

Research and evaluation summary

Academic Research and Professional Evaluation of Circles of Support & Microboards – COSAM

Academic Research and Professional Evaluations were completed as part of the establishment of the National Resource Centre for Circles of Support and Microboards (NRC COSAM, www.cosam.org.au). The NRC COSAM was implemented by Inclusion Melbourne and was funded by the 2018 NDIS Information, Linkages and Capacity Building (ILC) National Readiness Program. ILC builds innovative ways to increase the independence, social and community participation of people with a disability.

The NRC COSAM engaged a number of Australian organisations experienced in developing and maintaining Circles of Support and/or Microboards as partners and contributors. The individual and collective experience of these organisations, the people they support, their families and Circle/Microboard members provided important information for the collation and development of resources, and in the provision of information for this research. Partner profiles are available at www.cosam.org.au/services.

The NRC COSAM is a centralised online resource for relevant and useful resources relating to Microboards and Circles of Support. The NRC COSAM was established to:

1. Build awareness, and encourage the establishment, of COSAMs.
2. Empower and build the capacity of supporters, families, and organisations to create and sustain COSAMs for people with intellectual disability to reduce isolation and improve access and participation in the community.
3. To foster a culture of continuous improvement and data collection among organisations that facilitate COSAMs.
4. Undertake data collection, analysis, and reporting and produce relevant practice materials.
5. To develop a proof-of-concept benchmarking framework for the operational implementation of COSAMs by organisations and advocacy groups.
6. To connect major COSAM facilitating organisations in Australia (that is, those organisations that have evidence of having facilitated COSAMs and a model that is articulated or documented in some way) so that this benchmarking can take place.
7. To develop an operational model for COSAMs that accurately reflects costs and resources and is appropriate for Australian contexts.
8. Build an evidence base that meaningfully connects evidence-based support practices with COSAMs.

Background

There is a growing awareness and popularity for the concept of Circles of Support and Microboards for people with intellectual disability, however ambiguity exists in the broader Circles/Microboards community over form, processes and effectiveness. The existing literature includes unpublished reports and personal stories presenting anecdotes and desirable outcomes of various models for organising circles of support, and there is little empirical evidence about effectiveness or outcomes for people with disability, their families and services (Wistow et al., 2016). There has been limited formal evaluation or review of the ways that circles of support work in practice or organisational strategies necessary to develop and support them.

Approach

Academic Research

Academic Research was undertaken to review the strength of existing literature about claims and outcomes of COSAMs. An exploratory study of the process and outcomes of three Australian programs was also undertaken. This work was completed by Professor Christine Bigby and Dr Tal Araten-Bergman from La Trobe University's Living with Disability Research Centre.

- *Models for Forming and Supporting Circles of Support for People with Intellectual Disability, and Circles of Support & Microboards – Procedural and Operational Aspects*, 2018, Prof Christine Bigby and Dr Tal Araten-Bergman, La Trobe University, Living with Disability Research Centre. Electronic copies are available from the La Trobe University Research Repository <http://hdl.handle.net/1959.9/565745>.

Professional Evaluation

Professional evaluations tested the logic model articulated by partner organisations against self-described outputs and outcomes. The evaluations focussed on the outcomes and performance of COSAMs from the perspective of partner organisations responsible for promoting, establishing and supporting COSAMs. Professional evaluations were completed by Dr Leighton Jay from Sotica and Emeritus Professor Errol Cocks from Curtin University. This has been published as:

- *Circles of Support & Microboards Review – Ensuring personal governance with UnitingCare Queensland “One Disability Service”*, 2018, Dr Leighton Jay, Sotica.
- *Circles of Support & Microboards Review – Building Community Networks with Belonging Matters*, 2018, Dr Leighton Jay, Sotica.
- *Review of the Quality Achievements by Five Microboard organisations in Australia*, 2018, Emeritus Prof Errol Cocks, Curtin University.

