Australian Chinese Disability Peer Support Groups in Sydney

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January 2022

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Suggested citation: Fang, Q., Fisher, K.R., Poon, AWC., Duong, J., Lee, JS., Li, B. (2022). Australian Chinese Disability Peer Support Groups in Sydney. Sydney: Social Policy Research Centre, UNSW Sydney.

Contents

Executive summary

A lack of suitable disability support excludes many culturally and linguistically diverse (CALD) people with disability from one of Australia's major social policy reforms, the National Disability Insurance Scheme (NDIS). Their exclusion is due to two unresolved problems – inadequate understanding about what they need; and poor responses to their needs (Senerathna et al. 2018). Recent empirical evidence indicates that disability organisations working with peer support groups run by and for people with disability and their families from CALD backgrounds is a promising approach for organisations to improve their support quality (Fang et al. 2021). Evidence is needed to inform how to facilitate and support CALD disability peer support groups in culturally responsive ways.

Funded by the Disability Innovation Institute (DIIU) of University of New South Wales (UNSW Sydney), this research examined how disability organisations support and work with CALD disability peer support groups to provide quality and sustainable support in the context of the NDIS. We collaborated with three disability organisations in Sydney. These organisations established and support multiple peer support groups for people with disability and their families from a range of cultural backgrounds. We selected four disability peer support groups that the organisations work with. The four groups mainly support Australian Chinese people with disability and their families[1]. We looked at Australian Chinese as an entry point to future research, which will include other diverse cultural backgrounds.

This research was a qualitative study. We collected data from observations of six group activities and 40 interviews with group members and disability practitioners to understand how Australian Chinese people with disability and their families perceive good disability peer support; what factors contribute to the development and sustainability of the perceived good disability peer support; and the implications for practice and policy improvement for grassroots peer support initiatives and quality disability support.

Good disability peer support as perceived by participants

Drawing on their experiences of disability peer support groups, the Australian Chinese participants said good peer support contained two components: emotional support from people with shared experiences; and support to improve the peers' capacity. Peer support groups were a platform to socialise, develop bonds, share lived experiences, feel understood, and develop a sense of belonging. Young adults with disability referred to the capacity building as the capacity to make new friends. Family members expected good peer support to improve their capacity to navigate the NDIS.

Preferences for cultural responsiveness in good peer support varied among the participants relative to their primary language. Participants whose primary language

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[1] One of the groups was run by and for families of people with disability from Asian backgrounds, and most peer group members were Australian Chinese.

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 more likely to accept peers from various cultural backgrounds and used English to communicate across cultures.

Contributors to the development and sustainability of good disability peer support

Facilitating a disability peer support group that meets participants' expectations requires effort and support to the group in the way it operates internally and the way the group engages with the community.

Group facilitators played a significant role in the development and continuation of perceived good peer support. The participants suggested the qualities of a good facilitator include:

- Lived experience of disability or caring for people with disability
- Empathy with peers' experiences and needs
- No intention to make profit or take advantage of the peer support group
- Capacity to mobilise resources and organise activities with the group.

Disability organisation support was another contributor. Organisational support can focus on supporting the group facilitator and providing various resources for the groups' activities. The research identified elements for organisations to conduct constructive engagement with CALD disability peer support groups. These include:

- Assigning a capable staff member to liaise with the group
- Respecting the expertise of the group members and cultivating group autonomy
- Providing ongoing capacity building for the group facilitator and staff liaison
- Facilitating inter-agency collaborations with other organisations to mobilise resources for disability peer support.

Working with CALD disability peer support groups benefited both the groups and the organisations. The groups benefited from receiving the support they needed for development and sustainability. The organisations reaped further understanding about people with disability and their families from CALD backgrounds for the development of culturally responsive practice.

Support and resources from the disability sector and local communities complement those at the organisational level. The research found that collaborations among disability and community organisations helped mobilise resources for grassroots peer support initiatives.

Social policy influences the development and sustainability of CALD disability peer support groups in three ways:

- 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 CALD people and frontline professionals.

Implications for practice and policy for culturally responsive disability support

The research has implications for disability organisations to facilitate and support CALD disability peer support groups. These include:

- Facilitating and supporting CALD disability peer support groups is an approach to improve the organisation's disability support to people from CALD backgrounds
- Identifying, and supporting a good group facilitator is key to establishing and maintaining a good peer support group
- Organisation's engagement with peer support groups should include the expertise of the peers and respect group autonomy
- Continuous capacity building for the staff liaison and group facilitator contributes to the development and sustainability of peer support groups.

