

Communities of Practice and Communities of Interest

A Way of Sharing, Connecting and
Informing for People Living with Disability



This paper was prepared by

JFA Purple Orange
104 Greenhill Road
Unley SA 5061 AUSTRALIA

+ 61 (8) 8373 8333
admin@purpleorange.org.au
purpleorange.org.au
facebook.com/jfapurpleorange

Contributors

Mikaila Crotty
Robbi Williams
Jackie Hayes

ISBN: 978-0-6481903-1-8

Acknowledgements

JFA Purple Orange acknowledges valuable input from Mike Haines and Ann-Marie Loebel to earlier drafts of this paper.

This publication was made possible through the financial assistance of the Julia Farr MS McLeod Benevolent Fund.

Contents

04	Foreword
05	The benefits of a community of interest or a community of practice
09	Considerations from the perspective of living with an acquired brain injury or degenerative neurological disorder
13	Background
15	Introduction
16	Defining Col and CoP
16	Col
17	CoP
18	The similarities and distinctions between Cols and CoPs
19	Why now? The challenges presented by the NDIS and the NDS
21	Examples of Cols and CoPs at work
23	How to create and maintain Col/CoP
25	The challenges of Col/CoP
26	How Col and CoP can be applied to the stages in the NDIS
28	Recommendations
28	Concluding remarks
30	Summary and recommendations
31	Appendix 1

Foreword

The benefits of a community of interest or a community of practice

Considerations from the perspective of living
with an acquired brain injury or degenerative
neurological disorder

Christina was 58 and working full time in the corporate sector when she acquired a brain injury following a stroke. After several months of rehabilitation, Christina was able to speak more clearly yet still had very limited movement in her left arm and left leg. Her memory was deeply affected and she found that she tired easily. She became depressed and life was difficult for herself and her husband, Tim.

Through an association that exists in her city to support people living with brain injury, Christina was able to join a community of interest group for people in similar situations. This group met regularly to swap information, share their stories of recovery, enjoy social occasions and generally support one another. The group was facilitated by a staff member from the association and family members were welcome to join in the meetings.

After several months, Christina had settled into the group and enjoyed belonging. She had made a solid friendship with another lady who was a similar age, and they kept in close contact between group meetings via email and Facebook. A common topic of discussion was reorganising

or managing finances. Christina was chuffed that other group members asked her for advice, as she had previously worked in accounting. Together, the group assisted a young member to talk to his parents about living independently. Many of the families connected to the group had furniture and house items to offer him when he eventually made the big change in living arrangements. Christina was delighted to help him create a basic living budget.

Over time, this group became a significant part of Christina and Tim's lives, with Tim even becoming friendly with group members through social and fundraising events. Together with other group members, they developed a comprehensive set of fundraising, book-keeping and budget tools that went on to be used by a number of different community organisations.

The above scenario is a work of fiction yet it offers a realistic and poignant example of how a community of interest (CoI) or a community of practice (CoP) can be helpful to those living with acquired brain injury or degenerative neurological conditions.

A CoI can be described as a network of people who share the same interests, knowledge and understanding of a given subject. People take part to exchange thoughts and ideas about their common interest. A CoP generally refers to the use and understanding of a specific common interest or profession. For example, an organised group that shares and practices the same understanding and ways of doing things for a given subject. These terms, and their similarities and differences, are explained in more detail in section 4.

The term ‘community of practice’ was originally coined to describe the type of community atmosphere created by people who were apprenticing and mastering a trade. Now, a community of practice can refer to any loose or structured learning environment or situation where mentoring and the fostering of knowledge of a specific trade, specialised practice or genre of knowledge occurs.

CoPs have the potential to contribute to the National Disability Insurance Scheme (NDIS) through deepening and extending peer networks and activities in relation to accessing mainstream community resources. A CoI or CoP that benefits people living with an acquired brain injury or degenerative neurological disorder needs to have that as its primary focus.

Families4Families is a useful case study in relation to this. In 2012, in South Australia, people with acquired brain injury (ABI), and family members, established Families4Families as a way for local support groups or peer networks to provide mutual emotional support, social connection, information sharing and up-skilling. Goals include improved psychological wellbeing and greater control towards good life chances. Families4Families describe their group as offering ‘a new approach to providing support to families

impacted by ABI in SA. People living with ABI and their family members are designing, operating and evaluating their own support network’.¹

As shown by its growth, and the continued membership and momentum of the peer networks it has established, Families4Families has built successful and sustainable communities of interest. At least in part, this is because the organisation has a focused and well-defined purpose for such networks, which is to assist members build *capacity*. Each network develops its identity through members’ interests, goals and knowledge, and the types of information and discussions that can help them.

Each Families4Families peer network provides an opportunity to develop relationships, learn and develop practice, create new knowledge, connect into community and influence decision-makers. These networks provide a mechanism for people living with acquired brain injury or degenerative neurological disorder to initiate action and manage positive change in their lives.

As such, Families4Families is an excellent example of how CoIs can assist people living with disability to build capacity and prepare for new systems, such as the NDIS. The evidence suggests that the development of social capital and knowledge capital via CoIs/CoPs could bring significant gains to people living with disability and their families, especially in relation to preparing for the NDIS.



¹ <http://families4families.org.au/about-us/our-story/>

The benefits of CoPs for individuals include that they:

- enable people to manage change;
- provide the individual with access to new knowledge;
- foster trust and a sense of common purpose in the individual; and
- add value to lives.^{2, 3}

As a mechanism for knowledge creation, sharing and capability building, CoPs can also contribute significantly to organisational development via:

- the informal sharing of valuable information;
- improvements in productivity;
- the fostering of innovation;
- the reinforcement of strategic direction.^{4, 5}

As such, CoIs/CoPs can be contemplated not just by consumer-led organisations and groups, but also by service provider agencies interested in building a stronger sense of partnership with the people they serve, and in finding innovative, person-centred solutions driven by people's aspirations for a meaningful and fulfilling life.



² J. Mitchell, S. Young & S. McKenna, CoP and the National Training System, ANTA.

³ NDS, loc cit.

⁴ J. Mitchell, S. Young & S. McKenna, loc. cit.

⁵ NDS, loc. cit.

Background

There is a proverb used in reconciliation efforts in Rwanda that states ‘to go fast, walk alone; to go far, walk together’.⁶ This proverb is highly relevant to peer networks, which by their nature require members to collaborate with each other. In essence, collaboration begets collaboration and a healthy cycle is born.

For many people living with disability, the ability to stay connected to information, resources and other people is life-changing. Information and knowledge are powerful and enabling tools that help us to navigate our life circumstances. A peer network, such as a community of interest (CoI) or community of practice (CoP), can provide a useful way to gain more knowledge, information and resources from a network of group members.

This paper provides an overview of the nature, extent and benefits of CoIs and CoPs for people living with disability, both generally and in relation to the National Disability Insurance Scheme (NDIS).

The idea behind CoIs and CoPs is that people with comparable experiences spend time together to access information and share experience and mutual support. Each individual benefits from the learning while sharing their knowledge and experience for the benefit of others.

Given the large-scale policy reform that is taking place in Australia, there are increasing signals that people joining peer networks can be a really potent way for those living with disability to make progress in their own lives.





Introduction

Good investment in knowledge and, more importantly, in how knowledge is used, has gained momentum across many aspects of our daily lives. An *information economy* in which knowledge is the primary ‘raw material’ and source of value has emerged.⁷

However, the availability of information on the internet has not replaced the value that people get from simply talking to others as a way of gaining information and knowledge. The value of peer networks rests in the value of the shared understanding that comes with lived experience. Network members consistently confirmed that they are more receptive when information comes from their peers. This is because its validity and reliability is enhanced by the implicit knowledge and insights of people ‘who understand’.

Good (and bad) information can be gleaned from many different sources, but connecting with others brings a new way of learning and additional benefits. People need good information to make good choices; hence the term ‘informed choice’.

For people living with disability, there has never been a more important time to exercise informed choice. It is a key ingredient in the hoped-for success of the NDIS, which is founded on values about people having control and choice in their lives, and in ways that bring participation in community life and the economy. When a person has good information, then that person has a better chance of navigating complicated schemes such as the NDIS.

Arguably, knowledge is different to information. When people receive and internalise information, they will add, for example, their own perceptions, beliefs, previous known information, lived experiences and active testing of the information. As information becomes internalised

in this way, ideally with a sense of growing coherence, it becomes knowledge.

