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Supporting inclusion of people with cognitive disabilities

Models for Forming and Supporting Circles of Support for People with Intellectual Disability.

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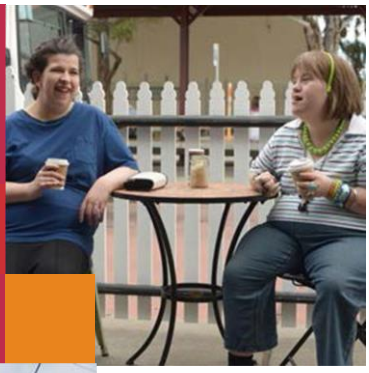

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Models for Forming and Supporting Circles of Support for People with Intellectual Disability

Executive Summary

Background

Scholarly research indicates that for people with intellectual disability forming and maintaining informal relationships does not happen easily and, in many cases, formal structures and strategies are necessary to complement natural processes. In the recent years many innovative strategies to foster social network development and person-centred planning have emerged, among these the most prominent is the concept of circles of support. At the most general level, circles of support involve a group of people coming together on a voluntary basis, with varying levels of formality to support a single individual through relationships of trust and intimacy (Macadam & Savitch, 2015). Circles of support are perceived to be noble strategies to harness social capital and promote the person's self-determination, social inclusion and choice. However, despite the growing popularity of the concept of circles of support in the field of intellectual disabilities, there is much ambiguity over its form, processes and effectiveness. To date, there has been limited formal evaluation of the ways that circles of support work in practice and of the organisational strategies necessary to develop and support them.

Aim

The study aimed to shed light on the organisational and operational elements of the concept of circles of support as well as its perceived outcomes. It explored key areas of staff, practice and organisational strategies used to develop circles of support, and perceptions about outcomes experienced by people with intellectual disability, the families and circle members.

The main research questions were:

1. How do organisations support the formation or maintenance of circles of support?
2. What organisational strategies, staff practices and resources are necessary to form and maintain circles of support?
3. Who is the target population for forming and maintaining circles of support?

4. Do organisational strategies, staff practices and resources differ depending on the person's existing informal network, the strength of their family ties, and social capital available to the network?
5. What are the costs and feasibility of establishing a circle of support?
6. What are the outcomes of circles of support?

Method

Three Australian circle of support programs were included in this study; Pave the Way (MAMRE Assoc) Queensland, Inclusion Melbourne and UnitingCare – LifeAssist Victoria. Data included qualitative interviews with program participants (people with intellectual disabilities, family and circle members); circle of support coordinators, staff and members of the organisations' senior management. Additionally, program and organisational documents as well as materials posted on the organisation website were also analysed.

Data analysis was conducted in two phases: first, qualitative analysis of the data from each organisation, using categories of program logic as a conceptual framework. For each organisation a detailed program description and analysis was developed, illustrating the programs' theory of change, program logic, target group, circles of support strategies and practices used by staff, and participants outcomes.

In the second phase, a cross-case analysis was conducted to compare and identify commonalities and differences in the events, activities, and processes of circles of support programs, and to use the accumulated case knowledge to reach a more general understanding that went beyond specific context and time (Khan & Van Wynsberghe, 2008).

Findings

The three case studies demonstrate the variability in circles of support programs. While all the programs had a similar overarching intent about sustaining informal support and the quality of life of the person with intellectual disability, there was no one standard of operationalising the concept 'circles of support'. The comparison illustrates that the tasks of paid staff, the practice, time and cost required to form and sustain a circle are primarily dependant on the nature of the person's pre-existing informal network.

Although positioned within the broad concept of circles of support, in each case program aims, strategies and target population differed and were shaped by the wider organisational mission of which they were a part. Specifically, in both Pave the Way and the Life Assist,

circles of support were perceived as essentially “family business”, relying on the motivation and contribution of family and other informal network members to lead development and the sustainability of circles. Targeting people with disabilities who had existing social networks both programs perceived circles of support as a community capacity building strategy which fostered greater involvement of community members in the lives of people with disabilities. The involvement of the program and thus professionals is short-term, aimed at providing families with the essential knowledge, skills and structures they require to develop and run their own circles of support and maintain them over time.

In contrast, Inclusion Melbourne perceived circles of support as “service business” with a much stronger role for the professional program coordinator in initiating and managing circle development. The focus of the program was more specifically capacity building for individuals and informal support networks. Inclusion Melbourne targeted isolated people, particularly those in supported accommodation without strong family support, or with little or no other forms of informal support. The program coordinator’s role in leading the process, and her ongoing responsibility to develop and maintain the circle of support, meant prolonged engagement with each circle and enabled a more flexible approach adapted to the focus person’s capabilities and existing social network.

The cross-case analysis suggests that regardless of the target population and service delivery mode, at the conceptual level the three programs had very similar positive outcomes for the individual, the family and the community at large. On the individual level, a circle of support strengthened informal supports and extended their social network, assisting in fulfilling goals and aspirations.

The process of building informal support gives voice to the person and the family. Communication in a circle seems to give meaning to family experiences; support is shared and families felt more comfortable to call on others. The collective nature of circles of support and the sense of community reported by the many people involved were associated with feelings of confidence, respect, reduced burden and an increased sense of belonging and well-being. Some families found circles of support a safe place to express emotions about their experiences and an environment to collaborate and problem solve with others.

For community members, circles of support seemed to build the capacity of communities to be inclusive. Circle members shared their experience that their involvement in circles

increased their community understanding of the rights and barriers people with intellectual disability face in being included.

The analysis highlighted difficulties that the current and future funding mechanisms pose for the programs. There was limited data on the sustainability and longevity of circles after the withdrawal of the program coordinator. It seems that relationship building and network development takes time, energy and long-term commitment of all involved. The service delivery under the NDIS model calls for a short-term capacity building service budgeted by billable hours. This does not allow for many unbudgeted activities such as building and maintaining relationships with the focus person and family, active monitoring and ongoing support for groups as they evolve over time. Another challenge is for services that rely on referral, where many hours are spent on developing marketing materials, communicating with service providers and planners to explain the model of circles of support, and reach out for potential participants.

Conclusions

Findings demonstrate the applicability and relevance of circles of support concept for people with intellectual disabilities without a strong informal support network as well as those with an existing network and strong family leadership. However, it is apparent that adapting the model to accommodate the needs of isolated people (without existing strong support) requires longer-term involvement and intensive commitment of the coordinator. This accommodation highlights the importance of taking note of cost differentials and the need for the organisations to explicitly determine their aims and target group of circles of support programs, and shape program components and funding mechanism accordingly.

Findings may be used as a benchmarking framework for the operational implementation of circles of support by organisations registered with the NDIS. They will also enable development of a set of blueprints or ‘how to’ guides about facilitating circles of support with differing sub-groups of people with intellectual disabilities according to the strengths of their existing informal networks, and form the basis for the development of training materials about the practice of forming and maintaining circles.

Models for Forming and Supporting Circles of Support for People with Intellectual Disability

The National Disability Insurance Scheme (NDIS) has marked a significant shift in the Australian Government's approach to disability policy and the provision of services. The scheme aims to give people with disability better access to personalised, high quality and innovative supports and services. A specific focus is placed on developing innovative strategies to enhance the independence, social and economic participation of people with disability and their carers (NDIS website). Two central principles of this scheme are perceived as individualised person centred planning (PCP) and systemic recognition of the significant roles natural or informal support plays in ensuring the person's quality of life and social inclusion (Dowse., et al, 2016).

Informal support is derived from relationships with family, friends, neighbours and acquaintances, and is based on personal ties rather than payment (Bigby, 2008). Members of informal networks may provide emotional, instrumental, or advocacy support as well as assistance with managing relationships with formal organisations (Horowitz, 1985). The literature suggests the social networks of people with intellectual disabilities are small and dense, often comprised of a small number of family members and peers with intellectual disabilities (Bigby, 2008; Robertson et al., 2001). Research findings suggest that people with intellectual disabilities are often isolated and the involvement of others in their life is limited, both in time and scope (Bigby, 2008; Forrester-Jones et al., 2006; Kamstra, Van der Putten, & Vlaskamp, 2015; Robertson et al., 2001; Van Asselt-Goverts, Embregts, & Hendriks, 2013, 2015; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009).

For many people with intellectual disabilities forming and maintaining informal relationships does not happen easily. For some, formal structures and strategies are necessary to compliment natural processes. Though something of a conundrum, formal programs can facilitate development of informal social networks that fulfil the spectrum of functions such networks can play in people's lives (Bigby, 2008; Bigby, & Craig, 2017; Neill & Sanderson, 2012).

In this vein, many innovative strategies to foster social network development and person centred planning have emerged (Bartnik, 2008; Etmanski, 2009; Hillman et al., 2012; Mansell, & Beadle-Brown, 2004; Neill & Sanderson, 2012; Ratti, Hassiotis, Crabtree, Deb, Gallagher, & Unwin, 2016). Among these the most prominent is the concept of circles of support. At the most general level, this involves groups of people coming together on a

voluntary basis, with varying levels of formality to support a single individual through relationships of trust and intimacy (Macadam & Savitch, 2015). A circle of support aims to create a comprehensive portrait of the person with disability and support them to plan new developments in their lives (Foundation for People with Learning Difficulties, 2014). These innovative interventions have assumed particular importance as they are perceived to be noble strategies to harness social capital and promote the person's self-determination, social inclusion and choice. Scholars have attributed a range of potential functions to circles of support including: an innovative way to sustain the continuity of care and support over the life of the person (Neill & Sanderson 2012); a forum to support decision-making (Nunnelley, 2015); a means of undertaking transition and succession planning (Bourke, 2005); a strategy to provide support to families through tangible and expressive support (Lord & Hutchison, 2003); a means of building the capacity of the community to welcome people with disability as respected members, and; a natural mechanism for providing ongoing and unfunded support (Etmanski, 2009; Neill & Sanderson 2012; Wisto et al., 2016).

Despite the growing popularity of the concept of circles of support in the field of intellectual disabilities, there is much ambiguity over form, processes and effectiveness. There has been limited formal evaluation of the ways that circles of support work in practice or organisational strategies necessary to develop and support them. While the literature includes unpublished reports and personal stories presenting anecdotes and desirable outcomes of various models for organising circles of support, there is little evidence about effectiveness or outcomes for the people with disability, their families and services (Wistow et al., 2016).

Inclusion Melbourne was funded through the Information Linkages and Capacity Building program of the NDIS (National Disability Insurance Scheme) to establish the National Resource Centre for Circles of Support and Microboards (NRCCOSAM). Its aims are, a) to develop a centralised repository of resources relating to the operation of Circles of Support and Microboards; and b) to conduct research to produce evidence-based framework and benchmark principles for the successful operation of the model by support services and advocacy groups. To conduct this project Inclusion Melbourne has collaborated with the major Australian organizations experienced in developing and maintaining circles of support and/or Microboards.

Five organisations, delivering circles of support services, agreed for a formal review of their services to be conducted; Microboards Australia; Belonging Matters Queensland; Uniting Care Queensland; Pave the Way (MAMRE Assoc) Queensland, Inclusion Melbourne; UnitingCare – LifeAssist Victoria. Additionally, the following organisations and people shared their experience operating circles of support and microboards as part of the development of benchmarking framework for the operational implementation of COSAM these organization are: Circles Initiative (SA), Valued Lives (WA), Imagine More (ACT), Community Resource Unit (CRU in WA), NSWCID (NSW), Brenda Schurmann (Vic), Jane Sherwin (Qld) and Leighton Jay (Sotica)

This report presents the findings from a study conducted by LaTrobe University, of the circle of support programs delivered by Pave the Way (MAMRE Assoc) Queensland, Inclusion Melbourne and UnitingCare – LifeAssist Victoria. The study aimed to shed some light on the organisational operation and perceived outcomes of the concept of circles of support. It explored key areas of staff practice and organisational strategies used to develop circles of support, and sought to assist in the understanding of the outcomes experienced by people with intellectual disability, the families and circle members.

The main research questions were

1. How do organisations support the formation or maintenance of circles of support?
2. What organisational strategies, staff practices and resources are necessary to form and maintain circles of support?
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4. Do organisational strategies, staff practices and resources differ depending on the person's existing informal network, the strength of their family ties, and social capital available to the network?
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Research methods and design

A case study approach was used to enable in-depth investigation of a phenomenon within its real-life context, in this case circle of support programs (Yin, 2003). Three case studies of Australian organisations delivering circle of support programs were undertaken to explore the program logic, program design, delivery and outcomes. Data were collected during 2017-2018 and across the three organisations included:

- Qualitative interviews with 11 program participants (5 parents; 2 people with intellectual disability; 2 siblings; one family friend and one volunteer member)
- Qualitative interviews with 11 staff members (3 program coordinators; 6 members of organisations' senior management; 2 support and development workers and one paid facilitator)
- Program, organisational documents and materials posted on the organisations' website.

All interviews were digitally recorded and then transcribed. The documents and interview data were analysed qualitatively using similar categories for each program based on elements of program logic model (Newcomer, Hatry, & Wholey, 2015).

Programs included in this study were selected based on suggestions from members of the steering committee for the project – the National Resource Centre for Circles of Support and Microboards (NRCCOSAM). The study was approved by the La Trobe Human Research Ethics committee, and all participants gave informed consent. The organisations were given the option of being identified or remaining anonymous and the senior staff member from each organisation agreed to their organisation being identified in this report. Nevertheless, the names of all informants have been changed so that individuals are not identified.

In the second phase of the study a cross-case analysis was conducted to compare case studies and use the accumulated case knowledge to reach a more general understanding that went beyond specific context and time (Khan & Van Wynsberghe, 2008). The cross-case analysis identified commonalities and differences in the events, activities, and processes of circles of support programs in terms of target groups, costs, outcomes, strategies and practice.

The qualitative data about participants' experiences supported initial perceptions of the project committee members and the organisations that these programs were enabling good outcomes for people with disability, their carers and the community. Data about program and

unit costs were not comprehensive, as for some organisations this is confidential information and there are also likely uncalculated cross subsidies between programs within the delivery organisations. At the time of writing, funding mechanisms and prices are changing as the NDIS is being implemented, and organisations' program costs as well as accounting systems are in a state of flux.

Findings may be used as a benchmarking framework for the operational implementation of circles of support by organisations registered with the NDIS. They will also enable development of a set of blueprints or 'how to' guides about facilitating circles of support with differing sub-groups of people with intellectual disabilities according to the strengths of their existing networks, and form the basis for the development of training materials about the practice of forming and maintaining circles.

Case study one: Pave the Way

Pave the Way was founded in 2002 as a project within the Mamre Association, Queensland. It was conceived as a family support project was designed to work with families on strategies aimed at enabling their relatives with a disability[1] to live a life of quality in the present and future (PTW, 2018). Pave the Way provides a range of flexible and individualised support to address the families' specific needs and circumstances. It is funded by the Department of Communities (Disability Services) to work with families and their relatives with a disability to develop and safeguard a vision for how they want to live their lives, to develop a plan towards making that vision a reality and ways to safeguard and ensure the continuity of this plan across the lifespan, including succession planning for when the family is no longer able to support the individual (Pave the Way website, 2018).