Social policy change could better support the grassroot CALD peer support initiatives. Changes include:

- Working with CALD disability peer support groups
- Including a position, such as Ability Linker, to cultivate organisation collaboration across disability and CALD communities
- Ensuring the expertise of CALD people and frontline practitioners are heard and included in policy making

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 run by and for Australian Chinese people with disability and their families. They were supported by three disability organisations[2]. The groups varied in size, ranging from 15-160 peer members. The groups ranged from 2 to 5 years in operation.

The research focused on the Australian Chinese disability peer support groups for two reasons. Given the heterogeneity of multi-cultural Australia, we used Australian Chinese peer support groups as an entry point to future research that will include other diverse cultural groups. The research team has bilingual researchers who speak Chinese and English, which made it easier to build rapport with the Australian Chinese participants and collect data. Chinese is the largest ethnic minority group in Australia.5.6% of Australians identify as having Chinese ancestry (ABS, 2016).

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[2] Two groups were receiving support from the same organisation.

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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[3] Some interviews were with couples (fathers and mothers of people with disability). The six sessions were organised by the three groups except for one group. The group was not running any sessions during the data collection period.

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 peer support groups: meeting people with shared experiences and providing emotional support to each other.

A participant, a young adult with autism, said that he liked to attend the group activities because they were a good opportunity to meet new friends. He mentioned that he regularly contacted the facilitator [a young adult with autism], discussing how to organise group activities, although they were not friends yet. He invited the facilitator to go out to watch a movie together before COVID. The participant's mother said that the peer support group established a platform for young people with disability to engage with each other and develop a bond. This met her expectation about good peer support for her son, although she noted that the group had space for further improvement. The mother explained her expectation about good peer support among young people with disability like her son was to:

> organise various outdoor activities, such as watching movies, going to cafes, and so on. The activities will attract young people and help develop a bond among them.

According to a mother of a young adult with disability from another group, the group organised many outdoor activities, inviting people with disability and their family members to BBQs, picnics in park, and one-day trips. The mother said these activities were particularly valuable for people with disability:

> Our children with disability don't have many opportunities to go outside and socialise. [These activities] bring them to outdoor work out, which is a good emotional outlet for them, and also enable them to meet new friends in a natural way.

Many parents said that their children with disability benefited from emotional support from peers. However, there were fewer peer support groups for people with disability than for family members. A mother commented:

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 about [the NDIS] funding, they just complained and nagged.

In addition, participants said that strong and stable emotional support occurred naturally among people with shared experiences over time. They did not like the occasions where they were forced to share their lived experiences in the peer support group. A mother of a child with disability recalled her experience attending a peer support event to articulate the difference:

I once attended an event … The organiser asked us to share our experiences… The requirement put me in a dilemma. [On the one hand], I felt my experiences were too heavy to share so easily with strangers. [On the other hand], I was afraid to annoy the organiser if I did not participate in the sharing... I prefer sharing my experiences in a natural way [with those I trust] rather than in a such intentional way... The facilitator never forced us to do that… He said it [emotional support] occurred naturally and by fate.

Participants said that they used another aspect to assess good peer support which was whether they could learn new things. Content of the expected learning varied by the group members' support needs. Young people with disability were keen to improve their social network through joining peer support groups. Good peer support among young people with disability was referred to the improvement of ability to meet people at their age and develop friendship, as said by a mother:

[Good peer support group activities should be] be run by the young adults ... through which, they develop their capacity... For young people with disability,

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 himself/herself.

It seemed that the two types of support, emotional and informational, complemented and influenced the quality of each other. Many participants said that they would sense emotional support from the informational support they received when they were in a good peer support group. A mother compared her experiences of attending two peer support groups:

> I like talking to the facilitator because we have similar experiences ... On the contrary, the facilitator of another group was a professional but had no family member with disability. He does not have a deep understanding about the tough challenges that we face. He organised sessions for us to get together, complaining and seeking comfort. He provided some formal disability support information... But he did not have an emotional bond with us.