This pool of knowledge is part of a person’s *knowledge capital*.⁸ It includes what a person knows and can do, and, crucially, it includes how people access information and from whom. JFA Purple Orange considers the development of knowledge capital as critical to a person’s life chances.

In this way, knowledge—driven by good information—is important to a person, not only in successfully navigating the NDIS but also in accessing broader opportunities to build a meaningful and fulfilling life.

This consideration of the role of information and knowledge in the emerging NDIS has in turn led to a renewed focus on how people can connect with others in similar situations as a way of learning. People living with disability can create the opportunity to connect to peers and hear from them about their views, decisions and actions, and the impact these are having on their quest for a fair go at what life has to offer. One term that describes these regular connections between a group of people is peer networks.

The mutual exchange of life experiences through a peer network can bring to each member a range of benefits, including affirmation, challenge, motivation, insight and practical suggestions; all founded on the sharing of information.

7 <http://www.businessdictionary.com/definition/information-economy.html#ixzz3VFjXBPIF>

8 R. Williams, *Model of Citizenship Support*: 2nd edition, Julia Farr Association Inc., Unley, South Australia, 2013.

Peer networks can be formal, but they also happen naturally in community life. There are many different ways that people ‘catch up’ with other people in their lives, such as at clubs, at barbecues, at community places or events, at each other’s homes or at the pub or café. When people get together they often share information about what is happening in their lives and have a chance to discuss things face to face. Sometimes they will talk through a trouble or concern where others can help.

While this happens organically for many people because of the connections they have, it can also happen in a more planned way; for example, via CoIs and CoPs. Such networks include formalised peer networks. Therefore, it is useful to look at the nature of CoIs and CoPs and how they can help people, because there is likely to be strong relevance for people living with disability, particularly if a CoI/CoP can help people navigate the NDIS.

The NDIS is anchored on the value that scheme participants—people living with disability—will have greater control and choice in their lives and will increase their participation in mainstream community life and the economy. Information and knowledge will be key to the success of the scheme and the outcomes for its participants.



Defining CoI and CoP

4.1 CoI

A community of interest (CoI) is a community of people who share a common interest, passions or concern. 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’.⁹

*These people exchange ideas and thoughts about their given interest, but may know little about each other outside of this area. Participation in a CoI can be compelling, entertaining and create a community where people return frequently and remain for extended periods. Often, they cannot be easily defined by a particular geographical area.*¹⁰

Examples of a CoI might include a book club, an informal playgroup organised by parents of pre-schoolers, or an online community of game enthusiasts.

The extent of CoI in the disability sector in Australia is difficult to determine. A search of internet resources provides no information about identifiable CoI focusing on disability issues. There are, however, organisations with formalised structures and identities that, even though they don’t use the term, have the characteristics of a CoI (for example, organisations such as People with Disability Australia, Physical Disability Australia, Brain Injury Australia, Women With Disabilities Australia, Inclusion Australia, Blind Citizens Australia, and Down Syndrome Australia).

Some general examples of CoIs may include:

- a group of family members, each of whom have an adult son or daughter living with

an acquired brain injury or degenerative neurological disorder, who might connect with each other to share information and ideas on how best to find good housing support for their family members;

- a group of young people living with disability, who might connect to discuss access issues and life chances; and
- family members, who might connect with other families interested in how their children living with disability can get a fair go in mainstream education.

Setting up a CoI can be straightforward, and can also involve important considerations, such as:

*... building a shared understanding ... of the task-at-hand, which often does not exist at the beginning, but is evolved incrementally and collaboratively and emerges in people’s minds and in external artefacts. Members of Communities of Interest must learn to communicate with and learn from others ... who have different perspectives and perhaps a different vocabulary for describing their ideas, and to establish a common ground ...*¹¹

The above quotation suggests that in order for a CoI to function well, over time the members must learn to work well with each other, communicate well with each other and establish shared goals and purpose.

However, while there can be practical challenges to overcome, if the potential members have a strong shared interest or passion, or a shared restlessness about a particular issue, then that will be an important anchor point for the CoI.

⁹ F. Henri & B. Pudelko, ‘Understanding and analysing activity and learning in virtual communities’, *Journal of Computer Assisted Learning*, vol. 19, 2003, pp. 474–487.

¹⁰ http://en.wikipedia.org/wiki/Community_of_interest

¹¹ G. Fischer, *CoI: Learning through the interaction of multiple knowledge systems* (2001), 24th Annual Information Systems Research Seminar, Bergen, Norway.

4.2. CoP

‘A community of practice (CoP) is a group of people who share an experience, passion, craft and/or a profession.’¹² They may connect and share information about a particular role they have, so they build a collective understanding of what good practice looks like and can use this knowledge to influence their own individual practice.

*The group can evolve naturally because of the members’ common interest in a particular domain or area, or it can be created specifically with the goal of gaining knowledge related to their field. It is through the process of sharing information and experiences with the group that the members learn from each other, and have an opportunity to develop themselves personally and professionally.*¹³

Educational theorist Étienne Wenger identifies three crucial characteristics of a community of practice:

1. The *domain*: an identity defined by a shared domain or interest. Wenger states:

Membership therefore implies a commitment to the domain, and therefore a shared competence that distinguishes members from other people.

2. The *community*: members build relationships with each other that enable them to learn from each other. While the community may learn from and with each other, they do not necessarily practice together. Each individual may use their knowledge alone. Wenger provides a useful example:

The Impressionists, for instance, used to meet in cafés and studios to discuss the style of painting they were inventing together. These interactions were essential to making them a community of practice even though they often painted alone.

3. The *practice*: members of a community of practice are practitioners, and they develop

a shared practice through sharing their resources. This requires regular interactions and commitment. It needs to be a sustained effort on the part of the members of the group. Wenger notes:

*A good conversation with a stranger on an airplane may give you all sorts of interesting insight, but it does not in itself make for a community of practice.*¹⁴

Each individual may benefit from the learning but that is not the sole reason for being part of the community. Each individual also wants to share their knowledge and experience for the benefit of others. This may be:

*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. In a nutshell: Communities of practice are 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.*¹⁵

CoPs are dynamic social structures that require ‘cultivation’ so they can emerge and grow. CoPs have a social architecture, which includes relationship building, collaborative learning, knowledge sharing and action.¹⁶ Most CoPs have a threefold circle structure: a core group, an inner circle and an outer circle. The core group acts as a managing group: this would include the facilitator, coordinator or community connector who gets the group running, coordinates the activities and organises the practical requirements of the CoP. The inner circle is the members of the group who actively contribute to the CoP and attend regularly. The outer circle consists of interested members. They are contributors and clients of the CoP.¹⁷

¹² http://en.wikipedia.org/wiki/Community_of_practice

¹³ J. Lave & E. Wenger, *Situated Learning: Legitimate Peripheral Participation*, Cambridge University Press, Cambridge, 1991.

¹⁴ E. Wenger, *CoP: A brief introduction*, <http://wenger-trayner.com/introduction-to-communities-of-practice/>

¹⁵ 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’.

¹⁶ D. Cambridge, S. Kaplan & V. Suter, ‘Community of Practice Design Guide A Step-by-Step Guide for Designing & Cultivating Communities of Practice in Higher Education’, EDUCAUSE Learning Initiative, 2005.

¹⁷ J. Skalicky & M. West, *UTAS Community of Practice Initiative: Readings and Resources*, University of Tasmania, Tasmania (undated).

While this provides a formal structural explanation of a CoP, and how it may be organised, many are more informal than this and evolve over time. 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.¹⁸ They have ‘been around for as long as human beings have learned together. We all belong to Communities of Practice, a number of them usually. And we travel through numerous communities over the course of our lives’.¹⁹



18 http://en.wikipedia.org/wiki/Community_of_practice

19 <http://infed.org/mobi/jean-lave-etienne-wenger-and-communities-of-practice/>, loc. cit.

The similarities and distinctions between CoIs and CoPs

Appendix 1 offers a comparison between CoIs and CoPs. However, the difference is less important than recognising that both sit within a spectrum, where CoPs tend to have more detailed organisation and more mutual commitments among the members in terms of how they share what they know and apply what they learn, than do CoIs.

