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Why Peer Support is Awesome

How **Communities of Practice** and **Communities of Interest** are helping people living with disability lead a good life

JFA

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Disclaimer: Please note that the authors have developed several scenarios within this paper for illustrative purposes. Many of these scenarios have been inspired by the real lives of people associated with the work undertaken by JFA Purple Orange. However, these scenarios remain entirely fictitious and any resemblance to actual events or a person, living or dead, is entirely coincidental.

Introduction

Why Peer Support is Awesome

How Communities of Practice and Communities of Interest are helping people living with disability lead a good life

In the late 1860s in Montmartre, Paris, the young painter Édouard Manet began frequenting Café Guerbois, which was located within easy reach of his studio. As the years went by, this café became the meeting place for other artists, such as Renoir, Sisley, Monet, Degas, Cézanne and Pissarro. It is unlikely that this group of artists had any conscious thoughts about conducting a 'community of practice' for individuals wanting to better themselves as Impressionist artists. Yet for years they would regularly meet at Café Guerbois on Thursdays and Saturdays to discuss forms of painting, their art techniques and to hold often heated debates over new forms of expression.

Manet—older, wiser and wealthier than the others—became seen as the leader and mentor of this group. Over time, other artistic personalities were attracted to the creative group, including writers, musicians and art critics. By the 1870s, the already famous photographer Nadar, and the writer Émile Zola, were also regular group members.

This regular group meeting of artists in Montmartre depicts what is now referred to as a community of interest (CoI) or a community of practice (CoP). A form of peer networking, CoPs are described by Étienne Wenger as 'groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly'.[1] There are many instances of CoPs that take place, with Wenger listing the following examples:

> *A tribe learning to survive, a band of artists seeking new forms of expression, a group of engineers working on similar problems, a clique of pupils defining their identity in the school, a network of surgeons exploring novel techniques, a gathering of first-time managers helping each other cope.*[2]

By contrast, a community of interest (CoI) is a community of people who share a common interest, passions or concerns. It is a 'gathering of people assembled around a topic of common interest. Its members take part in the community to exchange information, to obtain answers to questions or problems, to improve their understanding of a subject, to share common passions or to play.'[3]

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[1] Encyclopaedia of Informal Education, http://infed.org/mobi/jean-lave-etienne-wenger-and-communities-of-practice/, 2015, 'Jean Lave, Etienne Wenger and Communities of Practice'.

[2] ibid.

[3] F. Henri & B. Pudelko, 'Understanding and analysing activity and learning in virtual communities', Journal of Computer Assisted Learning, vol. 19, 2003, pp. 474–487

So what is the difference and does it even matter? Defining a community of interest and a community of practice

The difference between CoIs and CoPs is not always overly clear, but the good news is that it doesn't matter too much for a network itself.

In essence, some peer networks will focus purely on shared information. These remain as CoIs. However, some networks will go beyond that and provide informal supports for people to apply learning to their own practice. These are CoIs beginning to develop some characteristics of CoPs. Some networks will go beyond that even further and provide formal supports around individual practice, so there is movement towards best practice. These are CoPs.

Some common examples of CoIs might include a book club, an informal playgroup organised by parents of pre-schoolers, or an online community of game enthusiasts.

While it is usually necessary to have an organiser or leader who gets things moving, a CoP is less about structure and more about finding, sharing, transferring and archiving knowledge to the benefit of members. CoPs are not new: this type of learning practice has existed for as long as people have been learning and sharing their experiences through storytelling.[4] As Wenger tells us, CoPs have 'been around for as long as human beings have learned together'.[5]

Communities develop their practice through a variety of activities. The following table provides a few typical examples.[6]

Area of Practice	Example of Activity
Problem solving	*'Can we work on this design and brainstorm some ideas? I'm stuck.'*
Requests for information	*'Where can I find the code to connect to the server?'*
Seeking experience	*'Has anyone dealt with a customer in this situation?'*
Reusing assets	*'I have a proposal for a local area network I wrote for a client last year. I can send it to you and you can easily tweak it for this new client.'*
Coordination and synergy	*'Can we combine our purchases of solvent to achieve bulk discounts?'*
Discussing developments	*'What do you think of the new CAD system? Does it really help?'*
Documentation projects	*'We have faced this problem five times now. Let us write it down once and for all.'*
Visits	*'Can we come and see your after-school program? We need to establish one in our city.'*
Mapping knowledge and identifying gaps	*'Who has what knowledge, and what are we missing? What other groups should we connect with?'*

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[4] http://en.wikipedia.org/wiki/Community_of_practice

[5] Encyclopaedia of Informal Education, loc. cit.