As a family support service Pave the Way programs are based on the assumption that the individual`s safety and quality of life is dependent on the sustainable capacity of the family to be involved in supporting and advocating for their relative with disability. Families are credited with the knowledge, history, commitment, and a deep understanding of what "good life" for this person means and take an active role in supporting the person across their life.

Pave the Way provides information workshops and ongoing consultation for individual families around person centred support and succession planning but do not offer an ongoing case management role. It is within this context the circles of support program developed in Pave the Way.

Circles of support (support circles) are perceived as one of many strategies aimed at building family capacity to provide and sustain support for their relatives with disability. The organisation has supported the formation of circles of support for some years and in the absence of detailed records they estimate involvement in approximately 100 circles. This case study of Pave the Way is based on semi-structured interviews with members of four circles (3 parents, 2 siblings and 1 friend), and interviews with 4 members of the staff and management team (one development worker and coordinator of circles of support; one senior manager responsible for managing Pave the Way, a senior manager from the Mamre Association and a professional circles of support facilitator employed on a casual basis by Pave the Way). The

[1] Pave the Way target people with disability. A substantial portion of the clients are families of people with intellectual disability.

analysis also drew on a review of relevant documents, information sheets, training materials and Pave the Way website. Names have been changed to ensure confidentiality.

Aim

Pave the Way define a circle of support as "a small number of people who come together regularly to provide ongoing support for families with people with disability to assist in decision-making, succession planning and to help the family support the individual over time to live their goals" (Circles of support manual, 2018). Circles of support focus on supporting the family and their ability to provide quality informal support over time, create opportunities for social encounter and as a means for families and people with disability to get advice and support (PTW website, 2018). Circles of support are also perceived as building the community capacity to give ongoing support and to ensure succession planning as the family age and transition through the different stages of life.

The service aims to educate families about the model of circles of support, and to introduce structure and formality in existing informal networks in order to enhance and maintain the capacity of the family to provide ongoing support and advocacy. The basic notion is that families (usually the parent) have the best understanding of what a good life for the person with a disability means and are in the best position to advocate for resources to achieve this.

In addition, circles of support are perceived as a strategy to enhance and deliver person centred planning. A circle of support is a formal structure in which families can share with their informal networks, their vision and plan, and be supported in developing new strategies to implement this plan as demonstrated in the following quote:

> It's a group for Mum and Dad, to make decisions. It's like a think tank or a brains trust …long-term, if Mum and Dad suddenly aren't there, there's a group of people that intimately know what Mum and Dad wanted for their son or daughter. …. This is really about getting to know the person deeply. It's about succession planning where Mum and Dad aren't here. … But of course, the whole time, it's always about the person with the disability…because Mum and Dad do know best …. (Development worker and circles of support coordinator).

The underlying assumption of the program is that formalising informal networks and introducing structure into support activities contributes to the person's well-being across their lifespan:

> Support circles are all around supporting the family throughout their journey … I think it's probably more for the family, to benefit the person with the disability. So, it's more support – for the family so that they could get better supports and things for their child with the disability (PTW, Manager).

A circle of support provides the family with the opportunity to share their understanding and knowledge of their relative's (with intellectual disability) needs and goals; introduce new resources into the family and person's lives and may assist in their decision-making in regard to the person's life:

> So, it's having that circle of support there, so a bit of body armour to hear what their ideals are and what they'd like to succeed, and how can they do it, and, of course, as we all know it's all about who you know (Development worker and circles of support coordinator).

Program inputs

Circles of support is not a distinct program in Pave the Way, rather it is seen as one strategy offered to families by the organisation.

> We don't run a program where we develop circles of support to people – what we do is we work with one family or person at a time in planning their support, including life planning and who's in their lives, who are the people that can safeguard that person who's vulnerable and for some people what emerges is that a circle of support would be a really good strategy for that (Mamre Director).

Funding: circles of support have always been funded somewhat indirectly, initially included in the services offered to families funded by the Department of Communities (Disability Services) for person centred planning and succession planning. From July 2014, Pave the Way was also funded as part of the Department's NDIS Participant Readiness Initiative. As staff reflected:

> You know from Mamre's perspective, the way we've been funded now has kind of enabled us to be able to look at circles of support within our current infrastructure, really, it's come down to who has the capacity and who's a good fit, or good match with this family. So, we haven't had to do it you know necessarily as a billable service. (Mamre Director).

> The government used to fund us to do that, they never knew where to put us, and I think we came under information, referral, and it was like capacity building…They never knew where to sit us. We're always a bit of an unknown of where we sat...but we are doing our job helping families and we find the way to do it in our time. (Development worker and circles of support facilitator).

The source of funding scheme will change as the NDIS is rolled out in Queensland, and block funding will no longer be available. Pave the Way have estimated that their services and involvement in the launching of circles of support entails around 10 to 12 hours of billable service:

> Well, because of fee-for-service - we've looked at it, and it's about 10 hours initially to workshop, that conversation, that first meeting, and then the next one. (Development worker and circle of support coordinator).

The service also aims to provide ongoing support and guidance during the first year of a circle's operation in order to ensure its sustainability. This work has been estimated to require approximately two hours for each circle meeting.

Places: the organisation operates out of offices in Brisbane. However, the project's philosophy emphasises that a large part of their work happens outside of offices in the social and community spaces of significance to the people they support. Thus, the circles of support program activities largely occur in public places, restaurants, pubs and circle members' homes.

Skills and knowledge: staff need specific knowledge and understanding of the different forms of circles of support. They have invested time and energy in developing this knowledge and offer a range of opportunities for potential participants to become familiarised with the model and its various applications.

> To commit, people need to know what they're coming into, to commit we provide knowledge throughout workshop or our relationship with the family, there are actual resource books we recommend reading, and there's Canada, and Western Australia, and we recommend lots of different other types that people might want to look at and use them. (Development worker and circles of support facilitator).

The significance of understanding the principles of circles of support as a vehicle for families to commit to the process was also highlighted by family members:

> When I heard of circles of support I didn't know what it is, so before you invite people I wanted to understand what I'm my putting myself into, so Joshua (support worker) showed me a list of things so I understand what it is, how to do it. I remember reading the story of the family, just made sense it helped me understand what it is all about. (Mother, circle member).

In addition, program staff identified tools and strategies for "person centred planning" and "succession planning" as essential for helping families to establish and maintain their circles:

> Mum and Dad need to document the personal information, we teach them how to do this in our workshop… So that if Mum and Dad aren't here, something happens tomorrow, that Mary or Peter have to go to bed with a night light on, and they can't eat peanuts … That helps everybody to really understand the person then they all buy-in. (Development worker and circles of support coordinator).

Another area of knowledge required for families and other circle members is a deep understanding of the person and the services available to them. It is important to note that in most cases this knowledge stems from the family and professional understandings of the person's life circumstances and opportunities:

> It needs to be clear what's available to that person because as it is you have to jump through a million hoops. (Brother, circle member).

> Only because these people (circle members) know Mike and our family they can help, they know what he likes and what he is like, what he wants and what he doesn't want, we made sure that they know all of this. (Mother, circle member).

Participants have recognised the people involved in the circle should operate from the value place honouring the family experience and respecting its boundaries:

> I don't think you necessarily have to have people, you know with degrees, but you certainly need to have people who really understand the principles of and the values of what we're trying to achieve from a values-based approach is critical, not a clinical approach you're just there to help the family, to help your friends. (Circle member, a friend).

Participants identified several skills that are necessary for the successful operation of circles of support. These skills are required for the professional coordinator, as well as for all members of circles of support, and are perceived to be vital for fulfilling the purpose of circles of support overtime. Members of circles of support should have good communication skills, and the ability to work collaboratively for a goal is essential for the sustainability of circles of support:

> It's those people skills, whoever sits in a circle of support needs to have very good listening skills, you know what's said, what isn't said, really strong observation skills, very good communication skills and ability to be able to negotiate …. but it's that social and community framework really, ability to be nimble and a bit flexible when needed. So sometimes you think, you know you're heading in one direction and you're going to have to shift a little bit somewhere else and also that you don't have ownership over it and you're not there to fix anyone just to help (Circle member, friend).

Participants described facilitating a support circle as a unique experience requiring a particular set of skills and understanding: namely, how to balance the informal nature of a support circle with the level of formality needed to fulfil its purpose. They also recognised the unique challenges volunteer facilitator members of circles face:

> It's different because it's managing a group, so you have to have a lot of sensitivity of what's going on and still progress the process. You provide the clarity and structure to the process, but you don't own the process and you don't own that circle of support. I think they're probably fundamental aspects of being able to do this well…sometimes it is hard to know where to stop and how to move forward sometimes it's hard to tell my girlfriend to stop and listen, sometimes it's hard to tell the mum that she's too protective or just wrong. (Friend, circle facilitator).

Program Processes and Activities

Program processes and activities are described in Figure 1. (see page 24)

Staff effort is focussed on the initial stages of group formation and provide professional guidance to assist the family to develop a strong foundation from which to build a sustainable circle of support. Staff work with the family and potential circle members to form the base understanding of the circle process, making sure that all members are informed and able to function well over time. The service is perceived as flexible and responsive to the individual and family needs and circumstances:

> The approach of Pave the Way has been to provide families with information, consultations and assistance where families have sought it… We help them set up the circle to get it going and then we leave that to them, it is family business not service business. (Pave the Way manager).

Providing information

The concept and model of circles of support is introduced throughout Pave the Way services, whether through individual consultation or workshops on future planning and succession planning. Within these workshops circles of support are mentioned as a possible strategy for maintaining sustainable support for individual and family. Pave the Way has also developed information sheets, and provides e-access to a wide array of written documents and demonstration videos.

> Provide through papers that we have written, through our website, through workshops, through conversations, we talk about circle of support as being one thing that people might want to consider doing. If people show an interest in that they ask for us to be involved, then we can offer the process… (Pave the Way manager).

When a family expresses interest in circles of support, a Pave the Way staff development worker meets the family at their home and discusses with them the concept its principles and processes to establish an understanding about whether the strategy suits the family's needs and goals. In this stage the emphasis is on evaluating the family readiness for developing a circle of support:

> You don't want to set people up for failure, sometimes it's just not the right time for them…sometimes they're not ready to open up to different people, sometimes they can't commit. It's important to work to make sure that they will feel comfortable and supported in the circle. (Development worker and circles of support coordinator).

Circle preparation - relationship mapping and planning

If a family would like assistance in developing their circle of support, staff work with them to further develop an understanding of its purpose and to identify potential circle members and strategies to invite them. Staff use a variety of tools and techniques such as relationship maps and planning tools:

> We sit and have the discussion about where they are, what they are wanting to achieve. Those sorts of things, those fundamentals, whatever has been decided by the focus person and the parents around the purpose of that group. They need to be clear about where they want to get to with that group. What is that group doing for the person to get from here to here and then there to there. Maybe it's only for a year, two years, maybe it is about this is the piece of work we want to do, we want to move Julie out of living at home with us into her own place and we want to do this in two years' time, we want these people to come together to assist us to do that piece of work. (Pave the Way manager).

The development worker engages with the family to identify potential members from their existing informal networks and their potential contribution to the circle.

> We talk about who to invite and why, usually family starts by saying they have nobody but then I start asking I ask about neighbours, I ask about family, friends, people they know, maybe somebody from work, you know I mean it could be anybody …. And then they say "they don't want to come" I "don't know how to ask" and I just say ask, what's the worst that can happen. Usually we end up with a long list of people … (Development worker and circle of support coordinator)

Staff acknowledge that each circle of support will look different, reflecting the choices and the circumstances of the family environment. The parents' understanding of the needs of the person with intellectual disability is only the starting point for staff who then work intensively with the parent to build opportunities for meaningful and supportive engagement with the circle.

> Whatever has been decided by the focus person and the parents around the purpose of that group. They need to be clear about where they want to get to with that group. What is that group doing for the person to get from here to here and then there to there. Maybe it's only for a year, two years, maybe it is about this is the piece of work we want to do, we want to move Julie out of living at home with us into her own place and we want to do this in two years' time, we want these people to come together to assist us to do that piece of work. (Mamre director).

In this stage the family is encouraged to arrange an "introduction night", usually this is a social event occurring in the family house or public place over the weekend.

Facilitating an introduction night

An introduction night is facilitated by a Pave the Way coordinator. In this initial gathering with the family and their network, the coordinator introduces to the potential circle members the circles of support concept, process and key principles so they can make an informed decision about their involvement in the circle way:

> We talk about what is a circle, and who it supports and what it's all about. It's not about donating a kidney, it's not about any time – usually that gets people relaxed … we discuss the circle, we just talk about who we are and why we're there, and how we know the person with a disability or Mum and Dad. (Development worker and circle of support coordinator).

Following the introduction night families are encouraged to set up the first circle of support meeting, usually about three or four weeks after. Meanwhile, Pave the Way staff will work with the family to develop an agenda for that first meeting.

First meeting facilitation

Pave the Way staff facilitate the first circle meeting and help to set rules for discussions, introduce structure and support the family's efforts to develop an open and respectful group atmosphere and dynamic. By facilitating this meeting, the coordinator provides a facilitation model and sets some "housekeeping rules" and discussion norms as well as roles and structures (voluntary facilitator, note taker, etc.).

> So I will come along – I usually go to the first six meetings, sometimes some circles take off straight away, you don't need to go to many… we start with the social, I always say bring food tea and coffee, you know mingling and then we start planning, presenting the agenda. (Development worker and circles of support coordinator).

Within those initial meetings, Pave the Way staff help identify people that take essential roles like note taker and facilitator:

> So there's people in the room I can see that have got some skills, and so I think just to get us off, get the circle starting, "Is there anybody who'd like to be facilitator" and generally a lot of facilitators put their hand up. Lot of note-takers do, but if they don't, I'm happy to point them out too, and just say, "For the first couple of meetings would you be able to take the notes, and I'll help you with that", and, "I'll facilitate but would you co-facilitate with me", and people are happy to do that. (Development worker and circles of support coordinator).

Pave the Way staff participate in the meetings for up to one year, gradually allocating responsibility to circle members. Once the circle of support is formed and operating, Pave the Way staff withdraw their involvement:

> Once you get to meet for six, eight times they (the circle) are pretty concrete and they can go on and you say to them, "invite me back when you need me". (Development worker and circles of support coordinator).

Training and support for volunteer facilitator

Pave the way staff provide guidance and professional support for voluntary facilitators during the first year.

> Mira (facilitator) talked to James when we got stuck … it was great she brought a sheet of paper and we wrote what we have achieved and what else do we want to get out of the group. I think James helped her with the agenda and those kind of things. (Mother, circle member).

Outputs

It is estimated by different staff members that the organisation has been involved informing approximately 100 circles of support over the years. There are no data of how long these circles have operated nor their composition. Circle coordinators suggested that approximately 80% of circles supported by Pave the Way work successfully and had been meeting for at least a year.

Publications and supporting documents: Pave the Way staff have developed booklets, information sheets and supporting documents for families and potential members. These publications present the model of circles of support, discuss basic principles, roles and structures and provide examples of documents (invitation for circle members, agenda, etc.). Publications include 'Circles of support facilitation guide'; 'Support Circles - an Overview'; and 'What have Support Circles Got to do with Succession Planning?'