All participants said that good disability peer support had two parts: 1) emotional support among people with shared experiences; and 2) learning new things. While young people with disability expected to improve their social skills, families of people with disability and middle-aged people with disability or mental health conditions expected to obtain more quality information about disability support from the peer support groups.

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, including one of the groups in this research. She compared the development of a peer support group for Australian Chinese people and a

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... The group's size shrinks over time. I have to recommend some Chinese members from that group to the Chinese group... When people from different cultures form a group, it is very hard for them to develop a strong rapport.

Some people from different cultural backgrounds developed good peer support. One of the peer support groups in this research had primarily members from Chinese background, but the group also had members from other Asian cultural backgrounds, including Korean, Japanese, Sri Lankan and so on. The facilitator of that group said the shared lived experiences formed a solid foundation for the group members to develop rapport. A member from the group, a mother of a child with disability, shared her experience of receiving support from a Sri Lankan parent in the group:

> She [the Sri Lankan mother] once suggested that I could apply for 'Young Carer Scholarship' for my daughter who helped care for her sibling with disability... She gave me all the application documents she used for her son and encouraged me to follow step by step... without her encouragement, we would be scared off by the complexity of the application... [The scholarship] provided AUD 3000 per year for five years. It is a large amount of money [for us].

Some participants also expressed their awareness of limitations for a peer support group to be dominated by one culture and one language, although they admitted that the strengths outweighed the limitations. For example, each culture has its taboos. If a person's concern was related to a cultural taboo, he or she would find it very hard to discuss with the peers from the same cultural background. A mother of a young adult with disability said:

> I have a concern: how to arrange my child's life after I pass away. I know it is a heavy topic for most Chinese parents... I tried to bring up the topic, but other parents in the group quickly changed the topic. It seemed that they did not want to talk about it now.

A father mentioned another example to demonstrate that some shared information or experience in a Chinese group might be biased:

> Asian parents are protective, they're very afraid that their children might get hurt or make mistakes... Australian parents will allow their children to try... They give them a lot of independence... I find that Australian children are more confident than Chinese children... So this is one thing that perhaps Asian parents can learn from Australian parents... [When I attended another multi-cultural parent peer support group], sometimes when Australian parents shared their experience, I would ask myself, "can I do this or can I use that?"… As an Asian, it might be a new way of parenting. No harm trying.

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Young people with disability and their parents said that if the peer support group was run by and for young people with disability born in Australia, having the same cultural background was not necessary for cultural responsiveness. A mother from the group said:

> My son can speak Chinese, but English is his mother language. His friends come from various cultural backgrounds... Australia is a multicultural country. I encourage him to engage with people from different cultures.

A staff member who supported the group run by and for young people with disability from Chinese background contended that the current constitution of the group, all Chinese participants, was partially attributable to the parents' Chinese background and Chinese cultural values, as explained by her:

> The group had both young people with disability and their mothers attending at the very beginning... The peer facilitator [a young man with autism] might be soft-spoken, a little bit new to the peer facilitating role. His upbringing is you listen to your elders… He said, it's really hard when [the facilitator's] mother is always taking over the conversation.

People with disability and their families whose primary language was not English preferred engaging with peers from the same culture with their primary language and considered the same culture and language as essential to cultural responsiveness in peer support. Young people with disability who were born in Australia were comfortable with peers from different cultural backgrounds. Their participation in a peer support group that was mainly people from a Chinese culture reflected their parents' preferences and mirrored the child-parent relationship in Chinese culture.

2.3 Summary

All the participants held a similar perception about good disability peer support. The perception consisted of two components: 1) meeting people with shared experiences and providing emotional support to each other; and 2) learning new things from peers. The expected learning varied amongst cohorts of participants. Families of people with disability and middle-aged people with disability expected to receive quality information about disability support to navigate the NDIS. Young people with disability expected to develop friendships with other young people though good disability peer support.

The research suggested that cultural responsiveness was closely related to good disability peer support. Cultural responsiveness in good disability peer support referred to two parts: 1) responding to people's cultural preferences in peer support; and 2) responding to the cultural influences that prevent people from receiving quality emotional and informational support.

Shared culture and language did not necessarily lead to good peer support. Australian Chinese people whose primary language was not English were more likely to receive quality informational and emotional support from peers who were

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. Development and continuation of CALD disability peer support groups

Facilitating a disability peer support group that meets participants' expectations requires effort and supports for internal operations and external relations to the community. Contributing factors include: a good group facilitator, support from disability organisations, inter-agency collaborations among disability and community organisations, supportive policies. This section outlines the relationship between these factors and the development and sustainability of the four peer support groups.