[6] E. Wenger, CoP: A brief introduction, http://wenger-trayner.com/introduction-to-communities-of-practice/

Communities of practice are not described as such in all organisations. They are referred to as various names, such as learning networks, thematic groups, or even tech clubs in the scientific learning world. In the world of disability, a CoI is often goal-focused, where people with a shared experience of disability meet together to exchange information, ideas and experiences for a purpose. This purpose might be varied, including goals like protecting human rights, building knowledge and confidence, connecting to community opportunities, navigating systems like the NDIS, or building connections and averting isolation.

Where the CoI then deepens its work to undertake coordinated action on a matter of shared concern (for example, lobbying for more local accessibility), or using a group process to help people with individual practice (for example, people self-managing their disability supports), then it is becoming a CoP.

An example of the difference between CoIs and CoPs can even be seen in the earlier case study of the Impressionists' CoP in the late 1800s. Due to the appreciation they had developed for the Impressionist movement as a result of the regular café meetings, both the photographer Nadar and the writer Émile Zola publicly defended the work of the Impressionist artists against criticism, and were able to explain the artistic perspectives of the Impressionist painters who were café group members. Across their respective careers, Nadar and Zola became significant advocates for this new style of painting that did not follow the rules of conservative academic painting traditions. Their support heavily influenced other followers to take up similar viewpoints. Nadar and Zola's supportive following of the Impressionist movement began as a result of the CoP style of group meetings.

Examples of topics and issues that a CoI or CoP for people living with disability might focus on

There are all sorts of things that peer groups might want to talk about. We often describe our lives in terms of what we do, what we have, where we live, what we know, where we have been, where we are going, who we know, and all the other things that we do in our daily lives.

In our lives there are things we seek, want and need; things that will help us to live a rich and meaningful life. It can be good to discuss these things with people in similar situations.

The following table provides a list of common topics and questions that peer groups can focus on.

Main topic area	A bit more detail…
NDIS	What is the NDIS; how to be involved; getting ready; rollout; impact; choice and control.
Planning and plans	Pre-planning; planning meetings; planning life goals; what does planning mean; practising planning.
Support	Emotional support through sharing stories and experiences; friendship and social support.
Community	Accessing the community; mainstream community activities; developing community involvement.
Groups	Members discussing peer support groups and planning for the future; e.g., 'planning for future meeting of groups' or 'discussed benefits of peer groups'.
Goals	What is a goal; how to write goals; sharing goals; preparing for discussing goals at NDIS planning sessions.
Information	Verbal information sharing; e.g., recommendations for a health professional or school.
Disability	Sharing diagnostic information; general discussion about disability.
Resources	Relevant websites; books and other written material; games or activities.
Experiences	Sharing positive and negative experiences in relation to disability; lived experiences; and NDIS experiences.

A formal evaluation of peer networks, CoPs and CoIs was undertaken by JFA Purple Orange in 2016. This gave great insight into the benefits of peer networks and peer support as a whole for people living with disability. The main findings from this evaluation are shown in the table below.

THEME	DESCRIPTION
Range of benefits	People clearly outlined the benefits of peer support groups, from information provision, offering a support network and a social outlet, to increasing confidence and more informed decision-making.
Increased social connections	People's social connections have improved. In addition to the meetings, people email each other, have coffee and chats between events, and link in via various Facebook groups. People look forward to seeing each other if they don't live in the same area.
Higher self-confidence	People's confidence to make decisions has grown since joining a peer group.
Greater knowledge	People's knowledge of the NDIS has grown. Participants joined groups to keep up to date in the new NDIS environment. They are hungry for information. Comments are that the information has been 'fabulous'—accurate, insightful and has helped members to change their mindset and take new opportunities. People interviewed are now taking proactive steps to get ready for the NDIS by talking to people in their networks and beginning to plan. They feel more able to make informed decisions.
Form of support	Groups have grown into supportive networks that share similar concerns and demonstrate great empathy and support for one another. Some believe that it is an important source of emotional support for the most vulnerable group members as well as for members going through periods of risk and change.
Group assistance for personal challenges	Groups help individual members to solve their personal challenges. Members suggest possible directions to go if people don't have any experience or contacts. Peer groups give people the ability to do things themselves, and this enhances self-respect and self-worth.
Sense of membership	Members of the network indicated that attending meetings enabled them to feel supported. They found the group a place where 'people understood'; they could share their problems and get ideas and support to deal with their challenges.
Opportunity to develop 'your voice'	Groups were seen as a key way for people to develop their 'voice'; particularly for people living with intellectual disability who may not previously have had the opportunity to speak up about their needs and wants, and to represent these needs to government and other organisations.
Learning about disability funding and systems	People reported that discussions available through the peer groups helped them to learn about the NDIS, and was a more comprehensive, personal and easy-to-access method than trying to access the information via the internet.
Feeling safe	As trust has developed, people now feel safe in the groups to share their experiences with people who understand. Peer group members look to each other for mutual support for the change process they are either engaged in or preparing to undertake with the NDIS.
Enhanced self-capacity	People's capacity to contribute has enhanced. Some members have moved into voluntary roles (welcomer, morning tea, small group facilitator, making reminder calls) within the groups as they have become more comfortable and confident.