Training programs: A training programs has been developed and is delivered as a one-day workshop for diverse audiences including family members and volunteers. This workshop presents the concept of circles of support, its origin, rationale and strategy for establishing and facilitating a circle of support. It also presented some strategies to troubleshoot issues arising during circle of support meetings. However, it is important to note this training workshop has not been offered within the last three years.

Outcomes

The qualitative interviews revealed a range of perceived outcomes for individuals, families and for the community. Participants suggested that circles of support resulted in better communication and relationships for the person with the disability, and within their community fostered more opportunities for social inclusion and meaningful community engagement:

> Kate got an improved understanding and communication with those in the group so because they lost some of their fear of communicating with her and because she could see that they were actually interested in her she began to talk more to that circle of people, ladies in particular, and they became free to communicate with her… It gave Kate more social outlets because when she went to church, people knew more about her and so they could come and start a conversation with her. (Brother, circle member).

Through involvement in the circle, people with disability are offered an opportunity to introduce themselves to circle members and communicate within an accepting and warm environment. This open and free communication may strengthen existing relationships and may also assist in affirming the person's sense of belonging, self-value and self-determination.

> Every gathering Louise would share something about herself, she tells what she had done, what she likes, she just loves it. She just love being able to get up and tell everyone all the things about herself. It meant that she had her voice heard which was great because it didn't always get heard by that many people. (Mother, circle member).

The deeper understanding of the person gained by circle members may also lead to more opportunities for their participation and socialisation:

> One thing that truly is going nicely for my daughter, she loves photography. We sort of overlooked her potential for photography, you know how it is when you are living with a person with disability, sometimes you're just busy with the day-to-day so we overlooked her eye for photography. So people in the group help her set up what you call it "Instagram", she takes pictures I write the story, she loves it, people comment and she loves it. (Mother, circle member).

Circles of support have been a powerful way for people with intellectual disability and their families to broader their social capital and to reclaim their own sense of choice and autonomy. Family members described feeling supported in their decision-making, felt that they could better rely on their informal networks and were less dependent on services:

> It was time of increasing care for my husband, it was very hard to move everything forward. I needed people to actually step into these gaps … With the circle he focused on putting out an emergency action plan together where if I had to go, I would just send text message to someone and then these people, someone from the circle would be able to then put it out to someone else, and somebody would come at the car up from the train station. Out of all of those people, would have to be at least one person that will be able to pick her up (from the train) and off they go. I think it's more than that, I think she would feel comfortable with any of those people, that she knows from the circle. (Mother, circle member).

A mother describes how the circle have helped the family in their decision process:

> "You know when you get a group of smart people together who've got different life experience, they are very good at brainstorming…. They clarified issues, it clarified the fact that we really needed to sort out our legal things…. Having to talk about things in front of everybody provided motivation to move forward on issues like legals for the family, sometimes you're just stuck in a spot and you can't move forward out of it. So the circle people told me we need to get moving with this it does create a little bit of pressure to get moving, to continue to move forward … when people tell you, you have to do it you realise …. It gave me courage, every couple of months I have to fess up to what I've done or I haven't done, you know It does create that little bit of pressure to get moving, to continue to move forward (Mother, circle member).

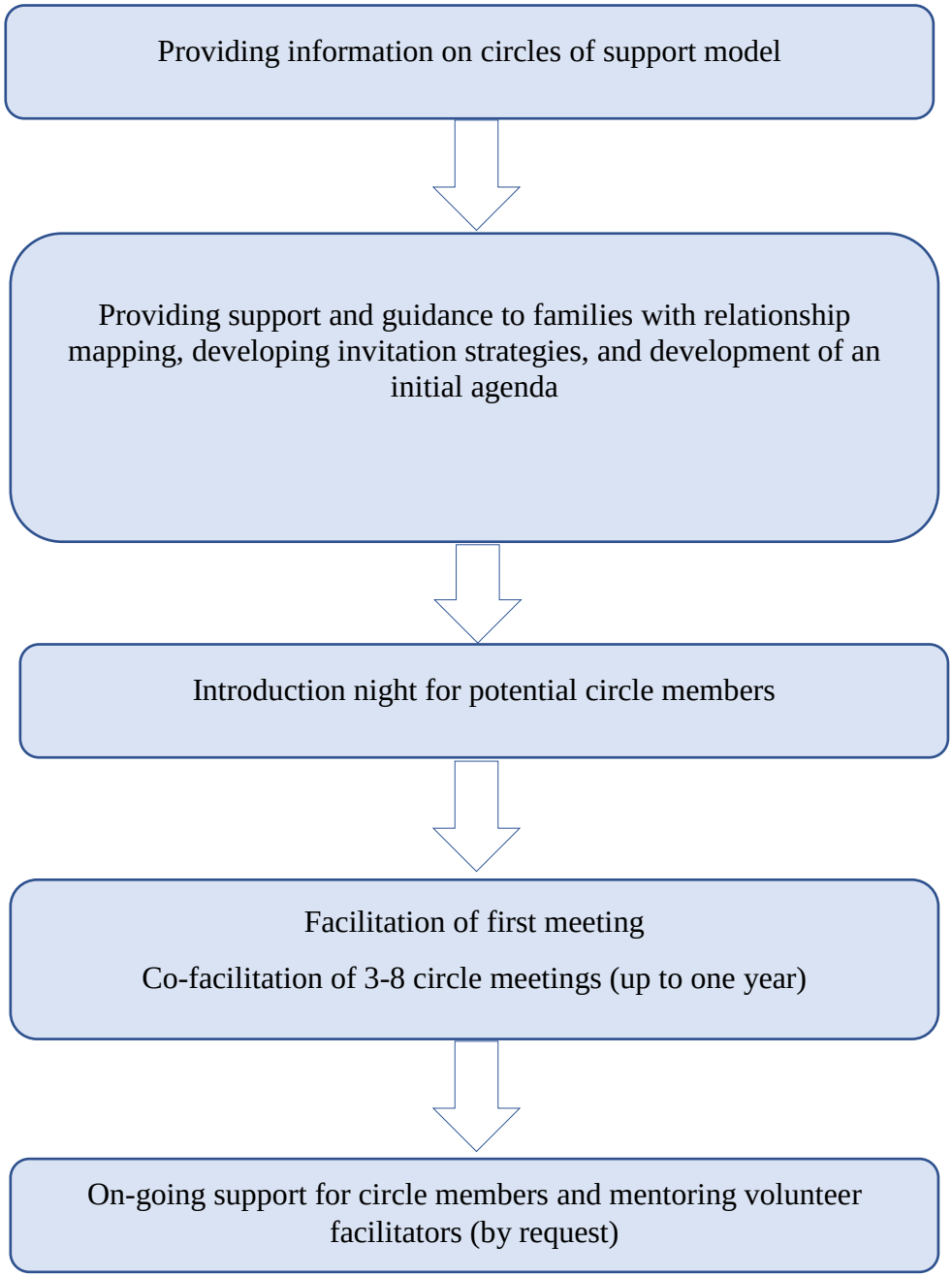
A circle of support was perceived to be a succession strategy as members share their vision and commitment over the long-term:

> "We believe circle members are the keeper of what the parents' hopes and dreams and goals are for their son or daughter. So if they're not there, they know that there's a group of people there that know, even though their son could never drive, he was to have his own car when he turns 18, or their daughter is to work, to find a job. There's something there, they've been working on it, and they just want them to keep working at finding that role for her in the community, or whatever those dreams and hopes and goals are, that they know there's a group of people who will help the siblings, if there's siblings, to keep that going…. We had a lot of people say to me it's just lifted this huge load off my shoulders, they didn't feel like they had to hold the whole world up, and it just gave them peace of mind they were able to sleep knowing that they knew Mary the facilitator had documented all their hopes and dreams, and they knew Peter was just so pedantic about following every step that they could just sleep a little bit more peacefully (Development worker and circles of support coordinator).

Circle members described feeling honoured and valued to have been asked to be involved in the life of the family. Circle members described their involvement in the circle as meaningful, or giving them a sense of purpose or acknowledgment:

> I didn't know what to do and how to help. I knew that they are struggling but I just didn't know. When they asked me to join I felt that finally somebody is going to tell me what to do, many times it was just having coffee together but other times I understood what is needed and I guess stepped up to the task (Friend, circle member).

Figure 1 – Pave the Way program processes and activities



Logic model: Pave the way Queensland: If families are supported and share their vision of their relatives' needs for quality of life in the present and future, then the individuals with intellectual disability will be better supported and will have a better quality of life in the present and future

Inputs/resources

Pave the Way see circles of support as one strategy within their PCP services. It is impossible to disentangle the specific Circles of Support and resources dedicated to circles of support.

Funding for all services: State government, moving to NDIS packages in 2019

Knowledge and skills:

Circle coordination: group facilitation; person centred planning knowledge and skills; disability service knowledge.

Facilitators: communication skills; organising skills; commitment and value-based.

Time: circle preparation – estimated 10 to 12 hours of counselling.

Ongoing training and support: responsive to request

Time & energy of: people with intellectual disability; family members; people in the focus person's existing social network.

Program components Circle

Providing information on circles of support model.

Circles of support information & preparation workshop (two hours)

Selection: relationship mapping

Preparation and group forming (10- 12 hours)

Relationship mapping and developing invitation strategies and materials.

Consultation meetings: setting timelines and agenda.

Selection process

Providing guidance and support for families, outreaching for potential circle members

Facilitation

Facilitating an introduction night for potential circle members

Facilitation of the first meeting:

Co-facilitation of 3-8 circle meetings (up to one year)

On-going support for circle members and mentoring volunteer facilitators (up to one year)

Outputs

Over the years Pave the Way and Mamre have developed over 100 circles of support.

Documentation: written documents, guidance for families, facilitators

Circle of support and succession plan workshops

Circle of support and succession plan supporting documents

Circle of support – facilitators guidelines

Information nights for potential circle members

Outcomes

Wider informal social networks for supporting people with intellectual disability and their carer.

Increased capacity of informal networks to provide sustainable and long-term support

Increased motivation, confidence for people with disability and their families

Increased participation in community life

Strengthened communication and relationships

Increased feeling of belonging to the community

Support in achieving desirable goals: moving out of family home, securing employment in the open market, pursuing interests and hobbies in the community, etc.

Increased community capacity

Increased community understanding of rights of people with disability

Increased involvement of the person with a disability in family life

Active involvement and collaboration in the community to drive inclusion for people with disability.

Context: The mission of Pave the Way: Ensure people all over Queensland who have a disability are supported and safeguarded by their family and others to have a good life, now and in the future.

Case study 2: Inclusion Melbourne

Inclusion Melbourne is a non-profit disability service that has been operating in Melbourne since 1948. Its mission is to "provide personalised, high quality support for adults with intellectual disabilities for a more inclusive community". Inclusion Melbourne provides services and supports and enables people to achieve and maintain an individualised and flexible lifestyle based on their needs and available resources. The organisation has a strong value base and prioritises person centred approaches and meaningful community participation. It is in this organisational context that the circles of support program was developed. The inspiration for the program came from a combination of a historical program delivered by Inclusion Melbourne "Circle of Friends" that focused on creating and maintaining informal support networks, and an increasing interest in innovative ways to deliver person centred planning.

The approach taken by Inclusion Melbourne to its circle of support program has been experimental; funding has been time limited and evaluation has been an integral part of the program's development and delivery. The Inclusion Melbourne circle of support program aimed to establish "proof of concept" for a sustainable program model targeting isolated adults with intellectual disabilities, such as those without family support or living in residential environments with little social supports.

This case study draws on data gathered from semi-structured interviews with five program participants, two adults with intellectual disabilities and three circle members (family members and volunteers). Interviews were also conducted with members of Inclusion Melbourne's senior management (including CEO and program manager), the circles of support program coordinator, and other staff at various levels in the community connections program. The case study also draws on a review of organisational and program documents. All names have been changed to ensure confidentiality.

Aim

Inclusion Melbourne defines a circle of support as "a group of people that come together, on a regular basis, to assist a person with a disability to develop, support and action their goals and aspirations" (circle booklet). In this organisation, a circle of support aims to formalise natural support networks to provide valuable and authentic support to the person; a circle member's role extends beyond providing emotional and social support and includes regular

and active involvement in the person's life, performing tasks to enable the achievement of the person's desirable goals and aspirations. As one support worker said, a circle acts as "a formalised friendship network of people who will step in to do tasks that are above a normal friendship".

At a general level, the aim of the Inclusion Melbourne program to provide professional coordination and guidance to assist people with intellectual disabilities to build and maintain their informal support network. The funding proposals and program planning documents emphasise the value-base of person centred planning and the significance of sustainable informal support. The project plan stated for example, "the core aim of the program is to work collaboratively with people with a disability, to assist them to establish networks and facilitate their own Circles of Support" (p. 2).

The program is informed by the theory of change that "by providing structure and formalising informal support activities and providing opportunities for individuals to become more involved in a person's life, we would contribute to the person's ability to create highly individualised and flexible lifestyles based on their needs and desires". The program staff recognise that the role a circle might play in a person's life is likely to vary according to their circumstances and desires. Participating in a circle may result in an array of desirable outcomes ranging from advocacy skills to quality of life and social integration.

The program targeted Inclusion Melbourne service users, particularly those who were isolated, especially those without family support or living in residential environments with little informal social support. The diversity of service users' characteristics, particularly the strength or otherwise of their existing informal network and communication skills meant that different strategies and aims were developed for each circle.

For a person with intellectual disability with strong and robust relationships, where family, friends and staff already had a deep understanding of the person's wants and needs in all walks of life, the aim of the service was to provide information and professional guidance, introduce structure into existing support activities and develop an intentional community (circle of support) led by person centred planning.

For isolated people with limited or no informal support network, those living in residential environments with few unpaid supports and without family members involved in their life, the aim was to gain a deep understanding of the person's wants and needs, and to develop an

intentional social network (circle) from volunteers and other people who were able and willing to be involved in the person's life (for details see the activity section).

Program inputs

Funding: At the time of the initial circles of support program, Inclusion Melbourne received core funding from the state government to deliver personalised support, inclusion training and support coordination services. The circles of support program was one of a series of separate projects intended to complement this core work. In addition, funding was sourced through various avenues, particularly philanthropic grants. The state government block-funding provided some security and a safety net for staff employed on the program.

Two philanthropic grants were received, providing $79,000 for 2 years (an initial grant of $9,000 was sourced for the first year 2014. A second grant of $70,000 was secured for the period of February 2015 to April 2016).

Funds were largely allocated to staff salaries, particularly that of a program coordinator. The coordinator worked for one day a week for the first year and three days a week during the second. Additionally, a manager provided supervision and oversight of the project for approximately two hours per week. Various Inclusion Melbourne staff were also funded to provide administrative support and the development of knowledge dissemination and training resources such as the circles of support information sheet, user manual and production of a participants experience video. The reliance on short-term philanthropic grant for funding restricted inclusion Melbourne ability to plan strategically for the future of the program ..