Purpose of this Research and Evaluation Summary

This document summarises the aims, methods, findings and conclusions of the research and evaluation as identified by the following headings:

- Academic Research – La Trobe University
- Professional Evaluation - Dr Leighton Jay, Sotica
- Professional Evaluation - Emeritus Professor Errol Cocks

Academic Research – La Trobe University

Aim

The research aimed to shed light on the organisational and operational elements 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 was drawn from qualitative interviews with program participants (people with intellectual disability, as well as family and circle members); Circle of Support facilitators, and staff and members of the organisations' senior management. Additionally, program and organisational documents and materials posted on organisations' websites were also analysed.

Data analysis was conducted in two phases: a qualitative analysis of the data collected; and a cross-case analysis comparing the Circle of Support programs.

Qualitative analysis of the data from each organisation was completed using 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 participant outcomes.

The cross-case analysis was conducted to compare and identify commonalities and differences in the events, activities, and processes of Circle 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

While all the programs had a similar overarching intent about sustaining informal support and the quality of life of the person with intellectual disability, the variability in Circle of Support programs meant that there was no one standard of operationalising the concept 'Circles of Support'. The comparison between programs illustrated 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, program aims, strategies and target population in each case differed and were shaped by the wider organisational mission of which they were a part. Specifically, in both Pave the Way and 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 drive the development and sustainability of Circles. The *focus person* of each Circle of Support had existing social networks and 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 disability. 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 worked with 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 their 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 focus person 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 wellbeing. Some families found Circles of Support a safe place to express emotions about their experiences and an environment in which 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 highlights difficulties that current and future funding mechanisms pose for the programs. There is 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. Service delivery under the NDIS model calls for a short-term capacity building service budgeted according to billable hours. This does not allow for many crucial yet 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.

Cross Case Analysis - What can be learned?

The report compares and contrasts key dimensions of the three case study programs and explores the design and practice issues they highlight. It draws 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 disability and their supporters and 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	<p>Building the capacity of the informal network in order to enhance and maintain the capacity of the family to provide ongoing support and advocacy.</p> <p>Give ongoing support and to ensure person centred planning and succession planning.</p> <p>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.</p>	<p>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.</p> <p>Provide professional coordination and guidance to assist persons with disability and their family to build and maintain their informal support network.</p>	<p>Building and sustaining the capacity of informal network members to support persons with disability and their family.</p> <p>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, neighbours 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.</p>

	Pave the Way	Inclusion Melbourne	Life Assist
Target population	<p>Families of people with disability.</p> <p>People with disability with existing social networks.</p>	<p>People with disability with existing social networks.</p> <p>People with disability with limited or no informal networks.</p>	<p>Families of people with disability.</p> <p>People with disability with existing social networks.</p>

<p>Primary Strategy</p>	<p>To provide information to families about the Circles of Support model; and to provide a professional structured process to introducing formality into existing informal networks.</p>	<p>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</p>	<p>Provide a structured process to introduce formality into existing social networks and to assist with the formation of Circles of Support.</p>
<p>Activities</p>	<p>Provide information about the Circle of Support model and application.</p> <p>Preparation phase: relationship mapping, support in invitation process and agenda planning.</p> <p>Facilitation:</p> <p>Facilitation of introduction night.</p> <p>Facilitation of first meeting.</p> <p>Facilitation and co-facilitation in meetings (up to a year of circle operation)</p> <p>Support, guidance and supervision for facilitator upon request during the first year.</p>	<p>Evaluation of the individual’s existing informal networks.</p> <p>Foundation circle: getting to know the person and building relationships with unpaid members and facilitating meetings</p> <p>Building circle: getting to know the person and their social networks, strengthening existing relationships, developing circle purpose and facilitating meetings.</p> <p>Thrive circle: identifying and working with primary supporter, facilitation of the first meetings.</p>	<p>Preparation phase: relationship mapping, support in invitation process and agenda planning.</p> <p>Facilitation: facilitation of the first circle meeting.</p> <p>Support, guidance and supervision for facilitator.</p>