How CoPs and CoIs can help people living with disabilities: scenarios that highlight the benefits of peer support

The following scenarios have been developed to illustrate the circumstances and life stories that people may face when living with a disability and engaging with a peer network. Whilst they are a work of fiction, they have been drawn from real-life situations and settings.

The group met regularly at a community hall and was made up of people from all walks of life who happened to live with multiple sclerosis. Through this group, James met older people who had lived with the disease for many years.

SCENARIO 1

The benefits of building knowledge capital through joining a peer network

James was 22 when he was diagnosed with multiple sclerosis—an autoimmune degenerative neurological disorder of the central nervous system. Within a few months, his health had declined rapidly and daily life had become a painful struggle with every movement being a task. His legs had become numb, making them heavy and painful to move. He also had similar numbness in his fingers, meaning he could no longer do simple everyday movements such as dressing, lifting things, driving a car or typing.

Whilst surrounded by friends and family, James knew that they were all leading busy, independent lives. He lived in his family home, dependent on the daily support of his parents, formal paid support workers or the few friends that would keep him regularly included in their lives. James became very depressed and could not see how he would ever lead a happy life filled with meaningful activities.

Reluctantly (to please his parents), James joined a peer support network for people living with multiple sclerosis. The group met regularly at a community hall and was made up of people from all walks of life who happened to live with multiple sclerosis. Through this group, James met older people who had lived with the disease for many years. There were younger people like himself, some of whom were only recently diagnosed. Some people in the group had mild symptoms and were quite physically mobile, whilst others needed to use a wheelchair. Some people had responded well to the latest wonder drugs offered to patients with MS, whilst others had gained significant comorbidities from medication side effects. James found that he quickly formed genuine friendships with people in the group. Social events were organised, such as movie nights, dinners and barbecues. However, James soon discovered that the most useful part of the group was networking with the other members about life with multiple sclerosis.

James gained so much expert knowledge that no amount of appointments with his GP, specialist neurologist, psychologist or physiotherapist could have ever have provided him with. Wise old Barry taught James that abstaining from alcohol in the 24 hours before a bout of intravenous infusion therapy greatly reduces the headaches and chills that follow. Sue showed James how to access a poorly advertised local disability access parking scheme, which entitles users to free use of multiple car parks across the CBD. Matt, Nadia and Sam were also in their twenties and could advise James on things like finding a job, talking to friends about MS and the art of managing a normal social life (including sex) despite aggressive, uncontrollable symptoms.

James soon found that he had acquired a circle of friends sympathetic to his life with MS. Through these connections, he was able to go out a lot more and eventually move into a share-house arrangement that suited him and his parents. Today, he leads a full life and keeps in regular contact with the people he met all those years ago in his first peer support group.

SCENARIO 2

Example of how a CoI can evolve

A large heated swimming pool surrounded by gum trees exists in a leafy suburban area of Adelaide. This pool is used for a variety of activities, including swimming lessons, school swimming carnivals and hydrotherapy for people living with injury, illness or disability.

The pool is a popular option for hydrotherapy because it has a nearby car park, a ramp at one end of the pool, a wheelchair hoist and handrails that extend along its entire length. Swimmers can move through the water and gaze up at the trees (spotting birds and the occasional koala). The atmosphere at the pool is enchanting and welcoming.

During a dedicated hydrotherapy session, where people register to attend for a 45-minute session of unstructured, self-directed swimming, a wide variety of people can be seen using this pool. At one end you might find older members of the community keeping fit while having a yarn. The other end may host people living with disability benefiting from gentle movement in the warm water. Sometimes there might be people who have sustained a sporting injury who are on a strict rehabilitation program to get back to their game.