Although there are differences in intent and purpose of CoPs and CoIs, they also share some common features. CoIs and CoPs differ in social context and learning continuums. CoIs focus on information exchange on a common topic, and in knowledge construction for individual use; CoPs stem from existing individual practice where development occurs through knowledge sharing among members, and incorporating new practices into individual expertise.²⁰

The commonalities for both community types include:

- shared interests;
- increased understanding of areas of knowledge or practice;
- problem-solving; and
- building relationships.

They are ‘groups which gather first and foremost because of shared beliefs, values and concerns rather than because of proximity of residence or because of established patterns of social relationships’.²¹

Due to the nature of the continuum between CoIs and CoPs, the boundaries between the two groups are not defined. One distinction might be that CoIs are focused on generating and sharing helpful information on matters of mutual concern, but how the individual community members then use that information is up to them. CoPs are also focused on generating and sharing helpful information on matters of mutual concern, but

in contrast to CoIs, they provide guidance to individual members in how to apply this to specific roles and tasks.

The diagram opposite illustrates that a group may come together around a common interest or shared passion. Over time, bonding and purpose can evolve the group’s purpose and goals.



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 but could include goals such as 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.

²⁰ F. Henri & B. Pudenko, loc. cit.

²¹ J. Dixon, *Towards an Understanding of the Implications of Boundary Changes – With Emphasis on Community of Interest*. Draft Report to the Rural Adjustment Unit, University of New England, Armidale, NSW: 44, 1981.

A clear distinction between CoIs and CoPs is not essential in supporting communities to achieve individual or collective goals. A group does not need to agonise over whether it is a CoI or CoP; the group will find its own path. Each CoI or CoP will develop in different ways, depending on the membership and focus on particular goals. Some networks will focus purely on shared information. These remain as CoIs. 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 and provide formal supports around individual practice so there is convergence towards best practice. These are CoPs.

However the network chooses to operate, it is more likely to be successful and sustainable if the network and its members have well-defined purposes. They are successful because there is potency and synergy between people with common interests, common concerns or common roles, who are connecting together to share information and ideas. This then helps people's individual decisions and actions.

These characteristics suggest that both CoIs and CoPs should be worthy of consideration for people living with disability interested in how they can build their chances of an ordinary, valued life.

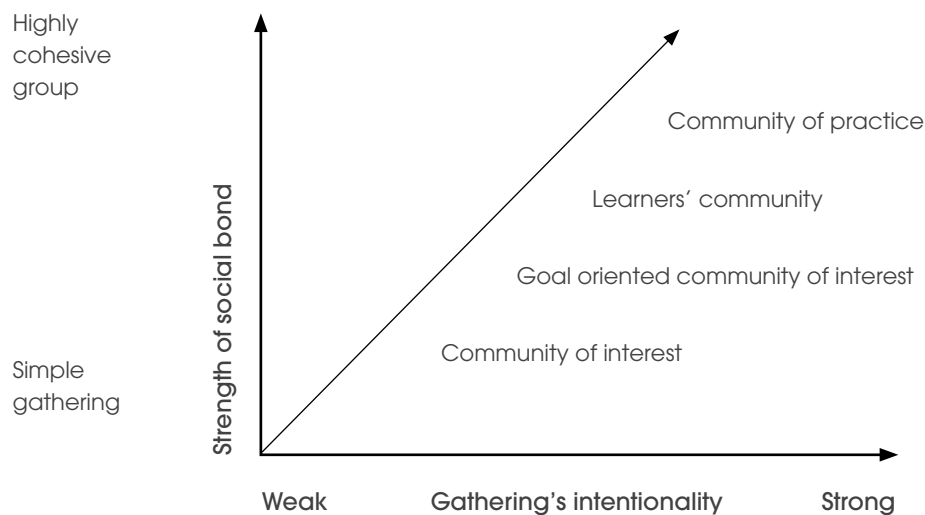


Fig.1. Different for virtual communities according to their context of emergence



Why now? The challenges presented by the NDIS and the NDS

CoIs/CoPs have been potent in various lines of inquiry where the primary focus is about building knowledge and working together.

CoIs/CoPs can provide a valuable channel for exchanging information between the NDIS and the disability community. The continued development of peer groups like these will help strengthen information exchange between the scheme and its participants across a range of key issues. This is important to people living with disability and their families, and to the NDIS' success and sustainability.

CoIs/CoPs can also provide a valuable gateway for people living with disability and their families who are preparing to enter the NDIS. They provide a space for people to test their ideas in their plans. As such, peer networks can assist the NDIS' planning process in ways that complement, and therefore ease the pressure on, the work of the National Disability Insurance Agency (NDIA) planning staff and local area coordinators (LACs).

For example, certain network activities have been shown to be particularly effective in promoting and sustaining CoP/CoI outcomes.

JFA Purple Orange was appointed as the national support agency for the Disability Support Organisation Capacity Building Initiative across 2014 to 2016. Aimed at supporting 18 agencies identified as Disability Support Agencies (DSOs), this project tasked each participating DSO with developing up to 20 peer support networks. Some of the findings from the evaluation of this project include significant outcomes for people living with disability who had joined peer support groups and networks, such as the following:

- Overwhelmingly, the evaluation participants felt that the peer support groups had been helpful across a wide range of areas.
- For participants living with disability, the most popular response was that people felt they had been helped 'a lot' by their participation in peer networks.
- Participants mentioned benefits in relation to access to information and related discussion, building belief about what might be possible, the material benefits of DSO assistance, and the value of fellowship and reduced social isolation.



Examples of CoIs and CoPs at work

There are existing examples of CoIs/CoPs within the disability sector. These enable people living with disability to gain knowledge and use that knowledge effectively to further enhance their life chances. These CoIs/CoPs may have existed before the implementation of the NDIS, and may not bear the title of a CoI/CoP, but they fulfil the criteria of being a group of people—a network—who are active members who share tips and experiences, ask questions of their peers and provide support for one another. The eligibility to be a member comes from the lived experience they share. The following are examples of such CoIs/CoPs.

1. Julia Farr Youth (JFY)²²

Julia Farr Youth comprises young people living with disability who have shared concerns about life chances for young people living with disability. This group is an example of a CoP that has spawned new CoIs over time. They are passionate about youth disability issues, and are focused on empowerment, raising awareness, amplifying concerns and ensuring young people living with disability have the same opportunities as their non-disabled peers. They have a clear membership, and their meetings are characterised by receiving and giving information, and formulating ideas and actions.

Feedback from members of Julia Farr Youth

“

It has given me the opportunity to share my experiences with others. I like to have the opportunity to share advice and strategies that I have learnt through my life. It's been great to meet other young people.

Before finding out about this group, I didn't have anywhere I could go and spend time with other people with similar experiences. This feels like a safe, inclusive space.

It has given me the beginnings of a network of supports (beyond the group) and made it easier for me to deal with my newer disabilities.

I feel less isolated from people with similar life experiences. It's a place to expand networks and meet new people without all of the negativity I experience from able-bodied people.

”



²² <http://www.purpleorange.org.au/projects/jfy/>

2. Inclusion Australia²³

Inclusion Australia (formerly the National Council on Intellectual Disability) is the national voice on issues of importance to people with intellectual disability in Australia. Inclusion Australia brings together members from across Australia, all of whom are connected locally to people living with intellectual disability and who are committed to the vision of inclusion. Inclusion Australia is also guided by the Our Voice Committee, whose membership comprises people living with intellectual disability. Inclusion Australia has extensive resources, information and knowledge, which is freely shared amongst all members.

Inclusion Australia is also a member of Inclusion International, the international network that represents people living with intellectual disability and their families. This provides many opportunities for peers to collaborate and share information internationally. Inclusion Australia is considered to be a CoI.

3. Blind Citizens Australia²⁴

Blind Citizens Australia is the representative body for Australians who are blind or vision impaired. Their mission is to achieve inclusion and equality by empowerment, by promoting positive community attitudes, and by striving for high-quality and accessible services that meet the needs of blind or vision-impaired Australians. Blind Citizens Australia is also considered to be a CoI.

4. Families4Families²⁵

Families4Families was established in 2012 in South Australia by people with acquired brain injury (ABI) for people with ABI and their families. Local support groups provide emotional support, social interaction, information sharing and up-skilling, assisting in mental health management and living lives with meaning and control. They describe their group as offering 'a new approach to providing support to families impacted by ABI in SA. People living with ABI and their family

members are designing, operating and evaluating their own support network'.²⁶

Families4Families is one of 18 agencies who were successful in securing funding under the NDIA Disability Support Organisation Capacity Building project (see below).

