disability born in Australia and their families. This section reports the commonalities and differences of the participants' perception about good peer support and the associated factors.

2.1 Perception of good peer support

When participants spoke about good peer support, they focused on a combination of receiving emotional support and learning new things. People with disability and their families held similar expectations about the emotional support in dpmpport -0.0h ea2[(,)2 (w)6 (h6 (r

We parents had found our peers. I hope my son could also meet young people with disability, chatting and developing a bond… [The group should be as stable as ours] with peers with similar disability and ages.

All the parents with children with disability held similar opinion about gaining emotional support from peers, as explained by a mother about how important emotional support was:

I finally found a place [this group] to talk about my daughter's situation. Before joining the group, I had no courage to disclose my daughter's disability. I even hesitated to talk about it within my family. They [the relatives] wouldn't understand it. My mother said 'It is all your fault. You did not educate her well. You spoiled her'... My emotional mood got much better after joining the group.

Many family members emphasised that they expected to receive positive emotional support which went beyond sharing personal struggles. Some participants had been in multiple peer support groups. They preferred a group that would be able to facilitate a sense of belonging to improve their mental wellbeing, as explained by a mother of a child with autism:

I once joined a mother group but soon stopped attending ... I found the mothers could not stop crying when talking about their experiences ... I don't like a group of people getting together and sharing negative emotions ... I noted [a similar scene] occurred in an online parent group. When the parents spoke

especially with intellectual disability, information sharing about disability support is of limited value.

The mother added that the peer support group activities gave her son, a young adult with autism, many opportunities to talk to people and develop friendship. He was asked to open group sessions, which helped develop his presentation skills.

> He becomes more confident, more willing to help others. He met more people [from the group]. He once told me that he felt [his life is now] quite full through making meaningful participation and contribution to the group.

Families of people with disability and middle-aged people with disability hoped to better navigate the disability system. Their focus of learning through peer support was placed on gaining more information about disability support. They said providing peers with quality disability information was one of the key indicators of good peer support. A father used a metaphor to emphasise the importance of receiving disability information from the group:

> I hope the group could continue running ... Without the group, my life would turn to be very difficult, …I would be an illiterate.

A staff member who supported one of the peer support groups reported how the group improved its members' capacity to navigate the NDIS.

> I noted significant empowerment occurring in the group ... I saw many peers making choice and control. This [choice and control] only happened when your capacity [is] achieved to a certain level .... I witnessed how the members supported each other bit by bit, from calling the NDIA to collect information for other group members to a member becoming an NDIS provider
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2.2 Cultural responsiveness in peer support

Participants held contrasting preferences about peer support that could met their cultural needs. One preference was engaging with people from the same culture with their mother language; the other was that same culture and language was not necessary for peer support. Participants who held the first preference were people with disability and their families who selected Chinese as their primary language. Those who had the second perception were young people with disability who were born in Australia and their parents.

Regarding the first preference of cultural responsiveness, the participants provided two reasons: 1) a sense of relaxation and confidence using Chinese; and 2) cultivating emotional bond among the peer group members.

Almost all of the participants mentioned that a relaxing and confident feeling meant a lot for them in peer support groups. People whose primary language was not English felt a sense of relaxation and confidence when they used their primary language, as emphasised by a group member as followed:

> Speaking mother language makes communication natural and relaxing. We don't need to be careful and nervous. Peer support sessions are supposed to be relaxing.

Some participants also mentioned that they felt nervous in cross-cultural communications because they were concerned about potential misunderstandings that might be caused unintentionally. In contrast, communicating with people from the same cultural background was much more relaxing to them, as a group member commented:

> Many people from non-Asian cultures don't like Asian people speaking loud. Some of our [Chinese] peers are used to loud voice. I sometimes did feel that they were too loud, but I understand it is a communication style in Asian communities. Some peers often interrupt others ... These [talking loud and interrupting others] are acceptable in our culture but are considered inappropriate in many other cultures.

Participants also pointed out that many conversations among peers were intimate, personal and emotionally heavy. Some of them felt more comfortable using their primary language for privacy. They said they preferred using primary language when they sought emotional support from their peers:

> I don't want my expressions in peer support groups to be involved in translators. I would rather talk about my experiences with a peer in privacy than with a translator in presence.

A disability practitioner had supported multiple disability peer support groups in CALD communities, and he commented that EMCi.002 Tw6 (n)d

multicultural group and concluded that the former group had a much higher level of solidarity than the latter group due to a shared cultural background.

> The multicultural group has not achieved as much as the Australian Chinese group. Peers in the multicultural group don't share much. They seem to have many hesitations to disclose much... They rarely shared their personal contact details in the group...

also from Chinese background and spoke the same primary language. On the other hand, young people with disability who were born in Australia did not consider cultural backgrounds of peers as a condition of good peer support.