Jill and Maria met at this pool in their retirement. They became friends and both invited other friends to attend the weekly hydrotherapy sessions, followed by a coffee afterwards. They would chat, discuss the various ailments that had arrived with older age and share information, stories and wisdom. In particular, they banded together to swap details from one another on how to get the most out of retirement.

One day, Maria asked Jill and the others if they would be interested in creating a more formal retiree group and expanding so that more people could come. Maria felt it was important for such a group to exist because she knew of many retired persons who were experiencing loneliness or isolation since giving up their formal work roles. The others agreed and they arranged to meet at each other’s houses and have structured meetings where people came along with a topic relating to retirement that they wanted to talk about. These included financial issues, travelling, hobbies and how to meet more people.

Over time, what began as a few people chatting during a hydrotherapy session in a swimming pool, evolved into a formal and thriving long-term CoI.

SCENARIO 3

How a CoI can practically assist members with stages of the NDIS

Lindy is an 18-year-old student living with cerebral palsy who belongs to a CoI for young people who live with disability. The group meets monthly and has tended to be based around social events rather than structured information sessions. The group is led by a paid facilitator, who also acts in the capacity of support worker to those who need any assistance.

Lindy is soon to be transitioning to the NDIS and has been quite anxious about what this will mean for her. She and her mother have read information brochures and website pages relating to the NDIS, but are still uncertain about how to do the planning process and what things they need to be describing when they meet with a planner.

Other members of Lindy's peer group shared the same concerns, so it was decided that for a few sessions the group would focus solely on discussing the rollout of the NDIS and what this transition would mean for them. The group facilitator organised for a representative from the NDIA to be present for one session so that people could ask private questions. They were also able to think of relevant examples to highlight to a planner what a 'typical' day is like for Lindy and what a 'worst-case scenario' day is like.

Through these NDIS-focused sessions, Lindy and her mother were able to make a draft plan, including swapping ideas with other group members around equipment, services and daily life needs.

Best of all, Lindy and her mother were able to discuss with other families whether or not they could self-manage Lindy's plan. One family had already been through the transitioning process for their young son, and were able to explain from their perspective what the process had been like. Other families were also able to recommend particular service providers to Lindy, or recommend against using others.

Following the information sessions, Lindy and her mother felt far less anxious and more 'in the know' about the NDIS rollout and the different stages of the pathway. Lindy was pleased that she knew so many other people in the group who she could talk to about these issues.

SCENARIO 4

How a small, informal community of interest can take action for change within a local community

Phoebe is a young mum who lives with an acquired brain injury (ABI) following a car accident. She enjoys taking her toddler, Felix, to local places within her community, such as the nearby wetlands, playgrounds, shopping centres and her local community library.

The nature of Phoebe's ABI means that she walks with the use of a walking stick and has very limited ability to move her left leg. Whilst she has been able to regain the strength and mobility to drive, she is unable to walk quickly, carry things easily, bend down or sit on the floor.

Phoebe belongs to a local parenting group, which runs as a community of interest for parents living in the local community. They get together weekly, rotating around one another's houses. The group operates as an informal playgroup for the pre-school-aged children. Sometimes grandparents, family friends, neighbours or visitors join too, so there is always a thriving group for the regular catch-ups. Phoebe enjoys the group and is grateful that a natural, unspoken arrangement has taken place: owing to her passion for cooking, she takes responsibility for baking something to share at each catch-up. In return, the other group members take it upon themselves to help Phoebe out physically during the catch-ups, such as helping Felix climb onto the play equipment, sitting down to play with him on the floor or chasing after him outside when he wants to run around. This gives Phoebe the chance to sit down and have a break, knowing Felix is safe.

One day, Phoebe's friend Melissa mentioned that she never sees Phoebe and Felix at the local library's baby playtime weekly sessions that most of the group members go to. Phoebe explained that she tried to attend when Felix was a baby but the whole session was geared around sitting on the floor and doing actions and movements with your baby.

'It's just too hard,' Phoebe said. 'I can't sit down on the floor and I can't do many of the actions. There aren't any chairs for me to sit on and there wouldn't be much space for that anyway.'

Melissa mentioned that her mother has the same problem following a hip replacement and also avoids joining for the library session. Another friend, Nicole, overhead the conversation and said that she, too, had missed out on the library baby sessions for more than two months after having her second child. She had been recovering from a Caesarean and couldn't sit on the floor and do the actions.