Due to its growth, Families4Families is considered to be a CoI that is now exploring CoP elements, such as around planning and self-management.

5. Parents Helping Parents

Parents Helping Parents is a CoI set up by a group of South Australian parents of children living with disability 'who felt that the best, and often only, way to get current, relevant information about services and supports for their children with special needs was by speaking with other parents'.²⁷

Parents Helping Parents delivers information through information sessions rather than regular group meetings, but the ethos is the same in terms of a CoP in that:

The sessions are all led by a parent of a child with a disability who has 'been there, done that'. That is our only 'qualification'.

6. WA's Individualised Services (WaiS)²⁸

WaiS describes itself as 'a community of likeminded people working in partnership at all levels with individuals at the centre to influence and develop innovative, individualised, self-directed supports and services'. It states that it:

*WaiS has a growing member community of people with disability, people with psycho-social disability, families and supporters (paid and unpaid) and service providers, who stand together in their commitment to show leadership and support to improving individualised services, and for people to have good lives in community as citizens.*²⁹

WaiS represents a growing CoI around individualised services.

²³ <http://ncid.org.au/about-us/about-inclusion-australia/>

²⁴ <http://bca.org.au/>

²⁵ <http://families4families.org.au/>

²⁶ <http://families4families.org.au/about-us/our-story/>

²⁷ Parents Helping Parents, 2015, <http://parentshelpingparents.org.au/info/#1>

²⁸ <http://waindividualisedservices.org.au/>

²⁹ WA's Individualised Services, 2015, <http://waindividualisedservices.org.au/about/>

7. West Lancs Peer Support (UK)³⁰

An example of a CoP is that of West Lancs Peer Support. Set up in 1999 by a group of parents whose sons and daughters live with some form of disability, it was felt that a community-based approach to support was the way forward, with parents and family members taking more control over the care their relative needed to lead a life of their own choosing. It was decided that 'direct payments' would allow their sons and daughters to take control of their lives by doing what they wanted to do, rather than someone else deciding for them. At that time there was little support to manage the payments so they formed a self-help group and helped each other to manage the payments. Since then, this has progressed into encouraging the parents the group has helped to in turn help more people new to the scheme.

8. Disability Workforce Innovation Network (Disability WIN)

The NDS established the Disability WIN, a CoP funded with the assistance of the Australian Government through the Department of Education and Training. It was a partnership project with the Community Services and Health Industry Skills Council to run until April 2016. Disability WIN aimed to build providers' knowledge of workforce planning and capability to respond to workforce challenges under the NDIS. The objectives of Disability WIN were to facilitate:

- workforce planning training tailored to the industry's needs;
- collaborative workforce development projects;
- the sharing of best practice;
- the collection and analysis of workforce data to create or strengthen local/regional workforce action plans; and
- networks and CoPs in trial sites to respond collaboratively to common and workforce issues.

9. The NSW Disability Justice Project³¹

This project is building local CoPs throughout NSW for professionals who are interested in promoting better outcomes for people living with cognitive disability, and who are at risk of coming in contact with the justice system. There are 17 groups operating across the state.

10. Disability Support Organisation (DSO) Capacity Building Initiative

During 2015–2016, the NDIA funded a two-year Disability Support Organisations Capacity Building Project (the DSO project). This initiative involved the development of local peer support groups to assist current or future participants in the NDIS and their families. The evaluation conducted at the end of the second year of this project clearly indicated the benefits of peer support groups.

During the DSO project evaluation, a number of DSO employees mentioned that they had worked on numerous time-limited change projects over the years, but rarely had they seen benefits and outcomes emerge as clearly as they did in the DSO project. The fact that NDIS is such a major reform has meant that the wider policy environment has been more willing to encourage change than has been the case in the disability sector for a long time. This was seen as creating the right conditions for the DSOs to generate conversations with their members about self-direction, community participation and future planning. Some employees said that these conversations, which were the central themes of the peer networks, had been happening previously, but in the NDIS context there was more intense interest in the issues, higher levels of engagement with the change process and also a great deal more optimism from their members.³²

In many respects, the momentum of peer networks created through the DSO project, and the collective community of practice, is still in its early stages. As such, the consistency of the benefits that have already emerged suggests that this momentum is worth maintaining and

³⁰ <http://ukpar.org/>

³¹ <http://dj.acwa.asn.au/>

³² JFA Purple Orange, 'The DSO Project: a Summary of Activities and Impact in Support of the NDIS Participant Voice', 2016.

expanding. It is reasonable to anticipate that similar and deeper benefits will emerge as the number of peer networks grows, and as each peer network builds its own deeper momentum. The peer networks that exist via this initiative could be considered CoIs with a larger CoP operating for the DSOs as a result.

11. National Disability Services³³

NDS has created five new professional CoPs to assist service providers' transition to the NDIS. These relate to NDIS:

1. coordination;
2. finance;
3. customers and markets;
4. information and communication technology; and
5. complex clients in the NDIS.

The CoPs are intended to facilitate the sharing of practices and strategies by organisations, and to strengthen professional relationships across the disability sector. Input from the CoPs will help shape priorities for other NDS transition projects and NDS advocacy to the NDIA and governments.

12. Hunter NDIS and Mental Health Community of Practice

The Mental Health Commission of New South Wales collaborated with the Mental Health Coordinating Council (MHCC) between June 2013 and 2016 to undertake a NDIS and Mental Health Analysis Partnership Project. This activity supported directions of Living Well: A Strategic Plan for Mental Health in NSW 2014–2024, adopted by the government in December 2014. A major achievement of the project was the establishment of the Hunter NDIS and Mental Health Community of Practice. This CoP enhanced learning, increased opportunities and reduced challenges associated with implementation of the NDIS in NSW from a mental health perspective. The experience, learning, activity and outcomes of the Hunter

NDIS and Mental Health Community of Practice informed a guideline about how to establish a CoP. It also considered the purpose, benefits, qualities and next steps to establish a CoP.³⁴

13. Reframing the Future³⁵

Reframing the Future was a Commonwealth-funded initiative to develop a new system for Australia's Vocational Education and Training workforce. Led by the Australian National Training Authority (ANTA), the project involved 16 CoPs, from different industries (including community services) each focusing on different aspects of implementing a new national training system.

ANTA found that there were better outcomes for organisations and individuals when people shared knowledge via a CoP. They found that CoPs played a critical role in implementing a new system: they were the 'major building blocks in creating, sharing, and applying organisational knowledge'. Ultimately, CoPs contributed to the development of social capital in organisations.³⁶

14. Understanding Dementia MOOC³⁷

Another example of the influence of CoIs/CoPs on knowledge development is demonstrated in the University of Tasmania's free 11-week Massive Open Online Course (MOOC) on Understanding Dementia. This was developed in response to the predicted sharp increase in the prevalence of dementia; tripling by 2050, with an increase to 890,000 people in Australia. It has been estimated that the current aged-care workforce in Australia must quadruple to accommodate the care needs of people with dementia.³⁸ There is, therefore, a need to provide quality dementia education for health professionals, care workers and family members who care for people with dementia. A lack of dementia-specific knowledge has the potential to diminish quality of care, and thus quality of life, for the person living with dementia.

³³ <https://www.nds.org.au/>

³⁴ http://www.mhcc.org.au/media/85848/ndis_cop_guidelines_final_200117.pdf

³⁵ J. Mitchell, S. Young & S. McKenna, loc. cit.

³⁶ J. Mitchell, S. Young & S. McKenna, loc. cit.

³⁷ University of Tasmania, Understanding Dementia MOOC, 2015, <http://www.utas.edu.au/wicking/wca/mooc>

³⁸ C. King, J. Kelder, K. Doherty, et al., 'Designing for Quality: The Understanding Dementia MOOC', *Electronic Journal of e-Learning*, vol. 12, 2014, pp. 161–171.

Although not named as such, the design of the Understanding Dementia MOOC is that of an online CoP. The MOOC provides expert dementia knowledge content from researchers, combined with students sharing individual knowledge and perspectives via online tutorials, seminars, email discussions, discussion groups, discussion forums and web-conferencing. It aims to create an online community that:

*...leverages the shared knowledge of members, but this relies on the presence of some 'more knowledgeable other in the group'. This approach requires students to engage collectively in developing shared knowledge but only works if students are motivated and technically competent to use and develop the MOOC environment.*³⁹

The evaluation of the initial pilot MOOC⁴⁰ indicated that providing an opportunity for students to contribute to international approaches to dementia care, via online knowledge sharing, added an element of peer support and enhanced connection to the Understanding Dementia MOOC.