Places: Inclusion Melbourne operates out of offices in Armadale. However, the philosophy of the circles of support program emphasises community engagement in natural environment, hence circles activities are performed outside of the physical office space in the social and community spaces of significance to the people supported. Often cafés, pubs or people's houses were the spaces where circles of support activities occurred.

Skills and knowledge: in the planning and development phase of the Inclusion Melbourne circles of support program and delivery model, the program coordinator and management staff have invested time and resources researching existing knowledge about circles of support models and strategies. They found little empirical evidence in the peer reviewed literature, and most of the resources they used came from the grey literature, online manuals or practice wisdom from other organisations which had delivered similar projects. The available knowledge was of mixed value.

> So I didn't start any circles until I had read a lot about different types of circles, so I found a whole lot of different manuals, I did a lot of research, I tried to find as many peer reviewed articles as I could but a lot of them only focused on Circles of Friends with kids with disabilities in integration into primary school, they call them "Circles of Friends". A lot of circles of support are mentioned in the person centred planning manuals, there's always a little bit on circles of support. That's when I went through various ways – I just read a whole heap of manuals and I picked out all the key things they had in common" (Circles of support program coordinator).

Extending the principles of person centred planning had been a key driver for management in initiating and running the circles program. Inclusion Melbourne staff already had significant knowledge and practice experience of person centred planning and they were an important resource for the coordinator. The work of the coordinator was guided by expertise in person centred planning and emphasised that all activities in the circles of support should be person centred and all circle members should understand and operate from this perspective. The program coordinator showed practice leadership as shown in the following quote:

> It's really hard for people to understand how to work for a goal, it's this placing in the centre of things even if she (focus person) cannot say what she wants all the time, it's just getting back to the basic questions, what do you think, what do you want, not what we think is available. (circle member).

Another example of the type professional knowledge required was understanding the disability service environment. The program coordinator had specific knowledge of support and funding mechanisms as well as the scope and nature of support provided for the focus person under the new scheme of the NDIS:

> ….. With John's circle we spent a whole meeting talking about the difference between IM as a day service and his accommodation service, we spent a whole lot of time talking about the staff structure in a house, we talked about so much stuff, we talked about how his money is managed through state trustees, because no one knows any of that so there's a lot of disability knowledge that you need to impart to people because they can't actually navigate or solve situations for a person without knowing that. (Circles of Support coordinator).

Time and commitment: Time and commitment of those involved was a central component of the successful delivery of circles of support. The people with intellectual disabilities at the centre of the circles of support contributed time and energy as did their supporters who volunteered to join a circle of support as members. People involved in networks, whether in a personal or professional capacity, consistently identified that knowing the focus person well and a commitment to a trusting and respectful relationship with them were the most important factors.

Passion and commitment were core inputs to the circles of support program. The circles coordinator proved highly committed to the project – beyond the formal boundaries of her role. She was willing to contribute additional time and tangible personal resources (such as paying for circle members' refreshments) to promote circle activities. It was estimated that in the initial program, Inclusion Melbourne staff had contributed 80 unpaid hours to the development and delivery of circles of support.

Program activities and processes

Mapping and evaluation of the focus person's informal network

The circles of support program process begins with the referral of an Inclusion Melbourne service user by a support worker. Before engaging with the individual, the coordinator evaluates the person`s personal and social circumstances, focusing on the quantity and quality of the person's informal relationships. The program coordinator then tries to identify whether the focus person has a "primary supporter" - a person in the individual`s support network who has a deep understanding of the focus person's life circumstances, wants and needs, and is willing to commit and take responsibility to build and facilitate the circle of support in collaboration with the Inclusion Melbourne coordinator. The rationale for this evaluation is described by the program coordinator:

> So what I realised from the first year is I kept trying to start circles for people and each person had different levels of support and different disabilities and level of disability and different family connections and different social supports, and I realised that you can't approach each circle in the same way, it will depend on their social networks. So what I realised is you have to do a social mapping thing before you even start engaging with a person about the circle of support …. One of my first ports of call when I was finding people was I'd ask the support coordinators about all the people they know in their lives, which in most cases for support coordinators only revolved around the activities that they did with IM. Sometimes I could find people outside of IM, but that took a lot of investigating. (Circle of support program coordinator).

Based on this initial evaluation the program coordinator identified the type of circle and strategy required. In the course of the program, Inclusion Melbourne developed a model with three distinct types of circles, each targeted at a different sub group of people with intellectual disabilities and requiring a different focus and strategy:

Foundation circle: people with intellectual disabilities who have little contact with friends and family and are prominently supported by paid staff. These people often have complex needs, difficulties in communicating with others and experience isolation and social disadvantage. The focus in this type of circle is finding people willing to become more involved with the person and to be part of a developing circle of support.

> It's where you literally cannot find three people that will be someone's circle. In that Foundation level, usually no one knows anything about that person outside of the services they attend, you will not get anyone to run a circle of support for them and you probably will not get over four people who would want to come. (Program manager).

Building circle: designed to assist people with intellectual disabilities who have some contact with family and friends, but no one is willing to commit to being, and the coordinator is unable to find, a "primary supporter". With this group of people, the focus was on building the capacity of the person's existing social network to be involved and support the focus person:

> We ended up naming it Building because it's like they have that base to have a really good circle but they're just not there yet so they're in the building stage, for instance George's circle, he does have people that know him very well, does have social networks, may or may not be family, but no one that is going to dedicate themselves to running a circle of support so we needed to build a relationship for them to be involved. (Circle of support program coordinator).

Thrive Circle: designed to assist people with intellectual disabilities who have strong relationships with family or other informal supporters who know them well and are committed to investing time and resources for the development and facilitation of a circle of support. The focus in the thrive circle is to introduce structure and formality into the existing support network, strengthen relationships and provide formality and structure in informal support activities in order to collaboratively fulfil the focus person's goals and aspirations.

The tasks for the coordinator are quite different for each type of circle, and are detailed below.

Preparation: program coordinator

In the preparation phase the program coordinator establishes an understanding of the person's life circumstances and goals, and engages in the process of relationship mapping to identify and categorise the people in that focus person's life who are best equipped to support the person in long term planning through a "circle of support", and discuss strategies to invite them. The focus of this process and time allocated varies in accordance to the person's existing network.

Foundation circles: The focus is strongly on identifying potential members that may become part of the person's informal network, by using a variety of tools to map out all people involved in the person`s life. The emphasis for the coordinator is on building a relationship with the focus person, spending time with them and getting to know others in their life. Once these others are identified, no matter how confined their current role is, the coordinator creates opportunities for them to be more involved in the person's life and invites them to become part of the person's social network.

> With Fred there was no primary person to go to, there was no knowledge base, so I found out about Fred – found out about all the things he does during the week, I found out about all the people he sees and talks to, I found out about his capabilities, I found out about his history, no one knew about his history …..anything like that I found out about that. To assess his relationships ……, I literally stalked Fred for the majority of his activities …..So I went along and I sat next to him and I would ask the staff who talk to him on a daily basis, "Which staff here like … which staff talk to him often, which residents or which people here talk to him?" I asked his house where he goes on weekends which is nowhere. He has one leisure buddy, doesn't see him very often (Circles of support program coordinator).

This process requires flexibility and considerable investment of time. It is estimated that this part of the process with a foundation circle requires a minimum of 25 hours of paid coordination and facilitation.

Building circles: the focus is to identify and strengthen the relationships with people who are involved in the focus person's life but were unable to commit to being a primary supporter or a member of circle. The coordinator is involved in mapping and strengthening these relationships by contacting and inviting people to be more involved in the person's life and encouraging them to take greater responsibility towards the person's wellbeing:

> Craig, when I was trying to start his circle of support, he had one person, not even a family, he didn't have any family, one very solid volunteer ben, whom he'd known for 16 years …. the primary person, but he also knows nothing about Craig's life outside of what they do in Monday lunchtimes between the hours of 12 and 1... So I helped a lot. I got some tips from Ben, who I talked to, and it was also good in a sense to get that primary person to introduce me to the person and spend time with Craig at the same time, otherwise I'm a random. But I spoke to Craig, we talked about all the people he'd invite, I helped Craig invite them, I ran the first meeting because Ben wouldn't take on the role, which is fine, he didn't have to (Circles of support program coordinator).

The professional coordination and guidance in this stage is estimated to require around 15 hours of facilitation.

Thrive circle: the focus is to introduce the concept of circles of support and through a collaborative process with the "primary supporter", assist in identifying and recruiting circle members and to develop the aim and desirable outcomes for the circle:

> So, I contacted Jeff`s mum and I said, "We have this program, we'd like to support you and Jeff to start a circle", she was like, "Great, send me the details" and I sent her the information and I sent her the circles of support perspective member information page on circles that I'd made. So I sent them to her, she sat down with Jeff, I was not involved in this process at all, they went through with that invite, they invited them, they made a time, they let me know the time, I just turned up. (Circles of support program coordinator).

Professional coordination and guidance in this stage is estimated to require around 10 hours of facilitation.

Facilitation of the first meeting

Once circle members are identified and recruited, the program coordinator assists in organising and facilitating a circle meeting, introducing structure and formality with flexible goal setting as a priority. The level of the coordinator's involvement is similarly determined by the circle type.

For *Foundation circles* the coordinator is taking the role of the facilitator (or the primary person). She is engaging with the focus person and circle members, setting the agenda and leading the discussion. She's also allocating tasks and, in many cases, continues to be involved in carrying out these tasks. The role of the coordinator is pivotal and very demanding, and the incipient circles are dependent on the ongoing involvement of the coordinator. It is estimated that each meeting requires 10 hours of coordination and

facilitation time. Usually in this type of circle most time is spent deepening the relationships between the focus person and others who are becoming more involved in their life.

> You have a circle meeting, you find out that every single person in that circle only knows the tiniest little miniscule thing about that person, so you spend the next four or five months just pretty much socialising. With Ken I had to create a whole like activity based thing, post-it notes and we talked about all this stuff we know about Ken and we talked about all the things that we don't know about Ken or we have to talk about what he likes, what he dislikes, and we ended up all having a better view of Ken after an hour than we ever had knowing him for how many years. (Circles of support program coordinator).

Building circles: the coordinator takes the responsibility to organise mutual meeting times, encourage members to explore possibilities, give guidance, demonstrate practice leadership and models person centred thinking. In addition, if goals have been determined the program coordinator monitors action items and sometimes assists circle members to take responsibilities further and design follow-up tasks. The program goal is to assist and facilitate an opportunity for circle members to build their capacity and to be more involved in the focus person's life in a more structured and engaged way. It is estimated that this role requires about 8 hours of facilitation for each meeting.

> With Craig I had to run it …. My role in his circle still was even though it was running I still had to prompt, just to organise a meeting, I had to give them (circle members) lots of advice, I'd have to help them come up with ideas on things they might like doing like the dog thing, someone said, "Craig likes dogs" so then I had to prompt the conversation about, "Okay, so how can he be more involved with dogs, what would we do?"…So there's stuff that happened from that, but if I wasn't there to prompt them with the conversation they would literally sit there and chat and have beers and then go home. So the conversation is prompted by me …. sometimes I had to do follow-up tasks. (Circles of support program coordinator).

Thriving circle: the coordinator relies on the commitment of the "primary supporter" and circle members, introduces formality and structure into existing relationships, and works together with the primary supporter to help shape a warm and productive group atmosphere, give guidance and provide information resources as required.

> Kate (the mum) asked me questions about how the first meeting should run, I told her based on what I had found in first meetings and what I had made up also because I thought it would be good to put in. She ran the first meeting, I wrote the minutes, I would put in a little bit every now and then and she ran it. (Circles of support program coordinator).

This stage requires 2 to 3 hours for each meeting. The program coordinator facilitated early meetings with a greater level of formality and structure, with goal setting as the priority. Minutes were taken, and agenda items followed up. With time, this formal structured approach is replaced with a more flexible, emergent process that allows for group dynamics and structures to form organically over time.

The circles of support coordinator is involved in the facilitation of circles of support through initiating regular meet ups, documenting meetings and eventually handing over duties to circle members.

> Knowledge inputs suggested the use of administrative processes to ensure a level of formality and accountability for circles of support. We'd organise the regular meetings and then I would attend with them and I would help that primary person with the Circle, not necessarily the person in the centre, because the intention was to make it sustainable and if there was always that primary person I was helping, then I would guide them rather than a whole circle. As the circle of support established, the coordinator would provide support to the troubleshooting and intervene, but facilitation and meeting attendance would be guided by the primary supporter. (Circles of support program coordinator).

The Inclusion Melbourne CEO explained*:*

The idea is that we would be in there, doing lots of the work to get it going, but over time we would withdraw our worker, so that the other supports could actually feel confident to take on the work for themselves. *(*Inclusion Melbourne CEO).

Outputs

The Inclusion Melbourne circles of support program ran for two years. During this time, the circles of support coordinator started the process with 9 focus persons and three circles of support were eventually established and ran for the duration of the project. Of these three, one circle continued after the funding ceased and the formal project ended. In addition, publications and training programs were developed by the organisation.

Publications: a booklet was published highlighting practice wisdom and the model developed that described the different approaches to facilitating circles of support, depending on the existing informal network and support needs of the focus person. In addition, a video was created that told the stories of circles of support and the focus people.

Training programs: A training programs was developed and delivered as a one-day workshop for a diverse audience, including family members, professionals and volunteers. This workshop presented the concept of circles of support, its origins, rationale and strategy for establishing and facilitating a circle of support, as well as strategies to troubleshoot issues arising during circle of support meetings.

Outcomes

The qualitative exploration of the lived experience of people involved in the circles of support identified a range of outcomes for individual circle members and for services.

Focus person: all stakeholders recognised that the formalisation of existing informal networks and development of support resources resulted in wider and deeper involvement of multiple people in the focus person's life, strengthening existing relationships and harnessing their social capital:

> Jeff had more people to call on following the program than before. (Mother, circle member).
>
> Ken had people in his life (Circles of support program coordinator).

Inclusion Melbourne CEO described the meaning of creating circles of support for people who are isolated:

> We've actually shown that a circle still has relevance for someone who has no family in their life, that you can actually start to provide some of these things. It's not a case of 'who will care about me when I'm gone and what will I be doing when they're gone?', it's actually around 'what can I do to have something now, that resembles a life?' that we'd like for someone to have, and be worried about when it's absent… Did we achieve a sustainable circle of support for Colin? No. But does he have a new pair of shoes and doesn't have wet feet, and did someone take an active interest in his life? Absolutely" (Inclusion Melbourne CEO).

The involvement of other people in the lives of isolated people or those who had complex needs was especially meaningful as it enhanced their feelings of safety, self-worth and personhood:

> I think number one, the value of having a circle for a person with a disability is that they internally see that they have value because people are coming for them. People are coming because they are interested in them as a person and not as a person with a disability who needs services and assistance, I think that's really good. (Circles of support coordinator).

The circles program allowed people with intellectual disabilities a wider opportunity to interact with others in social activities. The circle of support meetings themselves were perceived as an opportunity to regularly schedule and talk with friends. Focus people described how being part of the group was beneficial for them, increased their sense of social connections and identified:

> Catching up and good friends the most significant benefits of having a circle. (Circles of support program coordinator).