Good peer support needs to foresee and respond to the potential barriers of Chinese culture on peer members. Some Chinese parents of people with disability needed informational and emotional support outside the Chinese community for topics that were a cultural taboo. They were also interested to learn practices in other cultures. Some Chinese parents preferred their children with disability who were born in Australia to develop peer support with people from Chinese background. These parents' preferences were sometimes contrary to their children's preferences in meeting and making new friends.

Cultural responsiveness in good CALD disability peer support cannot be oversimplified as gathering people from the same language and cultural background. Good disability peer support reflects peer members' cultural preferences and provides support to mitigate the negative cultural influences on their peer members.

3.

Peers' perception of a good group facilitator
The research participants, both group members and professionals, agreed that a good group facilitator would have four qualities: 1) lived experiences of disability or caring for people with disability; 2) empathy with peers' experiences and needs; 3) no intention to make profit or take advantage of the peer support group; and 4) capacity to mobilise resources and organise activities for the group.

The first two qualities were closely related. Participants said if a facilitator had similar lived experiences to their peers, the facilitator tended to be empathetic and well understand the peers' needs. A facilitator explained how his lived experience motivated and helped him organise group sessions as follows:

> The main characteristic of the group [I facilitated] is that we have a lot of male carer members... nearly 40% are male. … It's very uncommon, in many other groups most group members are female... I know what male carers need, what group activities they would attend because I am a male carer too.

Most group members said that a peer facilitator with lived experiences would make thereBDC. 0.004 Tc -0.002 T3478 0 Td [(])2 (i)64 (no3.41 0.28[a m [)]TJ 03 0 1.661 0.28[a Tc -0.01

One organisation established a peer support group for parents with people with disability and assigned a bilingual staff to support the group. The staff member said that it did not take long for her to identify an ideal facilitator candidate, a father of a young person with disability. She noted that the father was a responsible person and keen to help other parents with children with disability. She organised substantial support for the group at the establishment stage. The support not only addressed most of the challenges that a facilitator would face at the early stage of facilitation, but also successfully developed a good rapport between the organisation and group, as she concluded as follows:

> Our [organisation] support to the group at the establishment stage concentrated on three aspects: leadership capacity building, financial support and recruitment support... I provided one-on-one support to the facilitator. We provided a block funding for the group to organise activities. We also helped him recruit group members... These were the most challenging parts for a group at its early stage. We did these so that he did not have to place too much time [which was one of his hesitation and concern when I invited him to facilitate the group]. We did these to reduce his worry. I think this was very important to strengthen his willingness to be the facilitator.

The facilitator appreciated the staff member and the organisation's support which became one of the drivers for him to organise the groups' activities. The development of the group further strengthened the organisation's trust and support, as the facilitator recalled:

> At the start, their [organisation] support was $20 per person. The amount increased because we continued to organise good events and activities.

The staff member emphasised that the trust between the group facilitator and herself enabled her to effectively support the group on behalf of the organisation. Especially when the group encountered crisis or a big challenge, trust was the key to developing a solution. Another benefit for the organisation to reap from the close engagement with the group was the enhanced understanding about Australian Chinese people with disability and their families, as the staff recalled how she drew on her engagement with the group members and shared her reflections in the internal organisational learnings about culturally responsive disability support:

> Engaging with the group confirmed the theories [I learnt from trainings], correct my thinking errors, and help me further understand person-centred services [because] I realise why they [Australian Chinese parents with children with disability] behave in certain ways.

> Once in a staff meeting, I gave a lecture on seeking medical support in China. After my presentation, my colleagues approached me and said 'now I understand why my Chinese clients talked to me in that way. I won't feel impatient anymore [in the future] because I understand the underlying factors'.

Coproduction

The coproduction that enhanced the development of a CALD disability peer support group had two features: 1) organisation's respect of the knowledge and expertise of the group members; and 2) a high level of the group's autonomy and participation in the group-organisation engagement.

All staff members stated that the lived experiences of people with disability and their families should be valued as an expertise in enabling peer support groups. A staff member described how they worked with the peers and included their opinions in group operations:

> Every year, we conducted a plan meeting in the first group session. Staff members and group members discussed together. [The meeting helped us] understand the group members' needs and their thoughts. We used the collected information to design the group sessions that year. We then conducted a mid-year review session, inviting the group members to comment on the previous sessions and their suggestions for the sessions in the second half of the year. In the end of the year, we held a final review, reflecting on the sessions in the year and working on the development the next year... We engaged with the group members throughout the year.

A frontline worker shared another approach of coproduction. Her organisation purposefully set up paid positions for people with disability in its projects to show its respect to the expertise of people with disability and demonstrate to them that their lived experiences were of value, as was explained by the staff as follows

> Everybody [people with disability from CALD backgrounds involved in a project] got paid for developing the concepts of the words and translation and the meaning and the stories that goes with it… people see you value them [people with disability from CALD backgrounds] not as a volunteer but actually as paid staff, as a member.