³⁹ C. King, J. Kelder, K. Doherty, et al., loc. cit.

⁴⁰ C. King, J. Kelder, K. Doherty, et al., loc. cit.

How to create and maintain CoI/CoP

For those contemplating setting up a CoI/CoP, there are certain elements that need to be present for a greater chance of success. CoIs/CoPs can enable people living with disability to share their experiences and support each other as equals and in ways that build resilience and enhance their lives.

There will need to be clear incentives for participation, clear short-term benefits and a momentum of activity that justifies a time commitment. There also needs to be leadership and perseverance, opportunity to develop skills, and a space that is welcoming and inclusive of a diverse community.

As with all groups, CoIs/CoPs have lifecycles—they emerge, grow, can decline, and can renew. Through a series of steps, individuals can design a network, formalise it, and run activities that grow and sustain it. Ultimately, the members of the network will define and sustain it over time.⁴¹

It is important to remember that not every CoI/CoP will operate in exactly the same way.

*Communities of practice are so many and so diverse that a step by step guide may seem rather presumptuous and linear. Indeed, communities of practice may start in different ways, becoming established out of disorder or conversely, from an already existing organization. However, judging by the processes described in literature and the author's own experiences, setting out a generic logical path is useful guide, even if the core steps are taken out of sequence.*⁴²

Given this, the material in this section is a general guide only.

A typical community of practice lifecycle may involve three phases, as outlined below.⁴³

Phase 1: Establishment

The first phase is one of ideas and discovery: this is a process of thinking, exploring and discovering to help identify the audience, purpose, goals and vision for the community.

*One of the very first and most exciting steps in establishing a community of practice may be in the creation of the idea, discovery of a need and imagining the possible ways forward. A key step at this stage is to harness the interest and enthusiasm of potential key members to see if it grows into something that captures the imagination of the group.*⁴⁴

Some of the questions that could be thought about in establishing a CoI or CoP include:

- Who is the network—the CoI/CoP—intended for?
- How might it help, in terms of benefits to members?
- What will be the network's primary focus?
- Given the intended audience, what are the key issues, needs and the nature of the learning, knowledge and tasks that the network can work on?

Thinking about these and related questions can help inform the design of the network, including whether it is more a community of interest or a community of practice. The questions can also help define the activities, technologies, group processes and roles that will support the network's goals.

Other questions to consider include:

- What kinds of network activities and interactions might help generate energy and engagement as well as support the emergence of community presence?
- How might network members communicate on an ongoing basis to accomplish the network's primary purpose?

41 D. Cambridge, S. Kaplan & V. Suter, loc. cit.

42 http://sydney.edu.au/halloran/publications/PROCTOR_CommunitiesOfPractice.pdf

43 Adapted from D. Cambridge, S. Kaplan & V. Suter, 'Community of Practice Design Guide: A Step-by-Step Guide for Designing & Cultivating Communities of Practice in Higher Education', EDUCAUSE Learning Initiative, 2005.

44 http://sydney.edu.au/halloran/publications/PROCTOR_CommunitiesOfPractice.pdf

- What are the network's learning goals, and how might shared learning be supported?
- How can resources be identified, such as people who can help run the network, a low-cost/no-cost venue for meetings, ways to support people to attend, such as text reminders, shared rides, etc.?
- Are there any other resources that can help the network be welcoming and accessible?

*Once a critical mass of members is on the way to being achieved, a launch event or kick off meeting is an important step, to mark a specific time and place where people can say "that was where it started, all those years ago, and look where we are now!" A kick off meeting should be followed closely by regular meetings so as not to lose momentum.*⁴⁵

Phase 2: Growing

It often needs just two or three people to help initiate a CoI/CoP to help momentum begin. However, maintaining that momentum typically involves more of the network's members getting involved. This includes participating in collaborative learning and knowledge-sharing activities, group projects, and networking events that meet individual, group and organisational goals, but also includes sharing in the jobs that need to be done to make sure the network can continue to operate. This type of network democracy, where CoI/CoP members share in the various tasks that need to be done, can help consolidate the network's identity and shared ownership.

Some of the ways that the CoI/CoP network can do this include:

- agreeing on the goals and rules of the group, and reviewing them regularly;
- agreeing a roster so people take it in turns to do jobs that help the network to meet; for example, arranging the venue, organising the refreshments, booking a guest speaker and researching information;
- finding a variety of ways for network members

to share their experiences and participate in shared learning; and

- running each meeting so that everyone has the chance to have their say and be involved.

Phase 3: Sustain

Over and above the items above, which can cultivate a shared ownership that helps sustain the CoI/CoP network, the network can also think about how it cultivates and uses the collective wisdom and insights that emerge from the activities the network members do together. This can help create new possibilities for the CoI/CoP going forward.

For example, Julia Farr Youth has spent time exploring what the members learnt from their school experience and what they wish they'd been told at the time. From this rich set of insights, the network came up with the idea of a peer mentoring network, involving young adults living with disability providing mentor support to high school students living with disability. This idea took shape and attracted multi-year government funding.

The independent evaluators of the JFY Mentoring program noted that:

The key strength of the program is that young people living with a disability draw upon the experience and expertise of other young people with lived experience of disability. This not only sets up a unique relationship for Mentees, of understanding and trust, but also has many positive outcomes for Mentors in building self-esteem and leadership.⁴⁶

CoI/CoP networks can also explore ways to build relationships with community leaders and create change.

*Communities should actively canvas sector / professional / industry leaders and through this process, enhance community contacts and capacity, and maintain active involvement with cutting edge innovation in the field.*⁴⁷

⁴⁵ http://sydney.edu.au/halloran/publications/PROCTOR_CommunitiesOfPractice.pdf

⁴⁶ Julia Farr Youth Mentoring Evaluation, Clear Horizons Consulting, 2015.

⁴⁷ http://sydney.edu.au/halloran/publications/PROCTOR_CommunitiesOfPractice.pdf

Some important questions for CoI/CoP networks to think about include:

- What are the necessary ongoing CoI/CoP processes and practices that will contribute to the liveliness and dynamism of the network and keep its members engaged?
- How does the CoI/CoP network provide opportunities in the community for members to play new roles within the network and more broadly?
- How are new potential CoI/CoP network leaders (official and unofficial) going to be identified, chosen, developed and supported by the network's members?
- To what extent is the CoI/CoP network serving its intended audience and accomplishing its stated purpose and goals, and what could help strengthen this?
- How does the CoI/CoP network gather information about the impact of the network on its members so that people can see the benefits they are gaining from being involved? This can also help show a return on investment if there are any sponsors involved.
- How might the CoI/CoP network share its insights—the ideas and materials it has developed—so that other people might benefit from them?

Developing a sustainable group culture depends on the actual group. Allowing each CoI/CoP network to evolve, and encouraging input from network members, is critical to a network's success. Different CoIs/CoPs will find their own 'sweet spot'—what works for them—in terms of how they organise themselves. While it can be helpful for different CoIs/CoPs to share their practices, a duplicate formula will not necessarily be successful in every situation.

It is important to note that:

- the more a CoI/CoP has members who are interested in helping out with how the group does its work, the more likely the group will maintain and strengthen its momentum;
- collaboration and trust are cornerstones of groups and communities, where common interests and commitments are shared and promulgated⁴⁸; and
- collaboration does not offer magic solutions and is often tough-going. But if it is done for the right reasons, and in the right way, it can open up possibilities and deliver breakthroughs that traditional means of planning and control cannot produce.

Some CoIs/CoPs will have members who are quick to take more control of the network meetings, meeting planning, where to meet, identifying common issues and solutions, etc. Other CoIs/CoPs will have members who take more time to build momentum before naturally moving into these responsibilities.⁴⁹



48 For example, see: D. Dredge, 'Networks, Conflict and Collaborative Communities', *Journal of Sustainable Tourism*, vol. 14(6), 2006, pp. 562–581.

49 JFA Purple Orange, 'DSO Capacity Building Project Initial Report on First Year Evaluation Data – A briefing paper to participating DSOs', 2015.

The challenges of CoI/CoP

CoIs/CoPs open up new possibilities for people to take control of their own lives, gaining confidence and self-respect through supporting others, improving health outcomes and building stronger social connections through friendships and mutual support.