The involvement of other people in the person's network through circles of support, and the activities that followed, were perceived to be valuable community strategies to develop person centred planning and resulted in higher levels of practical support for the focus person. For instance, circle members described how their involvement in the circle raised their awareness of challenges and prompted them to provide practical day-to-day support in areas such as managing finances and health:

> In one circle, suddenly by starting to talk about these issues, one of the members of one of the circles of support, just got on the phone and sorted out getting new glasses for someone. That was something that had been dragging on, that as the traditional day service provider you go, 'Well that's not our issue, to take someone to the doctors,….so therefore not doing it; and the member of the circle of support going, 'Well I think this is a real issue and we need to get it looked into' and then just taking it upon themselves to take the person to an appointment to have her hearing checked and eyes checked" (Inclusion Melbourne CEO).

Circle members brought new energy, a fresh perspective, skills and resources to issues presented in the circle, facilitated actions and provided responsive and creative strategies for problem-solving as challenges arose. A circle of support was perceived to be a successful strategy to execute an action plan. Circle of support members and the facilitator were spending time learning to get to know the person and gaining their trust. Often this deep understanding led to initiation of tasks and goals centred around community engagement of the focus person.

Circle members and staff described ways in which circles of support helped to safeguard the person:

> Craig, I call him the yes-man. He just says yes all the time. He'll just say yes to anything. But at one circle meeting he was upset about his house and we asked him "Craig, how does this make you feel?" and he said, "I feel really sad about this … and it was amazing. So I think there's a place for a circle to create a really safe environment for a person where they're able to express what they're actually feeling. (Circles of support program coordinator).

The coordinator also described how the involvement of circle members had resulted in better services for the focus person:

> I think the other part for the person is if a circle is done well, the person feels safe and I think in an environment where they're shuffled from service to service, I think having a feeling of safety is super important. (Circles of support program coordinator).

Services were held accountable for their actions which sometimes resulted in better services for the focus person:

> I think it's valuable for group homes and services because it keeps them accountable. We notice that, for example Ken, he always had really poor personal hygiene, the house was not very good at personal hygiene, and because Craig, his support worker in Inclusion Melbourne was on his circle of support, this is what – I can't confirm this but after like two months Ken's personal care got so much better. So, for me, that's like the house is only taking extra care because Craig is part of the circle of support and the Circle of Support was the one that was making waves to get the house to do different things. So, I think the value of circles is it makes services accountable for a person and to do the right thing. That's like a big element of advocacy there. (Circles of support program coordinator).

The circle has proven to be a valuable source for family members' sense of well-being and one mother had felt a shared sense of community as reflected in the quote:

> I think it's valuable to a family member because it kind of shows them that they're not alone and I think that's really important. Louise's Circle, her mum always said she always felt really good after circle meetings because she felt like she was being supported, which she was. Marcia, Jeff's mother, also says that. She was happy that there were other people in Jeff's life that were looking out for him that was not her. (Circles of support program coordinator).

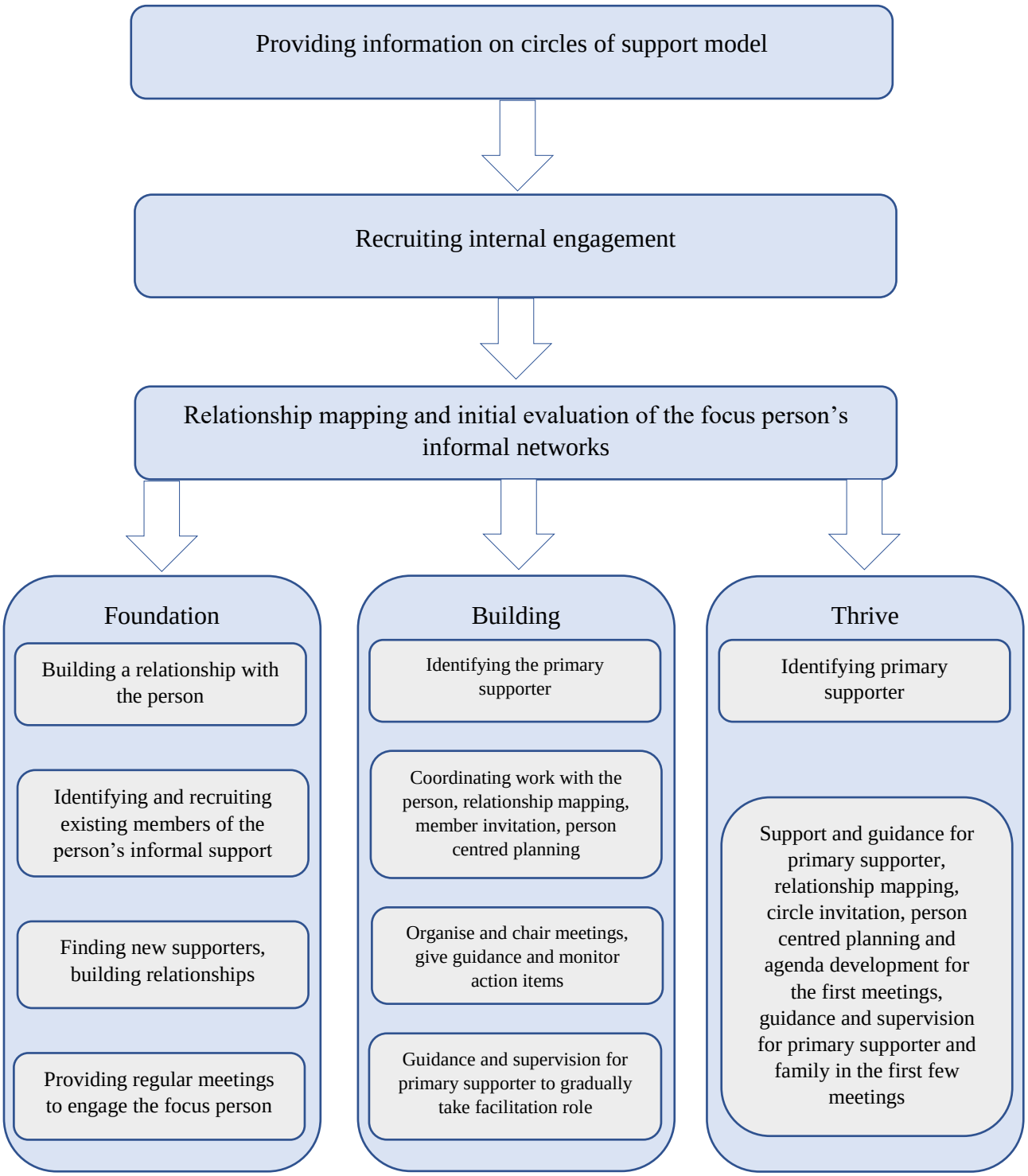
Gains for circle members were also described by the coordinator:

> There's a lot of social value in the circle. I think the value of a circle from a circle member's perspective is that circle members become more aware of what actually is involved in a person with disability's life… people feel better when they provide meaningful support" (Circles of support program coordinator).

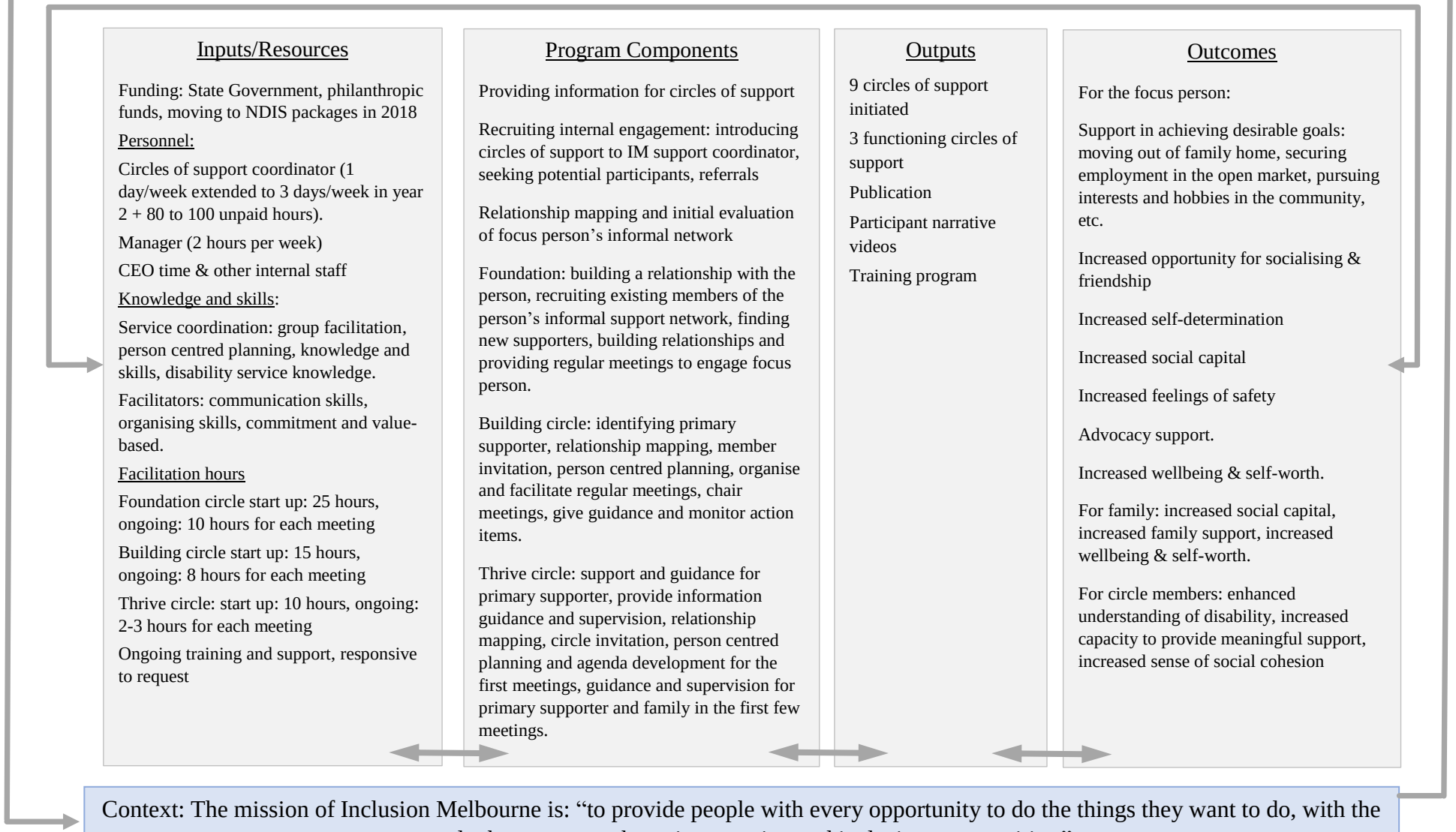
Circle members became more aware of what life for a person with disability might be like. Their involvement in the circle contributed to a positive change in circle members' attitudes and more broadly to community culture.

> John's circle had to learn a lot about residential group home related things that I don't think they would ever have thought of. They also had to learn a lot about disability services which can be really tricky, but I think it's valuable because they know it's not enough, it's not left for the family members only" (Circles of support program coordinator).

Figure 2 – Inclusion Melbourne processes and activities



Logic model: Inclusion Melbourne: by recruiting and training other individuals to become more involved in a person's life and by presenting formal structure into existing informal network activities, we would contribute to the person's quality of life, safety and ability for meaningful social integration.



Context: The mission of Inclusion Melbourne is: "to provide people with every opportunity to do the things they want to do, with the people that matter to them, in accepting and inclusive communities."

Case study 3: Uniting Care Life Assist Victoria

Life Assist is a not for profit organisation that has been operating in Victoria since 1987. The organisation provides disability, aged care and carer services throughout Melbourne and regional Victoria. In July 2017 Life Assist joined Uniting - the community services arm of the Uniting Church in Victoria and Tasmania. Currently, Life Assist provides NDIS preparation workshops and consultation, short term respite care, as well as ongoing support, coordination and transition planning for people with disability and their carers.

The circles of support program in Life Assist was initiated 12 years ago as a pilot project funded through a preventative respite initiative. After the successful completion of the pilot the organisation has continued to provide the circles of support facilitation service as part of their support coordination services for people with disability and their carers.

This case study draws on data gathered from semi-structured interviews with the Life Assist circles of support coordinator, the operations manager for disability solutions, the executive officer for Life Assist and team leader for the "Carer wellbeing and support" program. The case study also draws on a review of organisational and program documents. All names have been changed to ensure confidentiality.

Aims

Life Assist defines a circle of support as a group of informal people that meet together regularly to support the goals, interests and needs of the person with disability (focus person) and their family (carers). Circles of support are perceived as strategy for building and sustaining community capacity to plan and support person centred planning. The underlying assumption of the service is that providing structure and formality in existing informal networks strengthens and deepens the involvement of members of the informal networks in the lives of people with disabilities and their families.

The circles of support program coordinator describes:

> A circle of support is a group of informal people that meet together regularly for the good of the focus person. It ranges in size from the intimate to the extensive and can be made out of a range of people who are not paid to support the individual. It can be anyone, it could be family, friends, support workers…. They have to know the person and want to be involved and help with the purpose (Circles of support program coordinator).

The circles of support program in Life Assist has a structured process to introduce formality into existing social networks. The process helps to identify, invite and support family acquaintances, colleagues, neighbours and others, who are willing to contribute their time and energy, to be involved in person centred planning and working towards fulfilling the life goals of the person with disability.

> We help to intentionally bring that group together. So, to strengthen those relationships, relationships are really formed on the more we know about each other… it really is about meeting regularly, intentionally because, the individual might find it hard to. …So, it's just about providing that platform where they can actually make a you know…. the person with the disability has some people in their life and they are supported somewhat, but they're not sure how to utilise or interact with that group, to help them to meet their goals…. so circle of support is made up of supporters, they meet regularly to keep those goals alive. (Circle of support program coordinator).

The goal of the Life Assist circles of support program is to provide a short-term service for individuals with disability and their families to form a circle of support based on their existing personal network. The program coordinator guides the process by modelling and using a variety of tools to form the group, help shape the environment and provide structure:

> So it's (the service) about what can we get happening so this person is not reliant on whether the funding is in or not in the plan...It's empowering them to build their capacity with natural supports, people that care and want to be involved. So, it's about building capacity in community and being able to support that person to connect, which is often very hard to do. (Operations Manager).

Program input

Funding: Circle program activities are funded either through an NDIS plan, directly by the person with disability or their families, or through a carer support program, depending on the status of the person with a disability. Facilitation is charged at an hourly rate as "support coordination" based on the quote from the circle support coordinator. Forming a circle of support requires between 15-30 hours of facilitation depending on the person`s family, circumstances, strengths and needs (see process below).

Since 2018 the service has offered "circles of support facilitation packages" that can be factored into an NDIS plans under the support category of increased social and community participation, support item "innovative community participation". The package includes a minimum of 15 hours of facilitation to help establish a circle of support.