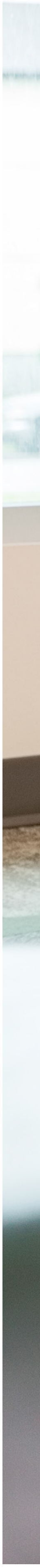
'It's silly,' said Melissa. 'Maybe the library isn't aware that this is a problem. What if we spoke to them to see if they could provide a few chairs or even a bigger space with lots of chairs?'

It was agreed that they would email the library to explain the situation. They carefully composed a friendly email that outlined the different situations members of their group had faced that had excluded them from joining in the baby playtime sessions. Melissa sent it to the local library after finding a contact email address on their website.

A reply came within a few days from a library representative, who thanked them for bringing this situation to their attention and ensured that the matter would be raised with management.

When the new term of baby playtime sessions commenced, Phoebe, Melissa, Nicole and their friends were delighted to see that the library was advertising a new venue for the baby playtime sessions. The community hall, nearby to the library, would now be used for all sessions. This venue came with lots of space, and people could choose whether to sit down with their child on big floor mats or use one of the many chairs available.

Phoebe and Felix are now regular attendees.



In return, the other group members take it upon themselves to help Phoebe out physically during the catch-ups, such as helping Felix climb onto the play equipment, sitting down to play with him on the floor or chasing after him outside when he wants to run around.

SCENARIO 5

How councils, governments or organisations can support local CoIs through a partnership approach

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Phil, Kevin and Shirley are friends through a peer support group for people living with early onset dementia (EOD). The group meets fortnightly at a space offered at the premises of a disability service provider. Meetings include a mixture of purely social get-togethers, occasional days out to a place of interest and information sessions.

Phil, Kevin and Shirley bonded quickly upon first meeting each other because although from different walks of life they all now experience early onset dementia, with symptoms and abilities varying between them. They soon realised that they all share a love of gardening, and so they started an informal gardening club where they would swap cuttings, tips and produce with other members of the group.

One day, Phil decided that he wanted to do more with his gardening skills. He suggested to Kevin and Shirley that they, and anyone else interested from the EOD peer group, should try to do something with their gardening skills within the local community. Several people were interested and Phil approached the local council within the area in which the peer group met.

‘We meet here regularly, and we have skills and time on our hands. Could we start a community garden?’

Sadly, the council was unable to endorse this idea, stating that there was no space nor funding for such an initiative. Phil and his friends were deflated by this but accepted it.

Some months on, Phil realised that there was a primary school close to the service provider organisation at which the peer group met.

‘What if we approached the school and asked if we could help them with any gardening projects?’ Phil asked the group.

They agreed to do this, and the school principal was very open to the idea of this group volunteering with gardening within the school grounds. After obtaining the necessary police clearances, Phil and the other group members cleared a big section at the back of the school oval and prepared the soil for a native plant and succulent garden.

The school principal was impressed at the dedication of this small group. He asked them if they would be willing to commit to a longer project should funding be successful. Phil and the group were excited by this and agreed. After several months, a formal project group was formed, backed by funding from the Education Department, to support Phil and the peer group members to create a ‘kitchen garden’ of herbs, fruits and vegetables for the school students to use, especially for those students in out-of-hours care who needed an afternoon snack following the school day.

As the funding allowed for transport assistance to and from the school, as well as a support worker to assist them as needed, Phil and the other group members were able to commit to this project even with the symptoms of their dementia worsening over time.

They soon realised that they all share a love of gardening, and so they started an informal gardening club where they would swap cuttings, tips and produce with other members of the group.

Why is peer support awesome? Feedback from involvement in CoIs and CoPs

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Quotes and stories from real-life people who have shared their experiences about belonging to a peer network, community of practice or community of interest.

'If it wasn't for the group, I'd live in a hermit shell. Staying inside with all my doors and windows locked. The group all have a disability, and we can communicate as a group and accept each other's disability, not be so judgemental, negative and all that. We step each other through our disabilities.'

– Peer network member, NSW

Some of the Hunter group speaking about what the peer support group means to them:

'The group has helped and is good because we receive important information to operate our own skills. There is more interaction through participating in meetings, but, most importantly, our peer connector is a fellow "consumer" and we are all on an even level. We have only been meeting a little while and I have gotten three big things from the meetings. The first was that our peer connector taught me to ask questions of my service providers. The second was being able to negotiate a shorter time for notifying the service of my not being able to go out for the day due to my mental health. I now only have to give 24 hours' notice, which is much better. I got this from our second meeting. The third big thing was that our peer connector went away and got information for me about how to get my statements from my service provider or the NDIS. I cannot use a computer or read very well and did not know how to get the information I wanted, and our peer connector got the information. He put it into easier language for me and explained it, and I went away and got what I wanted myself. Now I know where my NDIS money is being spent.'