Developing and maintaining networks are not without their challenges. They require intentional effort, cultivation and facilitation to define and sustain them so that they are helpful and meaningful to members. They are not one-off static events but an evolving community or place built on relationship, collaboration, learning, knowledge sharing and momentum, which can easily be lost or falter at different stages. It has been shown that the benefits make this effort worthwhile, but as Étienne Wenger warns: ‘It is important not to romanticize CoP or expect them to solve all problems without creating any.’⁵⁰

A research report from the University of Sydney⁵¹ summarised the potential problems of maintaining and sustaining a CoI/CoP. In particular, they noted that some CoPs could lose momentum if benefits don’t come through early and often, and also that CoPs can lose their way if the group’s leadership dissipates.

The research report also noted that sometimes CoPs can inherit problems of factionalism, or exclusionary practices, perhaps because of the way they are set up. This may also extend to the CoP being seen by other stakeholders as somehow ‘superior’ in its mindset.

CoIs/CoPs are seen as having a natural lifecycle, or one that ebbs and flows, and typical challenges can emerge. For example, a peer support network may lack purpose or vision, or one person leads the group and there is a lack of sharing the work around, or, as members come

and go, the peer support network hasn’t thought about how to get more members involved in organising the meetings.

How to troubleshoot common challenges:

- Think about the value proposition that a group would offer (information, mutual support, campaign hub or a combination).
- Agree on a set of rules for how people behave at the peer meetings.
- Make sure benefits are delivered early and often so that people keep coming.
- Make sure members share leadership early and often so that the group is not dependent on, or guided by, a single energy.
- Think about leadership succession in networks that might be at particular risk when their founders move on.
- Check in on the network goals regularly, and make sure members are happy with how things are going and have a say in what is happening next.
- Establish ways for network members to stay connected to each other between meetings: contact lists, social media, websites or other communications.

While it is true that a community of practice may simply be underperforming because of a lack of commitment, energy or leadership, or because it isn’t abiding by the principles it set out with, etc., it is possible to identify these risks early on and to find ways to reduce the chances of them happening. CoPs should identify both strengths and gaps early on.

50 E. Wenger, R. McDermott & W.M. Snyder, *Cultivating CoP: A Guide to Managing Knowledge*, Harvard Business School, 2002.

51 D. Proctor, ‘CoP: Getting to the Heart of Workplace Learning, Sharing and Innovation’, *The Henry Halloran Trust Research Report*, University of Sydney, NSW, 2010.

The Head, Heart, Hand model

A well-functioning CoP might exhibit a productive balance of intellectual (Head) enquiry, resulting in a clearly considered sense of identity for the community, with the emotional, personal (Heart) interactions fostering close and trusting relationships, and the practical (Hand) practice or craft that demonstrates competence and reliability that garners respect in the community.⁵²



⁵² D. Proctor, loc. cit.

How CoI and CoP can be applied to the stages in the NDIS

CoIs/CoPs can bring critical added value to the various stages of the NDIS pathway in terms of building participants' knowledge capital and, therefore, the way in which they effectively engage with the scheme. The emphasis is on people living with disability and their families being 'participants' of the scheme as opposed to 'recipients'. The next step is for them to also be practitioners in running their own support arrangements, using CoIs/CoPs to develop knowledge and skills through shared experiences of self-managed supports. This enables the person living with disability to more confidently navigate formal systems like the NDIS, based on what they have learned from other people in similar circumstances.

CoIs/CoPs have the potential to bring NDIS information, processes and possibilities to life. People talk about it, test it, relate it to their own circumstances, and this is particularly useful when navigating a complex new scheme such as the NDIS.

Given the complexity, it can help to look at the NDIS from the point of view of someone moving through the NDIS system, or 'pathway'⁵³. Taken simply, the NDIS involves a pathway that eligible participants navigate. At each step along the pathway there are likely to be options, constraints and decisions that the person and family need to be well-informed about, so that they can navigate each step in a way that strengthens the likelihood of building support arrangements that truly advance the person towards a good life.

These steps along the NDIS pathway might include:

- information and referral, assessment, planning and brokerage (where the person finds, or has someone find for them, the various support

options that might work for the person);

- coordination (making sure all the support arrangements are in place and running); and
- monitoring and review (to see whether the arrangements genuinely helped the person's chances of a good life).

CoIs/CoPs could prove helpful at one, some, or all of these steps, where the network members draw on one another's experiences, find and share relevant information, provide emotional support, etc.

The remainder of this section explores each of these typical steps, and how CoIs/CoPs could help.

Information and Referral

Access to, and the provision of, useful and enabling information has been assumed as the 'entry point' to the NDIS process for eligible participants. The depth and substance of information that is available and accessible for participants will be dependent on where and from whom the information flows. Some participants, because of previous experience of individualised funding, will be well-informed and knowledgeable, while others may not have as firm a sense of what is achievable and available, and their information and knowledge may be patchy and uneven.

The NDIS-funded DSO project, which involved the development of peer networks (CoIs/CoPs), included an evaluation, which provided insights into how peer networks can assist NDIS participants.

For example:

*As the group grows and develops, it is becoming more and more clear how crucial the group is, how much work there is ahead in preparing people [for the NDIS], how little many people know about the NDIS.*⁵⁴

⁵³ <https://www.ndis.gov.au/html/sites/default/files/My-NDIS%20-Pathway.pdf>

⁵⁴ JFA Purple Orange, loc. cit.

Knowledge capital is part of the foundation on which decisions about choice and control can be built. Therefore, it is at the beginning of the pathway into the NDIS that CoIs/CoPs present a real opportunity to make a difference, not only to the individual's experience of the scheme but also to the success of the scheme itself; it seems reasonable to assume that for the NDIS to be successful it needs informed and engaged participants.

In some sense, being eligible for NDIS funding, and gaining entry to the NDIS, demands that individuals seek information, particularly in the planning phases, in pursuit of a 'good life'. It is crucial for the NDIS and its participants that the exchanges of information are both effective and of the highest possible quality. Some of the essential work in information exchange and generating collaborative effort is in building and maintaining trust. Trust is seen as a key element in the development of effective peer support groups. Peer groups develop a stronger foundation and connection with others through building trust and having familiar people to talk through issues and work with.⁵⁵

This is a positive qualitative outcome for the NDIA and the government in that people with increased knowledge capital are better placed to make smarter choices in support of their life chances (and therefore NDIS outcome goals), and a quantitative outcome in that the person will spend the NDIS dollar more effectively.

It is also envisaged that people with greater knowledge capital are more likely to take up individualised (self-managed) funding options as well as access and buy services beyond the traditional disability services sector.

CoI and CoP are valid ways of sharing necessary information and building shared knowledge for dealing with the NDIS funding process. Information is the driving force of the NDIS; a primary source of information is embodied in people's lived experiences and this information, as knowledge, provides bases for choice, decisions and action. It is in harnessing

that knowledge that CoPs or CoIs come into play and have the potential to make a significant impact.

Assessment and planning

These are perhaps the two most important steps within any human service pathway because they involve building a picture of the person's circumstances, especially in relation to understanding the extent of the gap between the person's situation and an ordinary valued life. As such, the focus of assessment is less about measuring a person's disability, and more about measuring its impact on the person's life chances.

It then follows that planning involves developing a detailed picture of the life that the person wants for themselves, and the steps that can be taken to build a path towards it.

It is with these characteristics of assessment and planning that a CoI/CoP can assist, where members can hear about how other people are describing their situations, the goals they have, and how they are moving towards them.

Significantly, a CoI/CoP can be particularly helpful if its members are navigating a new system such as the NDIS, which includes assessment and planning mechanisms.

The NDIA has developed an operational guideline for planning and assessment⁵⁶. 'The Planning and Assessment Conversation' is an essential part of the consultation for developing a plan, which occurs between the agency, participants and those '... who are significant in the life of the participant'.

The focus of the process is to decide on the form and type of supports that will best deliver the goals of the individual participant; these should be tailored to the individual's needs, requirements and goals for a good life. For example, the NDIS planning workbook (current as at April 2018) is designed to help people living with disability in their discussions with the NDIS planners. The workbook addresses the full cycle of planning, implementation and review, which is split into five steps.

⁵⁵ JFA Purple Orange, loc. cit.