An alternative avenue for government funding has been referral from the "Carer Wellbeing" program in United Care. In this case the service (circles of support) is used as a strategy to build and sustain the capacity of the carer over time and maintain carers' well-being. When a family is referred by the carer's wellbeing program, Life Assist quotes for facilitation hours which are funded by the "Life Assist Carer Recognition program". These funds are available only to carers whose family members do not have an NDIS package.

> From our perspective we refer to circle of support for capacity building to value for our carers, to build a capacity and increase the sustainability of their caring role going forward." (lead of Carer wellbeing disability support program).

Finally, some clients are self-funded on fee-for-service basis:

> Some people learn on circle of support word to mouth…. sometimes people will ring up and typically go, 'Oh I heard you do circles' …sometimes they don't have an NDIS plan, sometimes they do but don't have circle of support. (Circles of support coordinator).

In the past the program has been able to draw on a Linkage grant and block funding to Life Assist to fund facilitation but is now becoming increasingly reliant on funding through inclusion of facilitation costs in NDIS plans.

Staff: All program activities are being delivered by one staff member with the dual role of support coordinator and specialist circle facilitator. The number of hours dedicated to circles of support facilitation are indeterminate. The coordinator's time is allocated to each circle in a flexible and responsive way.

> Unless the referrals come in the door you cannot commit any staff member to a role. So the strategy we would have is that Rachel's (circles of support coordinator) role will be predominantly support coordinator role and her role would continue and then as the referrals (for circle of support) come through and they're funded then we would prioritise those, and we would then monitor her workload. So, we're always looking at the staff's caseloads, how many hours they're allocated, how many referrals are coming through the door, how we allocate. That's just something we have to track all the time. So as circles referrals come through the door we would allocate those to her but of course not allocate support coordination to her as well because obviously there's only so much she can manage. (Uniting Care life Assist director).

Time: establishing a circle of support requires between 15-30 hours of facilitation depending on the focus person, family circumstances, strengths and needs. Circle meetings and planning are usually scheduled out of business hours, “usually Sunday afternoon”.

Places: Life Assist operates from their offices in Melbourne, however circle of support facilitation occurs in personal family homes and public places.

Skills and knowledge: The program coordinator is required to have knowledge of the circles support model, group facilitation skills and an understanding of the disability services environment. Also, specific knowledge is required on how to structure and facilitate person centred planning. These requirements are reflected in the following quote from the director:

> She (program coordinator) is doing something very special and it's not something that everyone can do. To be able to facilitate, draw people together in a room and provide structure…. There are multiple skills you need, it's very specific and tailored and not everyone can do it ….it needs to be someone experienced in facilitating groups, understand disability. You would need to ensure people have excellent listening skills, also understand how to draw people together to work towards common goals, person centred planning, building relationships ... So it's skills with mediation, group work, sensitive to different dynamics and situations because you can have competing ideas in a room ... Creativity, problem solving, thinking outside the square. (Uniting Care Life Assist director).

The passion and commitment of the program coordinator and circle members have also been identified as significant inputs to the circles of support program – the coordinator was highly committed to the project, beyond the formal boundaries of her role. She was willing to contribute additional time and resources for successful completion of the process:

> I don't want them to give up on the process halfway through, so yes, it makes it a bit more difficult, I'm not going to halfway through and go "That's it, you haven't got it, you haven't paid your bill and I can't keep going.", because it's quite personal and I'm involved in a very personal journey, and so you can't just stop halfway through. You do need to see it through to the end. So, sometimes we're not getting paid all the way to the end, but yes, I can't not continue to the end. (Program coordinator).

Circle members invest time, knowledge and personal resources into their activities. All activities in the circle are voluntary, and involvement in a circle of support is based on respect and understanding of the person’s life circumstances and driven by commitment for the focus person’s choice, autonomy and well-being.

Program activities and processes

Introducing the concept and evaluation

This process starts with either a referral or an inquiry from people with disabilities or their families who express interest in developing their own circle of support. The program coordinator assesses their knowledge and familiarity with the concept of circles of support. In an initial conversation the program coordinator introduces the client to a variety of resources provided by the organisation and assesses the nature of their existing social network:

> People that come and say I want a circle, I say “Yeah”, and explain the facilitation process. So, then they would fill in a form, a referral form and we have an initial conversation so, "How much do you know about Circles?" Sometimes families have already tried themselves to get the circle up and running and it's just too confronting sometimes they don’t know anything. (Circles of support program coordinator).

Based on this initial evaluation the circle facilitator provides a quote of the number of facilitation hours needed to the funding source (either government-funded or self-funded). This also provides a detailed plan identifying the goal of the circle and the process to the client:

> So, once we’ve had that initial conversation and get a knowledge of what their knowledge is about circles, then I can kind of do a quote. So, generally I would do a quote for somebody if they've rung and said yes, we've tried circles before, we just need that person to get it together, maybe to help us invite people to get it up and running. Then I probably put like 10 to 15 hours aside or something for that initially, just to help them to set it up. But, if it was somebody and I started the conversation about their knowledge of circles and they said, "I don't know much about it, I just think it would be good." Then it can take more hours … I can’t find them friends, but I can help them identify people in their life that they can invite. (Circles of support program coordinator).

This initial phase helps potential clients understand the facilitation process in Life Assist and decide whether this model is beneficial to them at this point in time. Staff involved in Life Assist programs place great emphasis on the choice and commitment of the client to lead the process:

> The quote and the model Rachel (circles of support coordinator) developed is quite clear what she’s advising the client, will be delivered, this many hours, this is the goal, we will meet this many times to give a clear expectation and after that point that’s what you’ll have. (Uniting director).

Preparation

Once a person/family expresses interest in developing a circle of support and a quote has been accepted, the coordinator meets the focus person and family in their home to establish the fundamental principles of circles of support, map available social networks and relationships, discuss different strategies for inviting people, and establish goals, the circle's purpose and an agenda:

> In those home visit meetings, I'm getting a snapshot of their life … So, whichever way I go, I'm not prescribing anything actually, I'm trying to listen to the individual in the best way that they can communicate what they need …. because I am involved in a short-term capacity, I'm trying to work out very quickly what's important to the individual and what's going to be the best outcome for them….The people that they will have involved in their circles, the things that they want to talk about in their circles, I'm trying to work that out in a way that's person centred but quite quickly. (Circles of support program coordinator).

Relationship mapping

In the first home visit, the program coordinator facilitates the process of relationship mapping to assist the focus person and family to identify people that are involved in their lives and assess the quality of relationships with them. The individual and family are encouraged to consider whether and why they would want to invite this person to participate in the circle of support.

Invitation

The coordinator places a special emphasis on supporting the development of invitation strategies, that the person or the family themselves can carry out. This involves encouragement, help in thinking about ways of overcoming barriers and findings comfortable ways to invite potential members. The organisation provides templates for electronic and hardcopy invitations and "role-playing" inviting people via phone or direct communication.

Develop a goal or a vision for the circle to work towards

The coordinator engages with the individual and their family to understand what is important to them, to set goals and to discuss how the involvement of others may contribute to make positive changes in their life, both in present and in future. The process is guided by person centred planning strategies and tools such as PATH toolkit, life pass and life stories:

> These plans I usually discuss in the first circle meeting as a tool to assist circle members to deepen their acquaintances and understanding of the individual and it helps to give direction to circle activities. (Circle booklet).

It is estimated that the preparation phase requires 3-6 hours of "support coordination". Following the two home visits the family is encouraged to set a time and place and to schedule the first circle meeting facilitated by the program coordinator.

Facilitation of the first two meetings

The first two circle meetings are facilitated by the program coordinator. In these meetings the coordinator helps introduce the concept of circles of support and engages in the process of introducing the person and circle of support members. The facilitator presents ground rules, providing structure and helping to identify roles and responsibilities, including a volunteer facilitator and note taker. In addition, the program coordinator models how to work in a person centred way and establishes a supportive and productive routine. Within the first meeting great emphasis is placed on creating a welcoming and warm environment, allowing opportunities for gaining a better acquaintance with the person and family and to allow relationships to flourish:

> I facilitate the first two circle meetings. In the first meeting, I generally introduce myself and my role as well. I talk about that I'm not going to be attending all the meetings into the future, that my role and the success of the circle really does depend on them. So, I'm kind of trying to get a bit of buy in as well. …. then I help the individual and people in the room introduced themselves, you know you need to get everybody engaged. If it could be somebody else that could work with the individual to decide when the next meeting is and go through all of those short details with them. Keeping the agenda, keeping it person centred, maintaining the integrity of the circle, that decisions do sit with the individual, and that it's being driven by things that are important to the individual. That's why I made the book too, it's just helping them to have a clear path. But one of the main responsibilities of myself as a facilitator is to help them to create a pathway to actually having the first meeting, and then after the first meetings - because it is so organic they can do it themselves. (Circles of support program coordinator).

Providing information

The program coordinator provides the groups with written materials like “Circles of support client handbook” and “circles of support planning and meeting” that may assist circle members in designing, structuring and operating their circles over time. At this stage the involvement of the program coordinator ends, and the circle sustainability relies on the commitment of its members.

Program Outputs

Life Assist does not keep records of the number of circles that have been developed through the program. However, the coordinator estimated that over the past 12 years she has been involved in developing around 60 circles of support, seven of them within the last year.

Supporting documents: the organisation has developed several publications including informational sheets “Circles of support planning and meeting” and “Circles of support client handbook” as supporting documents. These documents assist families to understand the concept of circles of support and provide operational principles and guidelines, strategies and tools for person centred planning, some example documents (such as invitations, agenda, etc.) and strategies to sustain the operation of the circle of support over time.

Program Outcomes

The program coordinator and staff have identified a range of outcomes. Some are the promotion of person centred planning and acting towards the predetermined goals, however, a set of unexpected outcomes resulting from the investment in informal social networks and personal relationships was also identified:

> I think that's what makes it very hard to measure the outcomes because, some of them, some of the outcomes might be expected, but most of the outcomes are totally unexpected and individual, depending on that circle and individual, who they are …The circle itself provides deeper knowledge of an understanding of the person and family, it provides opportunity to deepen relationships …. So even if they never had another circle meeting something’s been achieved just by that group coming together. There's more knowledge in those relationships and those people, it's been strengthened just by understanding that person better. (Circles of support program coordinator).

Additionally, circles of support have proven to be a successful strategy for goal planning and promoting realisation of goals. The process helps to involve people in planning and taking active roles in the social life of the person with disabilities. Participation in circles of support creates new opportunities for people to contribute their time and knowledge, resulting in new strategies for social participation:

> There are so many examples of things people achieve through their circle … a lot of people move out of home… there was a young lady that just wanted to catch up with lots of people… but just didn't have the capacity to organise time, so in the circle they created a schedule … So, the first session was about doing the schedule how she's going to meet everybody once a month, then thinking about who you would normally contact, often those people are in those people's circles, so they're able to help. (Circles of support program coordinator).

Another example demonstrates how the involvement of other people has resulted in better support and care:

> …. there were so many tasks to do every day, that that person maybe wasn't being supported as well as they could, being at home. So, in sharing that with the circle, then there were other people that said, "Why don't I come in on Monday mornings because I start work late?" Or whatever, so they could see exactly what support they could offer rather than go, "Do you need any help?" people knew what was going on and new ideas came into action. (Circles of support program coordinator).

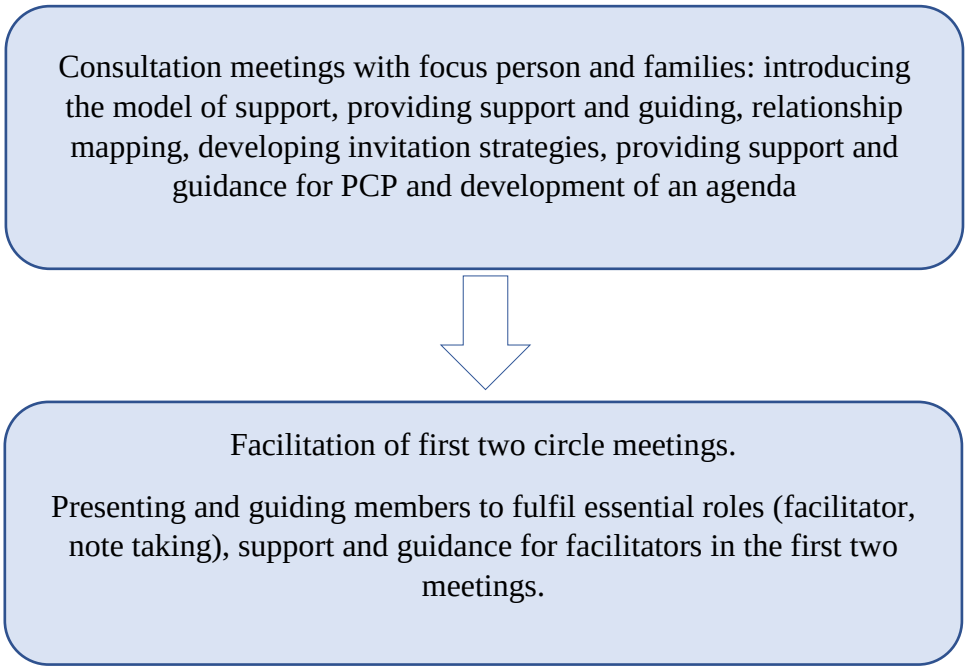
Involvement in circles of support has yielded better carer experience, helped to alleviate some of the care responsibilities and contributed to sustainable support. Family members and especially those in a primary carer role, felt more supported and sometimes they were able to alleviate some of the care responsibility by introducing new resources, ideas and people into their lives:

> It's that informal support, it's be mindful of the care recipient, they're comfortable with the people around them, because they know them, they're family, they're friends. And the outcome for us working with the carer is to give that carer a break from their caring role. They don't have to take on all of the responsibility of caring for that care recipient when other people can come on board and help… services in the future are not going to be always available but this informal capacity or informal support allows the carer to relax, because they know the care recipient is being supported by other people. (Lead of the Carer wellbeing disability support program).