'The group is good to learn about each other and reflect about learning as well, as it is good information.'

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'The Peer 2 Peer network has benefited me and my family immensely. I got a much better understanding of the NDIS through the monthly meetings. I was supported by the peer network when I came up against a few issues with providers and was given great advice on what to do to resolve issues in a positive way. I was encouraged and supported to self-manage my daughter's funding, which is working out very well and benefiting my daughter greatly. I am very grateful that a network like this exists and [I] couldn't have done this journey without them.'

– Peer 2 Peer network member

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'The Peer 2 Peer network has provided me with valuable support at a time when I felt great uncertainty and vulnerability. By sharing our knowledge and experiences of the NDIA/NDIS process specifically, and other matters generally, we have been able to feel more in control and less bewildered; more confident about making the best decisions for our family members. It is extremely rewarding to be able to give support when needed, and very comforting to have such support, and to know we are not alone.'

– Peer 2 Peer network member

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'Our facilitator is fantastic and we can rely on her to share good information about the NDIS, and support people in a very positive way.'

– NDIA planner

'A local support group in Kallangur is just another exciting way to bring people with disability together to fill in the tapestry of support for people with disability in the area. I would expect us to have lively meetings where people can have their voice heard and ensure that there is "nothing about us, without us".'

– A QDN board member

Members of the Fitzgibbon local support group:

'With the NDIS coming, groups like these will become more important. I am proud to be part of the formation of this local support group.'

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Another new member also shared that he is:

'looking forward to growing the group and sharing information'.

Some of the Team Up peer group members:

'There's this magic that happens when someone comes with a problem that they don't know how to solve, and someone in the group says, "oh, don't worry, I had to deal with that last week, this is what I did," and suddenly things that seemed impossible, become possible. Then that person comes back next week and shares what happened, and how they also took something else in their life on, like joining a gym, because they had been inspired by someone else's story. People take up all sorts of new opportunities that they didn't know existed.'

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'Advice from a peer group is practical, empathetic and authentic. There is no conflict of interest, no bias or business interest, and we have a lot of laughs along the way.'

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'Although the group was small, there was a lot of information sharing. One parent disclosed that she is dyslexic and was feeling overwhelmed to think she will need to navigate the NDIS with limited reading and writing skills. Although this parent had attended all other sessions, she had only hinted at limited computer skills in the past. I think because it was a session which had smaller numbers, she felt more comfortable to disclose to the group. Another parent has teamed up with her to help her navigate the NDIS. The peer support benefits of this group are evident when scenarios like this arise, and the parents are able to lean on each other outside of the sessions for support.'

From the Tweed Heads 'Café Our Way' group:

'Today was the first Tweed Heads meet for the Café Our Way group. Not only was I proud to be yarning about the NDIS to members of my local community, I was also able to host the event at the newly opened #CrackedBeans coffee van and open-air café. There was lots of community support in this more comfortable setting that made everyone feel at ease, and the relaxed vibe made talking about the NDIS easy for people with mental health and grandparents to understand information about assistance for their disabled grandkids.

'The information shared today was valuable for members as they had concerns about support needs and whether they would be able to get back to their homes after a social outing. Other important needs were mobility aids to get connected directly into community and visit grave sites unable to be accessed without the mobility aid.

'All the group are excited to come again to the safe place created for the Tweed Heads Café Our Way group.'

Notes from a peer network leader who facilitates a regular peer group for people living with an acquired brain injury:

'We have come to accept the highs and lows, and, in fact, we are not that keen on having too many in a group. Some members in large groups get smothered (i.e. can't get a word in), while others who would expose their trouble to a smaller, more intimate group, are embarrassed to do so to so many people of the larger group.

'I feel at the group meetings that food on the table whilst a session is in progress is a good thing. It is generally difficult for people living with brain injuries to concentrate for too long during a session, but the distraction of having to reach for and/or take a bite of a home-cooked sausage roll is sometimes enough to alleviate the tiredness that comes with concentrating. This may seem trivial but I've learnt with brain injury that minute things can be either extremely annoying or very uplifting.

'In this case, I feel the food we put on the table is uplifting and with that it is therefore an aid to ongoing concentration.

'Allocating specific jobs to specific members; i.e., that someone sets the tables, or the first one there turns the lights and air-con on, etc., is a good strategy to use. Just little jobs; give the members a sense that they are contributing and appreciated. It all adds up.