3.1 Group facilitators

Group facilitators and groups' development

The group facilitators played a key role in influencing the groups' operations. For example, one group facilitator, who was a person with mental health conditions, paid special attention to the mental wellbeing of his group members. He opened a Wechat group (social media) for the group members' daily engagement. The facilitator considered improving his group members' mental wellbeing as one of his group's responsibilities. He supplemented the monthly group sessions with online group chat which did not have time and space restriction and provided prompt support when the group members needed. Before COVID, the group's peer engagement was a combination of offline group activities and online chat. When COVID began, the facilitator ceased offline group sessions before the government's formal lockdown policy and started running group meetings via Wechat platform. During lockdown, he found professional IT support from a disability organisation, through which he moved the monthly group sessions to Zoom. Since COVID, the group members have been very active in online engagement. The Wechat platform had many posts from the members with a variety of topics, including various disability support information, updated COVID safety information, pictures of cooked food, cooking recipes, daily routines during COVID lock-down, greetings during important Chinese festivals, jokes, and popular videos. A mother described the Wechat group as a warm online big family which reduced many members' worries and concerns during the pandemic.

Another facilitator, a father of a young person with disability, did not establish any online platform engagement, although some of the group members expressed the need. Before COVID, in addition to monthly face-to-face activities, he drafted and disseminated monthly newsletters within the group through emails. Although the group sessions changed to Zoom meetings during COVID lockdown, the facilitator did not have a plan to establish an online space for the group. His decision was related to his concern about online disinformation. The facilitator was very serious about the credibility of the disability support information that was disseminated on behalf of the group, although he did not discourage the engagement and information exchange among peers at an individual level.

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 them feel safe to share their sensitive support needs, whilst a facilitator without lived experiences may unintentionally hurt other members. They also pointed out that facilitators without lived experiences were more likely to oversimplify peer support as a group of people getting together, chatting and complaining.

Moreover, the participants said that a good group facilitator should be a person who would not be motivated by financial gains. A group member explained as follows:

> A good group facilitator should not intend to seek monetary opportunities... it is hard [to resist the temptation] for many people... You can't calculate [cost and benefit in] facilitating the group... [The boundary is] you can't take it [facilitating the group] as a business.

Many group members welcomed a high level of information transparency within the groups because transparency demonstrated a group facilitator's commitment to the group's interests. The participants mentioned some indicators that they used to assess the group's transparency, such as developing a small committee with peer members, collective decision making within group, and financial reporting to funding agencies and group members.

The participants also emphasised another quality that they expected a good group facilitator could have is the capacity to mobilise resources and organise activities with peer members. All the four groups ran monthly information sessions or social activities to provide informational and emotional support for their members. Facilitating the sessions required various resources, which meant that the group facilitators needed to excel at seeking and organising resources.

Two peer facilitators received high compliments on their abilities to seek resources and organise group activities. They were not disability practitioners but excelled at securing funding from local councils and governments for group activities. One facilitator developed stable and long-term collaborative relationships with several disability support organisations. The disability support organisations arranged guest

speakers for topics that the group members were interested in and supported the facilitator in applying for external funding. In turn, the facilitator's group helped the disability support organisation gain a better understanding about Australian Chinese people with disability and their families. In addition, the two peer facilitators encouraged their group members to actively participate in disability research conducted by universities, providing another channel for the members to voice their thoughts and experiences. Many participants from the two groups said that they would turn down all other activities and even apply for leave from work to attend the monthly group events. According to them, these events were thoughtfully organised and reflected the group members' support needs.