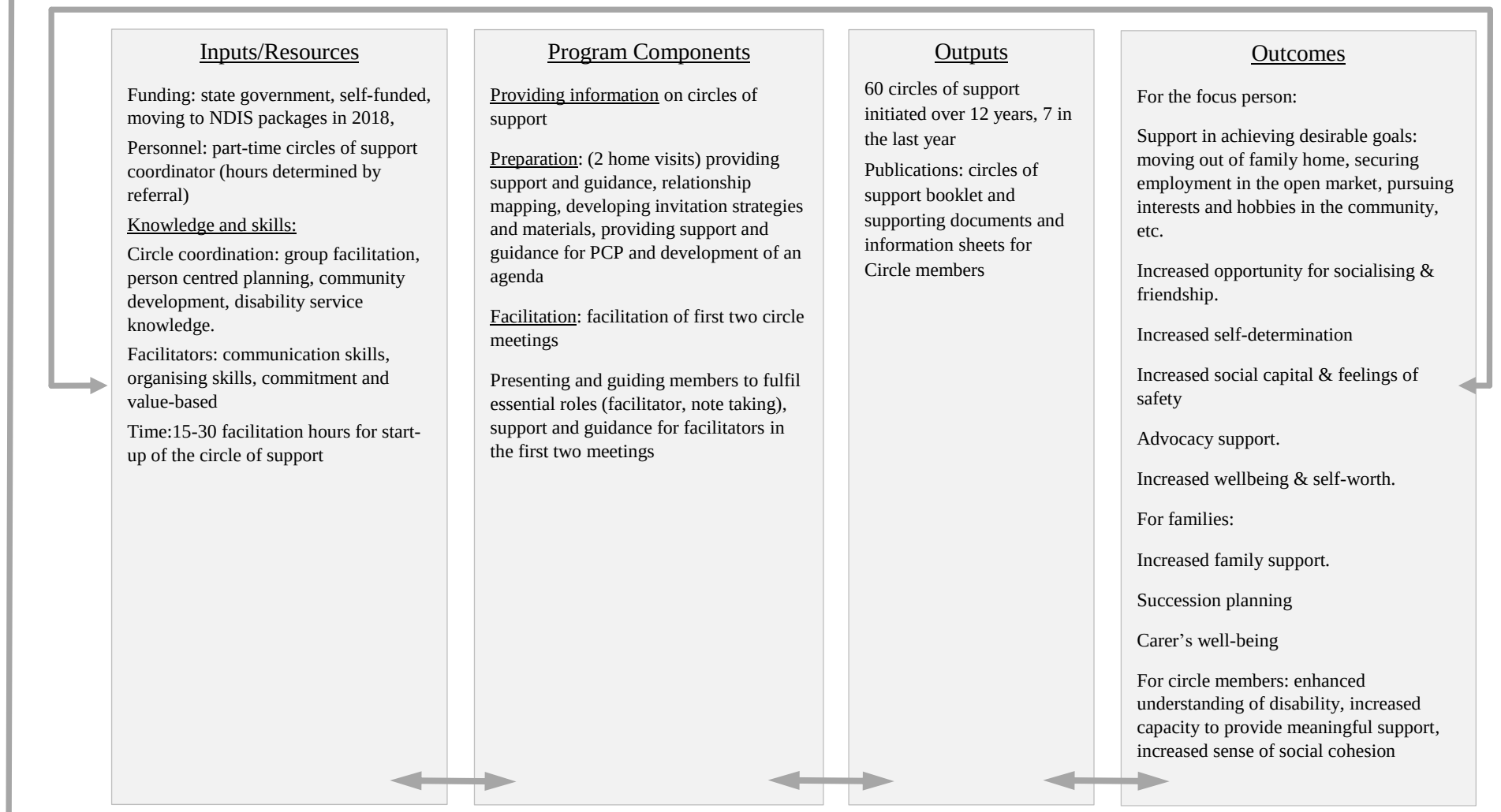
Involvement in circles of support has proven to be an effective strategy to build the capacity of the community to support the person with disability and their family. Circle members expressed feeling valued and were able to provide meaningful emotional and tangible support:

> … When somebody asked me, do I need help. I always answer I think I will be okay, because he just can't actually think exactly what that help might look like until you can identify it back in the circle, somebody can go "I can do this" because now they didn't know exactly what you need. (Circles of support program coordinator).

Figure 3 – Life Assist processes and activities



Logic model: Uniting Care Life Assist (Melbourne): By presenting formal structure into existing informal networks we would contribute to the person's quality of life, safety and ability for meaningful social integration.



Context: The mission of Uniting Care Life Assist is: "To work with vulnerable and disadvantaged individuals and their families so that they can live a valued and meaningful life and remain connected to their community".

Cross Case Analysis - What can be learned?

This section of the report compares and contrasts the key dimensions of the three case study programs and explores the design and practice issues they highlight. It aims to draw out the commonalities and differences between programs in terms of primary group served, program logic and activities, staff skills and outcomes. By capturing and consolidating the practice wisdom embedded in these different programs, which is seldom made explicit, the analysis provides valuable insights for organisations to develop or refine circles of support programs. Teasing out differences between programs may also help people with intellectual disabilities and their families to make choices about which aims they want to pursue and thus what type of program might suit their needs.

Table 1 summarises the program logic and core elements of the three programs.

Table 1: cross case studies analysis

	Pave the Way	Inclusion Melbourne	Life Assist
Aim	Building the capacity of the informal network in order to enhance and maintain the capacity of the family to provide ongoing support and advocacy. Give ongoing support and to ensure PCP and succession planning. The service aim is to educate families on the model of circles of support and to introduce structure and formality in existing informal networks in order to enhance and maintain the capacity of the family to provide ongoing support and advocacy.	Building and strengthening the capacity of the individual's informal supports to provide meaningful voluntary support, and to assist the individual to live a life of quality as part of an accepting community. Provide professional coordination and guidance to assist persons with disability and their family to build and maintain their informal support network.	Building and sustaining the capacity of informal network members to support persons with disability and their family. Circles of support program in Life Assist provides a structured process to introduce formality into existing social networks. The process helps to identify and invite family acquaintances, colleagues, neighbors and others that are willing to contribute their time and energy to be involved in the life of the person with disability, to support them in their planning and work towards fulfilling their life goals.
Target population	Families of people with disability. People with disability with existing social networks.	People with disability with existing social networks. People with disability with limited or no informal networks.	Families of people with disability. People with disability with existing social networks.
Primary Strategy	To Provide information to families on the circles of support model; and to provide a professional structured process to introducing formality into existing informal networks.	Initiating and providing a professional structured process to build and strengthen informal support networks for people with disability and to provide ongoing facilitation and coordination.	Provide a structured process to introduce formality into existing social networks and to assist forming circle of support groups.
Activities	Provide information on circles of support model and application. Preparation phase: relationship mapping, support in invitation process and agenda planning. Facilitation: Facilitation of introduction night. Facilitation of first meeting.	Evaluation of the individual's existing informal networks. Foundation circle: getting to know the person and building relationships with unpaid members and facilitating meetings Building circle: getting to know the person and their social networks, strengthening existing relationships, developing circle purpose and facilitating meetings.	Preparation phase: relationship mapping, support in invitation process and agenda planning. Facilitation: facilitation of the first circle meeting. Support, guidance and supervision for facilitator.

	Facilitation and co-facilitation in meetings (up to a year of circle operation) Support, guidance and supervision for facilitator upon request during the first year.	Thrive circle: identifying and working with primary supporter, facilitation of the first meetings.	
Program input: **Professional knowledge and skills**	Knowledge of disability service environment, person centred planning, group facilitation and circles of support model development and delivery. Communication skills, sensitivity and respect for diversity.	Knowledge of disability service environment, person centred planning, group facilitation and circles of support model development and delivery. Communication skills, sensitivity and respect for diversity.	Knowledge of disability service environment, person centred planning, group facilitation and circles of support model development and delivery. Communication skills, sensitivity and respect for diversity.
Program input: **Time and energy**	Development of a circle of support requires: preparation phase 10-15 hours of professional involvement and 2-3 hours for each meeting in the first year of operation	Development of a circle of support requires: Foundation circle: preparation phase 25 hours and 10 hours per meeting (not including tasks allocated at each meeting). Building circle: preparation phase 15 hours and 8 hours per meeting (not including tasks allocated at each meeting). Thrive circle: preparation phase 10 hours and 2-3 hours peer meeting.	Development of a circle of support requires 15-30 hours of professional involvement.
Program input: **Personnel**	Pave the way employs 4 Permanent staff. Two with expertise in circles of support development. Hours dedicated to circles of support are flexible and determined by the number of interested families.	Part-time program coordinator – one staff member with expertise in circles of support development. Supervision of senior management.	One staff member with expertise in circles of support development – hours determined by the number of referrals.
Outputs	No data collected on number of circles of support developed, estimated approximately 100 circles of support were initiated over the years. No data on their sustainability after service withdrawal.	Nine circles of support launched over two years out of which three circles of support were formed and operated for at least six months. One circle of support continues its operation after the withdrawal of the circles of support coordinator.	No data collected on number of circles of support developed; estimated approximately 60 Circles of Support were initiated over the years. No data on their sustainability after service withdrawal.
Outcomes	Wider informal social networks for supporting people with intellectual	For the focus person: Support in achieving desirable goals: moving out of family	For the focus person: Support in achieving desirable goals:

	disabilities and their carers. Increased capacity of informal networks to provide sustainable and long-term support Increased motivation, confidence for people with disabilities and their families Increased participation in community life Strengthened communication and relationships Increased feeling of belonging to the community Support in achieving desirable goals: moving out of family home, securing employment in the open market, pursuing interests and hobbies in the community, etc. Increased community capacity Increased community understanding of rights of people with disability Increased involvement in the person with a disability and family's lives Active involvement and collaboration in the community to drive inclusion for people with disabilities.	home, securing employment in the open market, pursuing interests and hobbies in the community, etc. Increased opportunity for socialising & friendships Increased self-determination Increased social capital Increased feelings of safety Advocacy support. Increased wellbeing & self-worth. For family: increased social capital, increased family support, increased wellbeing & self-worth. For circle members: enhanced understanding of disability, increased capacity to provide meaningful support, increased sense of social cohesion.	Increased opportunity for socialising & friendships Increased self-determination Increased social capital Increased wellbeing & self-worth. For families: Increased family support. Succession planning Increased wellbeing For circle members: enhanced understanding of disability, increased capacity to provide meaningful support, increased sense of social cohesion.

Target population

Although positioned within the broad concept of circles of support, in each case program aims, strategies and target population differed to some extent and were shaped by the mission of the wider organisational of which they were a part. For example, Pave the Way is defined as a "family focused service" and the logic of their circles of support program was that by strengthening and supporting the family to ensure continuity of informal support across the lifespan the person with disability would benefit. Reflecting the nature of other programs offered by Pave the Wave, the circles of support was perceived as one of a number of strategies to deliver and implement person centred planning and succession planning. In this context, circles of support was conceived as providing a safety net for family members and

assisting them in their decision-making processes to ensure their relative with disability lives a life of quality in the present and future. Similarly, Uniting Care Life Assist focussed broadly on both support planning services for people with intellectual disability and support and respite for their carers. The focus of their circle of support program was to build the capacity of the individual and their family to strengthen existing social network in order to support them to realise their goals and live a life of quality.

In both Pave the Way and the Life Assist programs circles of support were perceived as essentially "family business" relying on the motivation and contribution of family and other informal network members to lead development and sustainability of circles. The involvement of the program and thus professionals is short-term in order to provide families with the essential knowledge, skills and structures they require to develop and run their own circles of support and maintain them over time. Both programs relied on referrals or the expressed interest of families, and targeted only people with disabilities who had existing social networks. From a broader perspective both programs perceived circles of support as a community capacity building strategy which fostered greater involvement of community members in the lives of people with disabilities.

In contrast, Inclusion Melbourne perceived circles of support more as "service business" with a much stronger role for the professional program coordinator in initiating and managing circle development. By funding the program through philanthropic grants it could be targeted more specifically than the other programs. The program coordinator's role in leading the process, and her ongoing responsibility to develop and maintain the circle of support, meant more prolonged engagement with each circle and enabled a more flexible approach adapted to focus person's capabilities and existing social network.

The focus of the Inclusion Melbourne program was more specifically capacity building for individuals and building informal support networks. In contrast to the two other programs, Inclusion Melbourne targeted isolated people, particularly those in supported accommodation without strong family support, or with little or no other forms of informal support. This meant the role of the program coordinator was that of a "social broker" concerned with developing the informal network of the focus person by strengthening existing informal connections and assisting the development of new relationships. This type of role required significant and long term resources, and its centrality to the program meant that when short term funding was exhausted the circle of support program was not sustainable.

Each of the programs had a similar overarching intent about sustaining informal support and the quality of life of the person with disability. But it was clear that there was no one standard program 'circles of support' - each had different target groups and aims – each was effective in achieving what it set out to do. Comparison of these programs illustrates that the operationalisation of the concept of circles of support, tasks of paid staff, the practice, time and cost required to form and sustain a circle are primarily dependant on the nature of the person's pre-existing informal network.

It demonstrates the relevance of the circle of support concept to people without strong family support and the potential benefits to this group. However, the longer term involvement and more intensive work of the coordinator in this program suggests the importance of taking note of cost differentials and the perhaps the need for more explicit about the aims and target groups of circle of support programs.

Program governance, size and scope

The analysis shows the programs varied in scale and size, and in terms of budget, staff, participant numbers, and hours of support offered. Inclusion Melbourne was the only organisation with a discrete program designed and funded solely to provide circles of support coordination. Life Assist provides circles of support facilitation and coordination as one strategy for it broader person centred planning services on the basis of billable hours of "circles of support specialists". On the other hand, in Pave the Way, circles of support is not funded as a distinct program, rather it is perceived to be one strategy aimed at safeguarding and ensuring quality of life for people with disability and their families.

All three organisations had organisational mission statements that conveyed a strong sense of commitment to citizen rights, social inclusion of people with intellectual disabilities and the well-being of their families. Common to all circles of support programs were strong and charismatic leaders close to the operational aspects of the programs, and whose knowledge of participants illustrated the principles of equity valued by organisations, and absence of social distance between staff and participants.

Program input

Knowledge and skills: All programs identified similar areas of knowledge and skills for the program coordinator and circle members. These include knowledge of the disability services environment and the concept of circles of support, and expertise in person centred planning

and facilitation. Personal attributes, commitment and values were also recognised as important and included, listening and communication skills, respect for people and person centred thinking. The possession of qualifications, facilitation skills and specific knowledge were highly valued by the senior managers in all three organisations. They all stressed that forming a circle of support needed a "specialist coordinator" and the tasks are different from ordinary support coordinator work. However, despite this recognition only Inclusion Melbourne formally documented the specific knowledge skills and characteristics required for the circles of support professional coordinator.

This lack of formal documentation of required staff skills and knowledge has the potential to undermine the staff component of an effective program. The understatement of skills needed for practice in two of the three programs has potentially negative implications, as it fails to articulate a key program component potentially important to scaling up programs, and may hinder successful staff recruitment and maintenance.

Staff time and energy: The nature of circles of support requires group activity to occur in a comfortable time and natural setting. Therefore, most circles of support activities are determined by the availability of circle members and family, and happen predominantly in the weekend and after office hours. Staff members emphasised their flexibility, arranging their time according to the needs and requests of people with disabilities, families and circle members.

In all three organisations, staff showed extremely high commitment and willingness to provide guidance and supervision over and above the boundaries of their budget time and role, to promote circle activities. For instance, in Inclusion Melbourne it is estimated that staff contributed 80 unpaid hours to the development and delivery of circles of support and the coordinator contributed tangible personal resources such as paying for circle members' refreshments.

Places: The philosophy of circles of support emphasises that a large part of the work happens outside the office in the social and community spaces of significance to the people supported. Thus, program activities largely occurred in public places, restaurants, pubs and circle members' homes.

A particular challenge was experienced by Inclusion Melbourne in the *Building* and *Foundation* circles where there were no committed informal supporters involved in the focus person's life. In these cases, potential circle members were encouraged to meet the person on

a regular basis in recreational venues such as cafes and restaurants. In some of these cases the underlying expectation was that the cost associated with these outings would be covered either by the program or by the focus person. These costs were not accounted for in the program budget and many times resulted in the coordinator paying out of pocket for these outings.