'Peer support is definitely the way to go. Members heal their own problems, or at the very least feel good about themselves, whilst trying to heal others. The analysis of human nature indicates fulfilment of the soul comes from caring about our fellow man. Some care for profit, i.e. money or ego. But when caring becomes a not-for-profit gesture, the giver receives nature's reward as fulfilment.

'However, as much as the word "peer" indicates equality, I do think to overcome the many personality clashes in a group setting there should be a police person of sort. Not so much a leader, as one of the members will emerge as one willingly followed by the rest of the group, but a watcher or director of sorts, just to keep the ship floating.

'We want to be people talking to people; we are all in the same boat.'

How CoIs and CoPs can help advance the National Disability Strategy

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The concept of CoIs or CoPs is in line with the National Disability Strategy 2010–2020.

Outcome 4 states that: 'People with disability, their families and carers [will] have access to a range of supports to assist them to live independently and actively engage in their communities.'[7] The future action to 'promote and sustain community support networks which provide information and support to families and carers'[8] links nicely with the concept that peer support networks (such as CoIs or CoPs) can help strengthen people's decisions and actions in relation to, for example, public transport, housing, education, employment and health.

An example of a community of interest is that of 'Patients Like Me'[9,10], which is a 'patient-powered' research network that improves lives and, in conjunction with a research platform, advances medical research. As described on the Patients Like Me website:

> *…people connect with others who have the same disease or condition and track and share their own experiences. In the process, they generate data about the real-world nature of disease that help researchers, pharmaceutical companies, regulators, providers and not-for-profit organisations develop more effective products, services and care.*[11]

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[7] Commonwealth of Australia, National Disability Strategy 2010–2020, Commonwealth of Australia, Canberra, 2011, p. 47.

[8] ibid, p. 52.

[9] http://en.wikipedia.org/wiki/PatientsLikeMe

[10] http://www.patientslikeme.com/

[11] http://en.wikipedia.org/wiki/PatientsLikeMe

How government and community leaders can support CoIs and CoPs

Peer support groups are good examples of how CoPs/CoIs can deliver strong benefits in assisting people living with disability and their families to develop their knowledge base and take positive action in support of their life chances.

Government at all levels, and local councils, can assist CoP/CoIs by acknowledging the benefits that they bring and committing to sustained investment in building momentum for these types of networks.

In particular, CoIs/CoPs are potent mechanisms for assisting people living with disability and their families to acquire knowledge that will equip them to navigate the NDIS, mainstream services, and mainstream community opportunities. The Commonwealth Government can fund the continued development of CoIs and CoPs as a component of the NDIS implementation to full scheme and beyond.

In particular, given the current rollout of the NDIS, an investment in CoIs and CoPs can, at this stage, offer participant benefits in key areas, such as pre-planning, planning, self-management and community linkages, which will bring not only good outcomes to participants, but also a sustainability boost to the NDIS.

The responsibility does not only lie with the Commonwealth Government. Local council and communities can also support established and emerging peer networks by giving them access to local resources, which can assist CoPs/CoIs to gain momentum for the benefit of that council's community.

Partnership approaches with mainstream organisations (including local government and community centres) in delivering peer networks create potent links that benefit both peer network participants and partners.

This in turn will bring with it an opportunity for community groups to make submissions/bids to the NDIA—and other commonwealth, state, territory and local government—for funding to help people to act and implement ideas, and as a way of assisting communities to contribute to their own development. This is a form of community development where community strengths, such as skills, experiences and wisdom, are developed for the common good.

How you can start a peer network, CoI or CoP

There are a range of ways in which peer support networks can be of benefit to people living with disability and their family members.

Evaluation data has shown tangible benefits are emerging for people who are members of peer support networks. These benefits are in areas such as fellowship, information, increased confidence and capacity, and social connection and leadership, including impact on disability service design, such as the NDIS and community accessibility.

There is also a theory about the effectiveness of peer support that identifies five areas of psychosocial benefits that come from being around, talking to and associating with peers. Essentially, the theory is that hanging out with peers is a cool, fun thing to do, and it also does good things such as building individual capacity, providing emotional support, being able to help others and learning from others who have had a similar experience.