Supporting good facilitators

All the disability practitioners in this research admitted that it was very hard to identify a person that obtained the qualities of a good peer support facilitator. Once they identified one, they would support the facilitator as much as they could. However, the external support to the identified group facilitators concentrated on financial support, introducing guest speakers for group sessions, and providing introductory guidance about organising and managing group activities. Whilst the support was helpful, they were insufficient for the sustainability of peer support over time. A facilitator, who has voluntarily served the role for over eight years, expressed his complex feeling. According to him, he started facilitating the group out of a compassionate sense. Then, the group's development gave him a sense of achievement which served as a new motivation. However, in recent years, he felt that he was trapped in a dilemma, as he described:

> It [facilitating the group] is pure voluntary but involves huge time and energy. I have to establish and maintain relationship with funding bodies, deal with paperwork, design group activities, and so on. I never anticipate any financial benefit from the facilitation, but I do have some expectations. I hope there could be a peer support group for senior facilitators like me where I could exchange experiences and learn from others. [I expect there could be] a certain form that acknowledges my contribution, my capacity… I feel a bit lonely. Facilitating the group now is out of a sense of obligation rather than motivation. There is no one willing to be my successor.

3.2 Organisation-group engagement

Drawing on the engagement between the peer support groups and disability support organisations, the following three practices facilitated the development and sustainability of the groups.

Allocated staff liaison

All the three organisations assigned a staff member to liaise with the peer support groups. A dedicated contact person was a valuable asset to both the group and organisation in two ways: 1) the staff member would collaborate well with the facilitator to support the group; and 2) the staff member would help their organisation to enhance the understanding about culturally responsive disability support.

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 training for them to effectively engage with the peer support group. This factor relates to the third practice in organisation-group engagement, ongoing capacity building for facilitators and staff liaisons.

Ongoing capacity building for group facilitators and staff liaisons

Ongoing capacity building for group facilitators and staff liaisons supported the development of peer support groups. Many uncertainties and unexpected challenges throughout the development of a peer support group occurred. Continuous capacity building helped the group facilitators and organisation staff find solutions to the challenges, especially for the peer facilitators who might not have had professional experience in governance and management. For example, a group member contended that she and some group members expected the facilitator to develop a group charter. With the group's size expansion, these members thought that the charter would help the group's governance and management catch up with the group's development, save the facilitator's time on management, and reach a higher level of group transparency. However, neither the staff liaison nor the group facilitator foresaw and noted this need. This reinforced the necessity of ongoing capacity building support for group facilitators and staff liaisons throughout the development of peer support groups.

This project suggested two principles of ongoing capacity support to group facilitators: 1) providing ongoing training to cover a variety of stages of facilitation; and 2) facilitating peer support among group facilitators. One disability organisation ran a series of peer training sessions several times a year for the groups that it supported. The organisation's staff members were people with disability who were either peer members or peer facilitators themselves. In this light, the organisation integrated staff capacity building into the peer training:

- three-day training for new peer members providing a basic introduction about disability peer support
- three-day peer facilitator training for those who were interested to facilitate a peer support group
- four-day peer mentor training: inviting experienced peer facilitators to the training to provide one-on-one mentoring to facilitators

- 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.

In addition, community events served as a platform for the groups to recruit new members. Many participants said that they joined the peer support groups because they met a group member from a community event.

However, not all disability organisations were willing to support grassroots peer initiatives. A staff member said that protectionism was the biggest obstacle to inter-agency collaborations:

> [Disability peer support groups] are hard to facilitate… we know that's quite resource heavy. Some organisations are protective of their client base… worrying that you [will] then probably grab the team and other people around it.… So there is this little bit of gate keeping happening anyway if they don't understand what we do. I think that mentality has always been there, right, holding your clients.

It seems that the disability sector and local communities has resources that could be further mobilised through collaboration to support grassroots disability peer initiatives. Cultivating the inter-agency collaboration within the sector is beyond the scope of an individual organisation and needs support at the policy level.

3.4 Social policy

Social policy affected the four peer support groups in two ways: 1) meeting the peers' expectations about good support; and 2) influencing the development and continuation of the groups. All the participants expected to receive emotional support from peer support, particularly the support that could positively enhance their wellbeing. Some participants pointed out that their concerns or even stress stemmed from the unmet support needs of people with disability that were beyond the capacity and scope of their peer support group or any individual organisation. Although they had received some relief and comfort from their peers by complaining or expressing their concerns, they asserted that policy development was the only approach to substantially reduce their worries. For example, social support for young adults and middle-aged people with disability was repeatedly raised up in the interviews. A mother's words as follows represented many parents' worry about their children's future.

> There are many services for children before they graduate from high school... and many services for older people when the turned 60s. There is a support gap for young adults and middle-aged people with disability... Adults with disabilities have very few opportunities of socialisation such as parties and meals... I think government's money should invest more on cultivating the talent of these young adults [rather than] just sending them to day care.