All staff members agreed that disability organisations should ensure people with disability and their families have choice and control in the group-organisation engagement because a high level of group autonomy increased group members' commitment to their group's development, as explained by a staff member:

> Taking the leadership gave him [the facilitator] a sense of achievement and motivation... I noted that his performance enhanced. He became more active and efficient in managing the group. He even started applying for external funding [for the group].

In contrast, we noted that the members of one group did not take leadership of the group. Their participation was limited to advising on the themes of group sessions. Participants worried that the group's dependency on the organisation may undermine the development and sustainability of the group. A father described the group as "not having a strong solidarity". A mother provided a more detailed comment:

The organisation managed the group. This limited the group because no one from the group would like to take it over and lead… Without a key person from the group to stand out, I am afraid it will be very hard for the group to sustain… Some parents have become less keen to participate in the group activities, including me... Some parents are getting older and have attended the group activities much less than the first couple years.

Two staff facilitators of the group admitted that they had been trying to assign a facilitator with lived experience, but was unsuccessful. Two factors might be related to low level of group autonomy. Firstly, each staff facilitator worked with the group for no more than two years. In this light, staff facilitators did not have a strong capacity to develop rapport with the group to identify and cultivate a good group facilitator. Secondly, staff facilitators did not receive specific

The organisation also organised monthly meetings for all the peer facilitators to come together to exchange experiences, reflect on their facilitation, learn from each other.

The organisation's manager said that group facilitators were crucial to the development and sustainability of their groups. In this light, the organisation intentionally emphasised and integrated the spirit of peer support in its training:

We also have what's called a community of practice... We provide a space for peer facilitators to come together to support each other and learn from each other, and share experiences in that way, as part of the learning, part of the developing, as well... We make sure that we've got a certain number of times we meet a year.

The training brought positive outcomes. A group member said that she was now actively participating in government consultations and research projects on disability support for CALD communities. She started realising the value of her lived experiences because she was told by the organisation's peer facilitator that 'helping the government improving the NDIS is helping ourselves'. Another member said that the training reinforced her understanding about the value of peer support. She became more active than before in participating in the group's Wechat platform, joining the daily chat and sharing disability information.

3.3 Disability sector and local communities

Support from the disability sector and local communities played an indispensable role throughout the development of the four groups. The support was categorised into three types: 1) disability and community organisations collaborating with each other to provide resources for the groups; 2) resources scattered within the community for the groups to identify and use; 3) platforms in the community for the groups to recruit new members.

Three peer support groups in this research were established through the collaborations of organisations from the disability sector and local communities. Inter-agency collaborations kept supporting throughout the development of the four groups. This collaboration enabled the four groups to have guest speakers from different organisations to deliver information sessions.

Resources from the community, especially logistical and financial resources, supported the development of the four groups. Local councils provided two peer support groups with meeting venues. A group facilitator found financial support from local community:

We did not have an ABN. This meant that we can't apply for and receive external funding directly. We chose an auspice organisation to support us and keep the funding for us... our auspice organisation is now a community-based charity organisation with religion background.

performative because they did not receive any follow up responses or note any improvement in support delivery. A relevant example was that many participants had been dissatisfied with their Local Area Coordinators (LAC) in the NDIS for years, but nothing changed after repeated complaints with the organisations or the NDIA, as a father shared his experiences:

> We have participated in the NDIS for four years. [However] until this year, I was told that we are entitled to final check the funding application before it was submitted. No one [LAC] had told us this before. So irresponsible... They [LACs] had high turnover rate. I once met three LACs for a review. You never know whom to contact with.

In addition, social policy also affected the development and continuation of the four groups. Funded by the NSW government and first launched in 2013, Ability Links NSW aimed to offer aspirational, person-centred and flexible support for people with disability aged 9 to 64 years, their families and carers. Ability linkers,

cha and banquet. These events are now forbidden under the current policy... but, it was through these yum cha and banquets that the group developed a strong solidarity... The current policy did little in cultivating trust between peer members and that between organisations and groups.

The staff member added that she had accumulated many insights into supporting

The four disability peer support groups allowed a bilingual researcher (Qian Fang) to attend and observe their online group sessions[4]. The researcher started collecting observation data from June to September 2020. The observation notes focused on: the structure of each session; how research participants engaged in each session, including their comments, interactions with the group facilitator, guest speaker, and other group members; the research participants' informal communications with the researcher; and the researcher's reactions to the observations at the sessions. The aim of collecting observation data was to understand how the groups provided support to the peers; how the group facilitators organised the group sessions; and group-organisation engagement.

Inclusive methods were used to facilitate the participation of people with disability and their families in the research. Peer researchers were invited to ensure the expertise of people with disability and disability practitioners were included in all phases of the research. Interview questions were flexible and adjusted by the researchers according to the communication needs and preferences of the research participants. The research team developed bilingual versions of the information and consent forms written in plain English and Chinese to ensure that the research participants were more comfortable in participating in the research.

3. Data analysis

References

Australian Bureau of Statistics. (2016).