⁵⁶ https://www.ndis.gov.au/html/sites/default/files/documents/og_planning_assessment_planning_conversation.pdf

CoIs/CoPs can assist their members to build knowledge about the planning and assessment stages of the NDIS process. People living with disability and their families will likely benefit from hearing from other people who have navigated these processes in the NDIS, or previously accessed individualised funding options from other sources. This sharing of knowledge, and subsequent development of approaches, can assist participants to effectively use the NDIS scheme. Sometimes it may be a question of learning from others' mistakes, but also about finding out what works well and what choice and control really means, and what it looks like in practice.

Importantly, participants might learn through their CoIs/CoPs how to develop a more affirming view of their strengths, their voice and the key things they need help with. Following on from this, a CoI/CoP can assist participants to build a more positive vision of what might be possible in their own lives; to imagine doing ordinary valued things that most Australians perhaps take for granted, such as loving relationships, employment, a fair go at an education, a place to call one's own, and being part of a community.

This type of discovery work often happens in CoIs/CoPs, and can result in a very different plan for discussion with the NDIS. For instance, the evaluation of the DSO Capacity Building Project offers a salient example. This evaluation showed that some people are not aware of the fact that they are in charge of their own lives. About half the participants had thought about goals and plans previously; the other half had not really thought about this and stated they were kind of 'drifting through life', and had not yet thought about their future plans.⁵⁷

Brokerage

The step between the plan and having a set of services in place and ready is often called brokerage. This step involves finding out what the possible support options are and how they can come together. Sometimes a person might choose to do this and arrange supports themselves, and sometimes a person might have someone else do this for them.

Having access to a CoI/CoP can be helpful for exploring not only what support options are out there, but also what types of skills and knowledge to look for when choosing a broker, and in what ways people can do their own brokerage if they want to.

At the time of writing, a definition of the concept of brokerage is not available in the NDIA information; however, the term is used in a Participant's Workbook,⁵⁸ which was developed for NDIS Workshops in 2013.

As at April 2018, the NDIS offers three brokerage options, these are:

1. directly to the service (the same as now);
2. through an independent broker (to assemble a package of supports); and
3. directly to the individual/family to manage themselves.

CoIs/CoPs can generate a range of shared insights across all three options.

However, there is a broader way to think about brokerage, called community brokerage, which was developed by Duffy and Fulton (2010), and outlined by Duffy and Williams (2012):

*Community brokerage means treating the whole community as a potential source of support for people managing their budgets. The system requirement is to evaluate how effectively the wider community is working to support effective decisions and provide strategic support (which may or may not be financial) only where required.*⁵⁹

⁵⁷ JFA Purple Orange, loc. cit.

⁵⁸ V. Rose, Imagining and planning for the future under a NDIS. NDIS Workshop 2013 Participant Workbook, Future by Design, Springhill, Queensland: 10, 2013.

⁵⁹ S. Duffy & R. Williams, The Road to NDIS: Lessons from England about Assessment and Planning, JFA Purple Orange, Unley, South Australia, 2012.

This is an important dimension to brokerage because good life chances are not just about having enough formal disability supports; it is also about the informal supports that come with being known to, and connected with, other local people. After all, this is perhaps what community means.

A CoI/CoP can again be a potent place for gathering information about community options, the places of welcome, and the ways people are building connections into community life and belonging. Over and above information and emotional support to members, some CoIs/CoPs have even taken direct action to help grow community connectivity.

For example, Queensland Council of Social Services, the Townsville City Council and QDN, along with the Townsville Local Support Group, hosted a community-led event called 'Bringing the NDIS to life'. The two days were attended by almost 100 people from local businesses, services, community groups, families and people with disability who were interested in coming together to talk about and generate ideas about how they can bring the NDIS to life within that community.

The two days included hearing about what is happening with the NDIS, and was an opportunity to talk about three key areas that are important to the Townsville community. They also heard from some inspiring people who have been bringing this to life in their own lives.

The three areas for conversation were:

1. A place to call home
2. Pathways to employment
3. Reimagining the future.

An artist also worked throughout the two days on creating a piece of art, which was then presented to the NDIA to be the custodians of, to have at their office to remind the community of the event and illustrate what can be achieved when people come together.

This type of thinking is important so as to help avoid the NDIS just being the creator of arrangements where people feel more fully serviced because of their disability, but not necessarily more involved in life. CoIs/CoPs can

assist members to explore ways to move away from a life of 'service reciprocity' and towards a life of genuine, active community membership.

The NDIA acknowledges the importance of community-based resources and, implicitly, community brokerage within the NDIS.⁶⁰ However, for those who are not familiar with the terminology used within the disability sector (and that could include people living with disability, families and other informal supporters), a lack of common understanding about the functional and structural role of a broker and, by extension, brokerage, is a gap in information that might require addressing. This is again knowledge that could be built through CoIs/CoPs.

An example of knowledge around brokerage can be found in a story from the West Lancs Peer Support group, mentioned earlier. This is a CoI/CoP set up by five local parents to share their experiences of employing a personal assistant. The group was set up because they wanted to learn from each other and help other people in similar situations.

*We set up the group because there was a lack of knowledge. You're given these payments, but then you think, 'What happens now?' There were no support mechanisms around. The network has proved to be so useful that social workers often refer people to it if they need help managing direct payment.*⁶¹



60 NDIA, Operational Guideline – Planning and Assessment – The Planning and Assessment Conversation, NDIA, Geelong, Victoria, 2014b.

61 <http://www.in-control.org.uk/support/support-for-individuals,-family-members-carers/personal-stories/les.aspx>

Delivery

The NDIS has the potential to be an agent of change in the current forms of disability services delivery:

*The introduction of a National Disability Insurance Scheme (NDIS) will effectively double service provision over the next decade. It promises to transform service delivery premised on user choice. Delivering on this promise will depend on attracting, developing and retaining the required workforce in the context of aggressive competition for both market share and workforce supply and talent.*⁶²

CoIs/CoPs can be used to connect people's experiences of service delivery and service providers. In 2013, JFA Purple Orange conducted a consultation about the development of an NDIS 'eMarket'⁶³ (something like a TripAdvisor or Gumtree, but specifically for the NDIS). The consultation findings signalled that people liked the idea of an eMarket, not just for getting information about options, but importantly for reading about other people's experiences of service delivery by different providers. As such, an eMarket platform, depending on how it is built, could constitute an Australia-wide community of interest.

Peer support networks constitute a valuable channel for exchanging information between the NDIS and the disability community. CoIs/CoPs can help people build capacity and confidence to take service providers on about quality issues, to advocate for improvements, and to ensure service delivery is focused on the person and not the service provider. The continued development of this aspect of the network will help strengthen the quality and timeliness of information exchange between the scheme and its participants across a range of key issues important to the NDIS' success and sustainability.

Continued investment of development funds into DSOs and peer networks will help ensure that the NDIS market is influenced by demand perspectives as much as by supply perspectives.

Peer networks can be expert resources for the capacity building of community organisations, mainstream providers as well as disability service providers in regions to improve their services to people living with disability. Given the goals associated with the NDIS, and the broader National Disability Strategy, peer networks and DSOs are in a good position to assist other areas of development—mainstream community agencies and disability service provider agencies.

CoIs/CoPs can also help people build capacity and confidence to approach their service providers about quality issues, to advocate for improvements and to ensure service delivery is focused on the person and not the service provider.

Historically, people living with disability and their families have been denied the opportunity to build knowledge capital to enable them to navigate a complex service-driven system.⁶⁴ Many people have struggled to have their needs met by a 'broken' system yet alone use it to their best advantage, while others have disengaged because it was too difficult to access support. This has led to a sense of being 'shut out'⁶⁵, as described in a 2009 report by the National People with Disabilities and Carers Council.

The NDIS will challenge and change current ways of doing business in the disability sector. However, the changes envisaged are for improvements, not only in life chances and conditions, but also in funding and service delivery.

62 National Disability Services Victoria, 'Victorian Disability Services Transition Plan: The Report', National Disability Services Victoria, Parkeville, Victoria: 55, 2012.

63 <https://www.ndis.gov.au/html/sites/default/files/documents/JFA%20Purple%20Orange%20NDIS%20PDF%20e-Market%20report%20updated%2017%20May%202013.pdf>

64 National People With Disabilities and Carers Council, SHUT OUT: The Experience of People with Disabilities and their Families in Australia, Commonwealth of Australia, Canberra, 2009, p. 9.

65 Ibid.

Review

This is an essential component of any human service process because it is the step that is taken to find out whether the person's life chances are strengthening. Put another way, did the plan happen as agreed, and did it make a difference?