Another commonly mentioned problem by participants was the quality of disability support. Many participants said that they complained about their unsatisfactory disability service experiences and exchanged information about quality services in the peer support groups. However, they were aware that the emotional and informational support from peer support does not fundamentally address the problem unless some changes occurred at system level. Some peers shared their experiences of participating in government consultations with people with disability and their families. They felt disappointed and considered the consultations

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, professionals working under the Ability Links NSW, played a key role in the establishment of three peer support groups in this research. Three Ability Linkers helped realise the goal or need of their clients by finding organisations in the disability sector and local communities and collecting and mobilising resources from organisations to establish the peer support groups. When the groups went through the initial stages, the ability linkers gradually withdrew but left the groups with an organisation willing to continue supporting the groups or a network of organisations for the groups to partner with. Ability Links NSW ceased operations in 2019 and transitioned into the NDIS LACs. However, in this study, LACs received more complaints than positive comments by the participants. No participant mentioned that they had received quality personalised support from LACs.

In 2019, the Federal Government launched the Integrated Carer Support Service model, known as Carer Gateway, for anyone caring for a family member or friend who is living with a disability, a long-term medical condition, mental illness, alcohol or drug dependency or someone who is frail due to age. Helping carers access in-person peer support groups is part of the Carer Gateway support package.

A staff member whose organisation was a partner organisation of the Carer Gateway expressed her concern in the interview. Her organisation received government funding to establish and facilitate peer support groups and help allocate carers to the groups. However, she pointed out that the current policy design was rigid, using numbers to hold organisations accountable but overlooking some aspects that she thought were unquantifiable but essential for the development and sustainability of peer support groups. She pointed out that the detailed instructions for organisations to support peer support reflected the government's perception of peer support not the carers'.

> The policy [about facilitating peer support groups for carers in the Carer Gateway] was very strict and rigid. The funding only allowed a staff member to support a peer support group four times at most... Four times is insufficient to establish trust between a professional and a group. Also, the policy strictly limited the group activities that the government funding could sponsor... In the past, our [peer support] group used the funding to organise events like yum

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 grassroots peer support initiatives. However, she did not see the current policies reflect the knowledge of people with disability and their families, and frontline professionals.

Our reflections and learnings need a better channel to be delivered to policy makers... We [frontline practitioners] know what works and what not. We did include our insights in the reports to government. Somehow, the person who read the report was not the one who design the program [peer support from under Carer Gateway]... Some useful lessons from a program were not shared or reflected in another program... You see one step progress through a program and then two steps regress in the next program.

3.5 Summary

The development and sustainability of a disability peer support group that meets peers' expectations requires support and resources from different levels across the disability support system. Details about the factors that contribute are outlined below:

- A good group facilitator refers to a person with disability or family member from a CALD background who has a high level of integrity and commitment to disability peer support and obtains some capacity in event organisation.
- Identifying and supporting a good group facilitator is key to establishing and maintaining a good peer support group.
- Stable organisational support that follows these three principles helps enhance the development and sustainability of disability peer support: allocation of a dedicated staff liaison; coproduction principle that values the expertise and autonomy of the peers; continuous capacity support for staff and group facilitators.
- Inter-agency collaboration amongst disability and community organisations mobilise the availability of the resources in the disability sector and local communities for grassroots disability peer initiatives.
- Two aspects of social policy development are suggested: reflecting the expectation of people with disability and their families from CALD backgrounds about quality disability support in policy development; and including the peers' and practitioners' expertise in facilitating peer support groups in policy development.

4. Implications for practice and policy development

This section outlines the implications of the study for culturally responsive disability support.

4.1 Disability peer support groups are valuable support resources for culturally responsive disability support

This research provided rich empirical evidence that confirmed the value of peer support groups for Australian Chinese people with disability and their families. The study indicates that disability peer support groups provide people with disability and their families from CALD backgrounds with emotional support and knowledge that they are keen to learn. Some benefits from the groups are irreplaceable by formal disability supports.

The role of culture and language in quality peer support varies by the group members' primary language. People whose primary language was not English preferred engaging with the peers who spoke the same primary language and had the same culture with each other. The importance of the same culture and language for peer support depends on the individual preferences of people who were born in Australia.