These are the five areas of psychosocial benefits from peer groups based on an article by Mark Salzer:[12]

1. **Social support:** peer support groups give social support to people, which comes from being part of something, a sense of belonging, a feeling that people care about you and a connection to others. The supportive resources that come from peer support can be emotional or practical, such as gaining information, as well as providing companionship and connection to others.
2. **Knowledge gained through experience:** peer support is unique because it is support through perspectives that people have from living through a particular experience. This makes it specialised knowledge that only people with a lived experience (of disability, in this instance) can bring. It cannot be taught or learned, it has to be lived.
3. **Social learning theory:** this is the idea that people can develop new and helpful habits by observing and learning from what other people do (sometimes called role models). If a person sees or hears peers doing something a certain way that seems to be helpful, then that person may try the same things.
4. **Social comparison theory:** this is the idea that we all compare ourselves with others. It explains how, by making such comparisons, people can evaluate their own opinions and abilities. If people hold similar views, then this leads to reinforcement and a building in confidence. If the views of others are markedly different, then this can lead to someone testing and perhaps modifying their own view to help move towards their goals.
5. **Helping others helps you:** this is the idea that by helping others we get a benefit to ourselves. Peer support has the potential to be mutually beneficial for all parties involved. It may be that a member of the peer support group gets help from the group, but it is also likely that at some point they will also be able to assist another member. Doing this can be a real confidence booster because it means the person has valuable experiences to share that can help another person along.

While this is the theory, the reality is much more straightforward: people benefit when they connect with people they feel are ‘like’ them. Peer support usually comes from a development of relationship and trust between members and a sense of solidarity. It can be informal and can take many forms, such as face-to face meetings or online.

Peer support is seen as increasingly important because it acknowledges and uses the power of lived experience. This can reap many benefits both for the individuals and also for the wider community, as people become more confident, capable and informed so as to influence their lives outside of the peer group. It doesn’t replace ‘experts’ or professionals but it is seen as a way of achieving positive outcomes.

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[12] M. Salzer, ‘Consumer-Delivered Services as a Best Practice in Mental Health Care and The Development of Practice Guidelines’, Psychiatric Rehabilitation Skills, vol. 6, no. 3, 2002, pp. 355–382. M. Salzer, ‘Consumer-Delivered Services as a Best Practice in Mental Health Care and The Development of Practice Guidelines’, Psychiatric Rehabilitation Skills, vol. 6, no. 3, 2002, pp. 355–382.

Where you can find more information

There are lots of online resources about peer support groups.

Peer Connect has a great video about peer networks based on Families4 Families:

- *peerconnect.org.au/*

The Centre of Excellence Peer Support – Mental Health has great resources about peer support. This page explains what peer support is:

- *peersupportvic.org/index.php/2014-12-15-22-41-58/2014-12-15-22-59-27*

The above resource also has a Charter of Peer Support:

- *peersupportvic.org/index.php/2014-12-15-22-41-32/2014-12-15-22-46-46*

Peers for Progress is a website all about peer support:

- *peersforprogress.org/*

Funding opportunities for peer networks, CoIs and CoPs

The Cancer Council offers an online resource that includes a good guide relating to managing groups and how much thought should go into the financial aspects of peer support group establishment at:

- *canceraustralia.gov.au/sites/default/files/publications/peer_supports1_504af01f596c3.pdf*

Australian Government Grants information can be found at a range of sites. You can search online for specific local council and state programs (such as SA's site:

- *grantassist.sa.gov.au/community*

You can also go to the federal site:

- *grants.gov.au/*

This will direct you to additional grant opportunities.

The Centre of Excellence Peer Support – Mental Health hosts great resources about peer support. There is information about funding and items to consider in the guide available here:

- *peersupportvic.org/index.php/2014-12-15-22-42-49/2014-12-16-02-22-27/Resources/CEPS-Setting-up-a-Peer-Support-Group/*

National Disability Insurance Agency (NDIA) offer funding opportunities from time to time, and these are managed via the government's community grants hub:

- *communitygrants.gov.au/*

Other useful stuff

Peer Connect

The Peer Connect website is dedicated to providing information and resources related to peer support:

➔ *peerconnect.org.au*

Peers for Progress

A website all about peer support:

➔ *peersforprogress.org/learn-about-peer-support/what-is-peer-support/*

SHARC

An organisation that advocates peer support for people and families impacted by drug and alcohol misuse:

➔ *sharc.org.au/peer-support/*

Mental health sector

Reimagine Today is a dedicated website assisting people living with mental health conditions to navigate the NDIS:

➔ *reimagine.today/*

Peer Zone

Peer-made resources for people with mental distress and their supporters:

➔ *peerzone.info/*

Brook Red

A Brisbane-based, peer-managed and operated community mental health organisation:

➔ *brookred.org.au/peer-support*

Notes

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