The review step is an important opportunity to see what is working, what the evidence is and what changes might need to be made. A CoI/CoP can be a helpful network for exploring this, to assist members to build their skills and knowledge in measuring progress, problem-solving and making changes.

This thinking applies to the NDIS because it is the main way of assessing a return on public investment. It asks how much the person's chances of a good life have been strengthened (the 'return') as a result of the NDIS individual budget (the 'investment'). After all, the NDIS was created with the goal of supporting people to participate in community life and the economy, and to get there by exercising control and choice.

Because of this, it seems important that NDIS participants and their families go into the review process with a clear line of sight on the gains they hoped for, and the extent the NDIS support arrangements have helped.

However, there is another value that is influencing how the scheme is operated. It is the value of financial sustainability. This is an important value because the scheme needs to be sustainable into the future. The problem comes when the value of financial sustainability is in conflict with the values of control, choice and participation in community life and the economy. They don't need to be in conflict, but it is possible that some scheme decisions can be made, either systemically (they affect everyone) or in a person's individual review, which are driven by anxieties around financial sustainability but which, by their nature, undermine the other core values of the scheme.

Because of this possible tension, and to help get the best outcome from the review process, a



CoI/CoP could be a valuable source of support to a person going into a review. It could help the person build confidence, knowledge and determination, and could lessen the risk that the review results in a smaller package that diminishes the person's path to stronger life chances (as opposed to a smaller support package that preserves the person's path to stronger life chances).

Potentially, at the information and entry stage to the NDIS, a participant's knowledge base might be quite limited because they haven't yet evolved as a practitioner and therefore have limited experiences on which to draw. By the review stage, however, a person's experience is much broader, including learning from successes and frustrations, and the person's practice will have developed accordingly.

It is at this review stage that the CoI/CoP benefits of collaborative information sharing (and decision-making) can accrue, and where peer network members share their experiences and hear from others, resulting in a common understanding of 'good practice'⁶⁶.

⁶⁶ For example, see: American Institutes for Research, *Shared Decision-making and Benefit Design: Engaging Employees and Reducing Costs for Preference-Sensitive Conditions*, Robert Wood Johnson Foundation, Princeton, New Jersey, USA, 2013

Recommendations

This paper has outlined a range of ways that CoIs/CoPs can be mobilised to bring benefits to people living with disability and their families. This is particularly important at this time, given the changes taking place as a result of the introduction of the NDIS and the broader National Disability Strategy.

For people living with disability and their families, we recommend seeing yourself and your peers as a wise resource, and taking action to connect with other people in similar situations for the greater good.

Communities of practice, such as local support groups or peer support networks, can build members' knowledge that will potentially change the way in which NDIS plans are transacted, resulting in a more effective outcome as well as better outcomes for life chances.

This includes:

- success in helping people make the transition to the NDIS language and system;
- success in helping people see the empowered role they can have as NDIS individual budget holders; and
- success in shifting people to a broader conversation about what it means to have a good life.

For Commonwealth, state, territory and local governments, we recommend you develop a funding strategy to invest in peer networks—Cols/CoPs involving people living with disability and their families—not only as a way to invest in the capacity-building of the people involved, but also as a way to invest in your own policy analysis and decision-making. People living with disability, their families and informal supporters can be a potent source of good information about community wellbeing issues, and can be valuable partners in the policy/decision-making process.

This includes investment from the NDIS. We recommend the Commonwealth Government fund the continued development of CoIs and CoPs as a key strategic element of NDIS implementation. This will help capitalise on the benefits and insights generated from existing/previous projects, and help build momentum for NDIS participants to genuinely shape the 'market'.

For agencies that provide practical assistance to people living with disability and their families, we recommend you develop a strategy for promoting peer networks among your stakeholders, and find ways to assist their development without taking them over.

As above, this is not just as a way to invest in the capacity-building and wellbeing of the people involved, but it is also as a way to invest in quality improvement in the services you provide. People living with disability, their families and informal supporters, can be a potent source of feedback and wisdom about what types of services and supports are most helpful to their life chances.

Concluding remarks

CoPs and CoIs are relevant concepts for knowledge building within the disability sector and, in particular, the NDIS. The NDIS embodies and signals change, not least in the nature of funding for people living with disability; shifting to a national approach to individualised funding, providing the capacity on a large scale for choice, control and improvements in life chances. The scheme also represents changes and challenges for administrative practices, financial sustainability and interactions between participants, service providers and bureaucrats.

CoPs are important to people living with disability because they connect individuals who might not otherwise have the opportunity to interact, either as frequently or at all. The benefits are clearly outlined in a publication on the use of CoPs in higher education in the USA:

*They provide a shared context for people to communicate and share information, stories, and personal experiences in a way that builds understanding and insight. They enable dialogue between people who come together to explore new possibilities, solve challenging problems, and create new, mutually beneficial opportunities. They stimulate learning by serving as a vehicle for authentic communication, mentoring, coaching, and self-reflection. They capture and diffuse existing knowledge to help people improve their practice by providing a forum to identify solutions to common problems and a process to collect and evaluate best practices. Help people organize around purposeful actions that deliver tangible results and generate new knowledge to help people transform their practice to accommodate changes in needs and technologies.*⁶⁷

Ultimately, it is through talking with others about what is possible in people's lives that a person can build knowledge about what is possible in their own life.



⁶⁷ <http://www.communityofpractice.ca/background/why-communities-of-practice-are-important/>

Summary and recommendations

People benefit from connecting to other people. People living with an acquired brain injury or degenerative neurological disorder can gain greatly by sharing their experiences with similar people. Talking with others about what is possible in people's lives, and how that can be a reality, in turn contributes to a person's knowledge about what is possible in their own life.

People benefit from being assisted to interpret and discuss information and ideas with their peers to come to new understandings (this is separate to the formal processes of the NDIS). This is particularly true for people living with a cognitive disability who may struggle with static information from brochures, websites or single information sessions. The process of a peer network that spends time together to inform, interpret and to talk their way to a deeper understanding of the material is seen as an effective approach to translating NDIS information.

The primary aim of a CoI/CoP is to create, expand and exchange knowledge to develop individual capabilities. Such networks focus on shared interests, increased understanding of areas of knowledge or practice, problem-solving and building relationships. While there are some differences between CoIs and CoPs, the critical point is that there is potency and synergy where people have common interests, common concerns or common roles, and where they can connect to share information and ideas. This then helps people's individual decisions and actions. The dedicated national website titled 'Peer Connect' (www.peerconnect.org.au) offers invaluable resources, information, videos and examples for individuals looking for further details about peer support networks.

Recommendations for people living with disability and their families

JFA Purple Orange recommends that people living with disability, and their families and informal supporters, explore the availability of peer networks and how a peer network might be helpful for them.


CoIs and CoPs can play a key role in helping a person living with disability to reclaim their life chances, improve wellbeing and contribute through sharing knowledge, experience and practical ideas with others. These networks can grow connections to others and can help to equip a person to navigate complex schemes such as the NDIS.

Recommendation to government

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

Therefore, JFA Purple Orange recommends there be sustained government investment in building momentum for these types of networks, and in the continued development of CoI and CoP as a component of the NDIS scheme.

JFA Purple Orange considers CoIs/CoPs to be 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.

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

Appendix 1

Dimensions	Communities of practice	Communities of interest
Major objectives	Creates a collated, organised and shared knowledge.	Shared understanding; making all voices heard.
Weaknesses	Group-think (decisions made as a group).	Lack of a shared understanding.
Strengths	Shared purposes and goals.	Social creativity; diversity; making all voices heard.
People	Beginners and experts, apprentices and masters.	Stakeholders (owners of problems) from different domains.
Commitment	These communities are committed to developing expertise, skills and proficiency in the specialty. The motivation is to master the discipline, learn about the specialty and solve problems together.	No commitment to deliver something together. The motivation is to stay current on the topic and to be able to ask and answer questions about it.

Table 1: Distinguishing between CoIs and CoPs.⁶⁸

⁶⁸ Adapted from G. Fischer, 'Beyond Binary Choice: Understanding and exploiting trade-offs to enhance creativity', First Monday, vol. 11, (4), 1996

Notes

JFA Purple Orange
104 Greenhill Road
Unley SA 5061 AUSTRALIA

+ 61 (8) 8373 8333
admin@purpleorange.org.au
purpleorange.org.au
facebook.com/jfapurpleorange