Funding: Detailed budget information was not available, but the estimates suggest that these are small scale programs. Primary sources of income were small local government or philanthropic grants and state government disability support service funding. In addition, shared administration and cross subsidisation of programs within organisations made it difficult to accurately identify program budgets, and sometimes boundaries between different programs were blurred. For example, in Pave the Way it was challenging for participants to distinguish between activities that were part of the general support planning, and those part of the circles of support program. Some families attended the succession planning and documenting information workshops the organisation delivered, but whether these workshops were a separate or integral part of the circles of support development was not fully clear.

All the programs were in the process of rethinking budgets and calculating costs per participant hour in order to align their business models with the NDIS individualised funding model. Considerable uncertainty existed around future funding when the data was collected at the end of 2017 – 2018.

Program activities and processes

All programs used a structured process comprised of sequential steps, commencing with providing general information, followed by a preparation phase, relationship mapping and facilitation, co-facilitation of the circle in the forming phase, and withdrawal.

However, there were considerable differences between programs in the amount of structure and flexibility they allowed in the process. For instance, while Life Assist quotes for a package of billable support and coordination hours with a predetermined service withdrawal, Pave the Way provides a structured process but the service involvement in the coordination phase is determined by the circle of support's maturity which can take up to a year.

Inclusion Melbourne's process on the other hand is less linear and dependent on the focus person's existing informal network. The model accommodates for the person's needs and distinguishes between a) people with disabilities with no or very little social networks, b)

people with social networks that are not able or willing to commit, and c) people with strong and committed members in their social networks. This model includes an additional evaluation phase where the coordinator evaluates the person's social network and assigns a different strategy and goal for the development of a circle of support.

Another unique aspect to the Inclusion Melbourne model is the focus on developing new relationships in foundation and building circles. For instance, in foundation circles the program coordinator's goals are to build a relationship with the person, actively search for new members in the person's informal network, and to provide opportunity for social engagement and involvement in the focus person's life. Although the underlying philosophy of programs are similar they differed in whether circles were predominantly seen as "service business" or "family business".

It seems that the simplistic notion that once a circle of support is established, professional mentoring and support can be withdrawn fails to take account of changes to groups over time, or indeed the time-limited nature of some groups. All the programs emphasised the need for availability of ongoing support and mentoring throughout the life of the circle but none had developed a mechanism for delivering in the longer term.

Moreover, our analysis exposed the hidden and multi-faceted work required from program coordinators in all programs for the development and maintenance of circles of support, as the participants' experiences exposed the significant work done "behind the scenes" by the program coordinators. It is evident that developing a circle of support goes beyond one to one consultation or providing general information and guidance. Both program staff and circle members described how the circles of support were based on relationships of trust and confidence. Coordinators had to establish warm and accepting relationships with the person with disability, their family and potential circle members, and these relationships were the basis of any meaningful activity in the circle.

Outcome domains

The cross case analysis suggests that at the conceptual level, the three programs had very similar positive outcomes for the individual, the family and the community at large. On the individual level, a circle of support strengthened informal supports and extended their social network, assisting in fulfilling goals and aspirations. It is important to note that outcomes were mostly identified by family members, as in this study we were able to interview only three people with intellectual disability (all from Inclusion Melbourne). The interviews with

people with intellectual disability provided first hand evidence that circles of supported had assisted individuals in achieving goals such as moving out of home, provided more opportunities for social inclusion, the involvement of others in their life and an increased sense of safety and well-being.

The process of building informal support gives voice to the person and the family. Communication in a circle seems to give meaning to family experiences; support is shared and families felt more comfortable to call on others. The collective nature of circles of support and the sense of community reported by the many people involved were associated with feelings of confidence, respect, reduced burden and an increased sense of belonging and well-being. Some families found circles of support a safe place to express emotions about their experiences and an environment to collaborate and problem solve with others.

For community members, circles of support seemed to build the capacity of communities to be inclusive. Involvement in circles can result in increased community understanding of the rights and barriers people with disability face in being included. Involvement in a circle of support is also likely to have had an indirect impact on attitudes toward people with intellectual disabilities, as the circle creates opportunities for community members to communicate with people with intellectual disabilities under the type of conditions contact theory suggests foster breaking down of prejudicial attitudes. These conditions are ones that, (a) allow opportunities for a meaningful level of communication that is personal in nature, frequent, and of reasonable duration; (b) promote equal status; and (c) foster cooperation in working toward shared goals (Craig & Bigby, 2015; Novak & Rogan, 2010; Pettigrew & Tropp, 2006). Circles of support are also a mechanism to build social capital in a community, enhancing the level of trust, participation and relationships in that community.

These outcomes are aligned with the NDIS statement vision “to optimise the social and economic independence and full participation of people with disability” and reflect the ILC outcome framework which is seeking to invest in activities that develop independence, self-determination and community inclusion.

It is difficult to compare outcomes across programs with differing contexts and client groups. In addition, the personalised approach means that each circle is unique, and its purpose and dynamics may change over time. Given these factors, success should be measured both for each individual against their own goals as well as the specific goals of the program.

Our cross analysis of programs demonstrated the importance of employing individually referenced indicators of success such as goal achievement or changes in quality of life, social inclusion, social capital, the quantity and quality of interpersonal relationships, and changing community attributes such as social capital and community cohesion.

The challenge now is to develop robust and efficient methods to capture the intended and unintended outcomes from multiple perspectives, capturing the impact of a circle of support on the person, family and community. In addition, consideration should be given to developing robust more methods of evaluation using observations, and more rigorous analysis of the costs and benefits over time.

Conclusions

These case studies have demonstrated the variability in circles of support programs. The detailed exploration of each program's logic has provided a detailed understanding and made explicit some of the embedded program and practice wisdom. In some ways the case studies are blueprints that could be used to develop or refine programs that aim to support the development and maintenance of natural support networks for people with intellectual disabilities. The cross-case analysis highlights several issues that require further consideration:

First, the case studies have illustrated the limited choice of program types that may be available to isolated people with intellectual disabilities or those with limited informal networks. Although quite small, in our sample only one type of program included this group of people. This finding is worrying especially in light of research indicating the large proportion of people with intellectual disabilities with no unpaid people involved in their lives (Bigby, 2008). For instance, in Bigby's study 72% of participants had no family member who knew them well and actively monitored their well-being. It seems that the model employed in Inclusion Melbourne may be beneficial for this population, however the case study highlights the difficulties in building social relationships and the high demands from services in terms of professional commitment, program input and funding needed to implement the service effectively. This suggests a need for programs aiming to build informal networks and strengthen relationships to consider what changes to design might be required to include isolated people. Also, that new funding for innovation or demonstration pilots should be directed towards programs that are inclusive of people with limited social networks to ensure this group has choices comparable to other groups.

Second, this detailed review has enabled an initial mapping of the range of knowledge areas and skills that staff involved in circles of support used in these programs. Further mapping of skills and competencies of staff is required, as well as bringing together these various approaches into a coherent practice framework. Recruiting staff with preferred attitudinal attributes and training them to be competent practitioners with the types of skills identified as necessary will be a major challenge for disability support organisations as the demand for support for "informal support network development" grows with additional funding available from the NDIS.

Finally, the analysis highlighted difficulties that the current and future funding mechanisms pose for the programs. There was limited data on the sustainability and longevity of circles' after the withdrawal of the program coordinator. Yet it seems that the simplistic notion that once the circle has been established, the capacity of the community to carry this knowledge and sustain the activity over time is not established. Research conducted in the general population suggests that relationship building and network development takes time, energy and long-term commitment of all involved (Heaney &Israel, 2008).

In addition, group and community development theories suggest that as community group dynamics change, relationships evolve and purpose should be constantly accommodated to sustain group activity and purposeful engagement (Welch &Yates, 2018). The service delivery under the NDIS model calls for a short-term capacity building service budgeted by billable hours. This does not allow for many unbudgeted activities such as building and maintaining relationships with the focus person and family, active monitoring (Wilson et al. 2010; Chng et al., 2013) and ongoing support for groups as they evolve over time. Active monitoring aimed to ensure provision of the right type and intensity of support to either the individual or those in their support network, at the right time to enable the individual with intellectual disability to participate in group and social activities, recognizing this would vary over time.

Another challenge is for services that rely on referral. In these services many hours are spent on developing marketing materials, communicating with service providers and planners to explain the model of circles of support, and reach out for potential participants. In the current time of changing funding schemes, special attention should be given to those challenges and to develop mechanisms to ensure adequate funding of the program.

To conclude: The knowledge developed from this study can inform future design of programs to support the development and strengthening of existing informal networks.

It may also inform individual NDIS planners, and broader decisions by the NDIS about types of effective programs. Setting out the common characteristics and differences between programs will also be useful to people with intellectual disabilities and their families in making decisions about planning and purchase of services. There is significant room for further development of this material into more accessible guides for professional interventions aimed at informal support network development for people with intellectual disabilities, their families, NDIS planners and local area coordinators.

References

Bartnik, E. (2008). Getting Serious About More Positive Pathways to Relationships and Contribution. *Magazine of the Australasian Society for the Study of Intellectual Disability, 28*(2), 3.

Bigby, C. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability, 33*(2), 148-157.

Bourke, S. (2009). *Building Intentional Lifelong Safeguards*. Mt Gravatt, Queensland: Pave the Way Mamre Association Inc.

Clark, D., Garland, R., & Williams, V. (2005). Promoting Empowerment: Your Life Can Change If You Want It To. In S. Carnaby & C. Cambridge (Eds.), *Person Centred Planning and Care Management with People with Learning Disabilities* (pp. 67-84). London: Jessica Kingsley.

Dowse, L., Wiese, M., Dew, A., Smith, L., Collings, S., & Didi, A. (2016). More, better, or different? NDIS workforce planning for people with intellectual disability and complex support needs. Journal of Intellectual and Developmental Disability, 41(1), 81-84.

Etmanski, A. (2000). *A good life: For you and your relative with a disability*. Burnaby, British Columbia: Planned Lifetime Advocacy Network.

Etmanski, A. (2009). *Safe and secure: Six steps to creating a personal future plan for people with disabilities – RDSP Edition*. Burnaby, British Columbia: Planned Lifetime Advocacy Network.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Hallam, A., Knapp, M. & Wooff, D. (2006). The Social Networks of People with Intellectual Disability Living in the Community 12 Years after Resettlement from Long-Stay Hospitals. *Journal of Applied Research in Intellectual Disabilities, 19*, 285-295.

Giesbers, S. A., Tournier, T., Hendriks, L., Hastings, R. P., Jahoda, A., & Embregts, P. J. (2018). Measuring emotional support in family networks: Adapting the Family Network Method for individuals with a mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. Advance online publication. doi: 10.1111/jar.12512

Hillman, A., Donelly, M., Dew, A., Stancliffe, R. J., Whitaker, L., Knox, M., …& Parmenter, T. R. (2012). The dynamics of support over time in the intentional support networks of nine people with intellectual disability. *Disability & Society, 28*(7), 922-936.

Horowitz, A. (1985). Family caregiving to the frail elderly. In D. Maddox (Ed.), *Annual review of gerontology and geriatrics* (pp. 174–246). New York: Springer

Kamstra, A., Van der Putten, A. A. J., & Vlaskamp, C. (2015). The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities, 28*(3), 249-256.

Khan, S. & VanWynsberghe, R. (2008). Cultivating the under-mined: Cross-case analysis as knowledge mobilization. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research, 9*(1). doi: 10.17169/fqs-9.1.334

Lipold, T. & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research, 53*(5), 463–473.

Lord, J. (1999). *Constructing Social Support with Vulnerable Citizens: Promise and Problems*. Paper presented in Holland. Retrieved from: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.507.5286&rep=rep1&type=pdf

Lord, J., Zupko, B., & Hutchison, P. (2000). *More Choice and Control for People with disability: Review of Individualised Funding*. Ontario: Ontario Federation for Cerebral Palsy.

Macadam, A. & Savitch, N. (2015). Staying connected with circles of support. *Journal of Dementia Care, 23*(1), 32-34.

Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities, 17*(1), 1-9.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006a). "I Get by with a Little Help from my Friends": Adults with Intellectual Disability Discuss Loneliness. *Journal of Applied Research in Intellectual Disabilities 19*, 191-203.

Neill, M. & Sanderson, H. (2012). *Circles of Support and Personalisation*. Retrieved from: http://www.helensandersonassociates.co.uk/media/75948/circlesofsupportandpersonalisation.pdf

Newcomer, K. E., Hatry, H. P., & Wholey, J. S. (2015). *Handbook of practical program evaluation*. Hoboken, New Jersey: John Wiley & Sons.

Nunnelley, S. (2015). *Personal Support Networks in Practice and Theory: Assessing the Implications for Supported Decision-Making Law: Legal Capacity, Decision-Making and Guardianship*. Ontario, Canada: Law Commission of Ontario.

O'Brien, C. L. & O'Brien, J. (2002). The origins of person-centered planning. In S. Holburn, P. Vietze (Eds.), *Person-centered planning: Research, practice, and future directions* (pp. 3–27). Baltimore, MD: Brookes Publishing.

O'Brien, C., O'Brien, J., & Mount, B. (1997). Person-centered planning has arrived… or has it?. *Mental Retardation, 35*(6), 480-484.

Robertson J., Emerson E., Gregory N., Hatton C., Kessissoglou S., Hallam A., & Linehan C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation 39*, 201-214.

Ratti, V., Hassiotis, A., Crabtree, J., Deb, S., Gallagher, P., & Unwin, G. (2016). The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review. *Research in developmental disabilities, 57*, 63-84.

Sherwin, J., (2009) *Evaluation of the Circles Initiative, for Community Living South Australia*.

Sherwin, J. (2012). *Gathering the lessons: a focus on Circles of Support Project*. AccessEzer/JewishCare

Stancliffe, R., Bigby, C., Balandin, S., Wilson, N., & Craig, D. (2015). Transition to retirement and participation in inclusive community groups using active mentoring: An outcomes evaluation with a matched comparison group. *Journal of Intellectual Disability Research, 59*(8), 703-718. doi: 10.1111/jir.12174

Van Asselt-Goverts, A. E., Embregts, P. J. C. M., & Hendriks, A. H. C. (2013). Structural and functional characteristics of the social networks of people with mild intellectual disabilities. *Research in Developmental Disabilities, 34*, 1280–1288. doi: 10.1016/j. ridd.2013.01.012

Van Asselt-Goverts, A. E., Embregts, P. J. C. M., & Hendriks, A. H. C. (2015). Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research, 59*, 450–461. doi: 10.1111/ jir.12143.

Verdonschot, M. M. L., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research, 53*, 303–318. doi: 10.1111/j.1365-2788.2008.01144.x

Wistow, G., Perkins, M., Knapp, M., Bauer, A., & Bonin, E. M. (2016). Circles of Support and personalization: Exploring the economic case. *Journal of Intellectual Disabilities, 20*(2), 194-207.