In addition, disability peer support groups provide a valuable source of information for disability support organisations and policy makers to understand the needs of people from CALD backgrounds. Participants in peer support groups are more willing to express their opinions where they feel safe and encouraged by their peers. Working with CALD disability peer support groups is an approach for organisations and governments to include the expectations of people from CALD backgrounds in practice and policy development.

4.2 Disability peer support groups need external support across the society

The development and continuation of CALD disability peer support group needs ongoing external support from the disability sector, local communities and efforts at system level. Support could centre around three aspects: resources for group operations; group facilitator's capacity building; opportunities for peer support groups to influence practice and policy development. Support that reflects the expertise of CALD people with disability and their families and encourages their autonomy contributes to the development and sustainability of grassroots peer support initiatives. In addition, continuous support is needed throughout the development of peer support groups.

This study reinforces the key role of a good group facilitator in the development and sustainability of a good disability peer support group. This study suggests four traits and capacities that peers value as a good group facilitator: 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.

Group facilitators need continuous support to enhance the following capacities: resource seeking and mobilising, group governance and management, stakeholder engagement, presentation skills, event organisation, and so on. Group facilitators' commitment and contribution are under-estimated and deserve a certain form of acknowledgment by government.

Disability organisations who aim to engage with CALD disability peer support groups for culturally responsive support could invest in three aspects in the engagement: 1) assigning a committed staff liaison with the group; 2) coproduction with the group: cultivating and including the peers' expertise, autonomy and agency; 3) continuous capacity building for the staff liaison and group facilitator.

Creating opportunities for CALD disability peer support groups to influence practice and policy change is another additional level of support for CALD people with disability and their families for two reasons: 1) there are support needs of group members that are beyond the capacity of peer support groups, which needs effort from disability sector or policy changes; 2) the value of CALD disability peer support groups for culturally responsive disability support in the NDIS context has been underestimated.

Appendix 1 Research methods

This section presents a brief summary of the methods employed by the research.

1. Ethical considerations

The research was a qualitative study and incorporated inclusive research principles to prioritise the voices from Australian Chinese people with disability and their families. The research team acknowledged the importance of disability inclusive research practice (Fisher & Robinson, 2010) so that people with disability and their families could actively engage in providing a valid evidence base that can inform practice and policy development. The research team consisted of five university researchers and two peer researchers with lived experiences from a Chinese background and a peer researcher who is a disability practitioner. The research team followed the principles of the National Disability Research and Development Agenda, which reflects the UNCRPD and refines knowledge from international research experience.

The research complied with ethical standards outlined in the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council, 2007). In the research, ethical conduct included recruitment of research participants at arm's length from the research team, collecting observation data after receiving consent from the research participants, providing bilingual version of information sheet, and protecting the research participants' personal privacy. The methodology outlined in this report have been approved by the UNSW Ethics Committee, approval number HC 200018.

2. Data collection

The data collection methods comprised observations and semi-structured interviews with the parties involved in CALD disability peer support, including the Australian Chinese participants, frontline staff members of the three disability organisations who facilitated or supported the peer support groups, and representatives from the NDIS stakeholder organisations who were involved in the group activities. The interview sample sizes are presented in Table 1. The topics of interviews included the participants' reflections or comments on good peer support; contributors to the development and continuation of the perceived good peer support; and relationship between disability peer support and cultural responsiveness in the NDIS.

Table 1: Research participants

		Number
Australian Chinese participants:	People with disability	5
	Family members	35
Representatives of the three disability organisations		5
Representatives of the NDIS stakeholder organisations		1
Total		46

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

The research employed thematic analysis to analyse data. Thematic analysis was used to interpret the themes associated with the research participants' understandings of good disability peer support, culturally responsive disability support, and development and sustainability of CALD disability peer support.

4. Reporting

The draft report will be amended with comments from the three industry partners, the Australian Chinese participants and other stakeholders as agreed. The final report will be provided to the industry partners and Australian Chinese participants. With the permission of the industry partners, the report will be published online. In addition, the report may be distributed specifically to disability advocacy organisations for dissemination and enhance awareness of culturally responsive support to grassroots peer support initiatives.

A summary of the findings will be returned to the research participants. The summary will be in bilingual form written in plain English and Chinese. The research findings will also be disseminated through conference, seminar presentations, forums and journal articles.

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[4] All physical group sessions ceased during COVID.

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