	Pave the Way	Inclusion Melbourne	Life Assist
Program input: Professional knowledge and skills	<p>Knowledge of disability service environment, person centred planning, group facilitation and Circles of Support model development and delivery.</p> <p>Communication skills, sensitivity and respect for diversity.</p>	<p>Knowledge of disability service environment, person centred planning, group facilitation and Circles of Support model development and delivery.</p> <p>Communication skills, sensitivity and respect for diversity.</p>	<p>Knowledge of disability service environment, person centred planning, group facilitation and Circles of Support model development and delivery.</p> <p>Communication skills, sensitivity and respect for diversity.</p>
Program input: Time and energy	<p>Development of a Circle of Support requires: preparation phase 10- 15 hours of professional involvement</p> <p>and 2-3 hours for each meeting in the first year of operation</p>	<p>Development of a Circle of Support requires:</p> <p>Foundation circle: preparation phase 25 hours and 10 hours per meeting (not including tasks allocated at each meeting).</p> <p>Building circle: preparation phase 15 hours and 8 hours per meeting (not including tasks allocated at each meeting).</p> <p>Thrive circle: preparation phase 10 hours and 2-3 hours peer meeting.</p>	<p>Development of a Circle of Support requires 15-30 hours of professional involvement.</p>
Program input: Personnel	<p>Pave the way employs 4 Permanent staff.</p> <p>Two with expertise in circles of support development. Hours dedicated to Circles of Support are flexible and determined by the number of interested families.</p>	<p>Part-time program coordinator – one staff member with expertise in Circles of Support development.</p> <p>Supervision of senior management.</p>	<p>One staff member with expertise in Circles of Support development – hours determined by the number of referrals.</p>

	Pave the Way	Inclusion Melbourne	Life Assist
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	<p>Wider informal social networks for supporting people with intellectual disability and their carers.</p> <p>Increased capacity of informal networks to provide sustainable and long-term support</p> <p>Increased motivation, confidence for people with disability and their families</p> <p>Increased participation in community life</p> <p>Strengthened communication and relationships</p> <p>Increased feeling of belonging to the community</p> <p>Support in achieving desirable goals: moving out of family home, securing employment in the open market, pursuing interests and hobbies in the community, etc.</p> <p>Increased community capacity</p> <p>Increased community understanding of rights of people with disability</p>	<p>For the focus person:</p> <p>Support in achieving desirable goals: moving out of family home, securing employment in the open market, pursuing interests and hobbies in the community, etc.</p> <p>Increased opportunity for socialising & friendships</p> <p>Increased self-determination</p> <p>Increased social capital</p> <p>Increased feelings of safety</p> <p>Advocacy support.</p> <p>Increased wellbeing & self-worth.</p> <p>For family: increased social capital, increased family support, increased wellbeing & self-worth.</p> <p>For circle members: enhanced understanding of disability, increased capacity to provide meaningful support, increased sense of social cohesion.</p>	<p>For the focus person:</p> <p>Support in achieving desirable goals:</p> <p>Increased opportunity for socialising & friendships</p> <p>Increased self-determination</p> <p>Increased social capital</p> <p>Increased wellbeing & self-worth.</p> <p>For families:</p> <p>Increased family support.</p> <p>Succession planning</p> <p>Increased wellbeing</p> <p>For circle members: enhanced understanding of disability, increased capacity to provide meaningful support, increased sense of social cohesion.</p>

	Pave the Way	Inclusion Melbourne	Life Assist
	<p>Increased involvement in the person with a disability and family's lives</p> <p>Active involvement and collaboration in the community to drive inclusion for people with disability.</p>		

Conclusions

Findings demonstrate Circles of Support can be as applicable and relevant for people with intellectual disability 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 a facilitator. 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 mechanisms 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 disability 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.

Professional Evaluation - Dr Leighton Jay, Sotica

Aim

To review a sample of the Circles of Support and Microboards work being undertaken across Australia. Reviewing the approach to assisting individuals to have governance over their own lives, which can include supporting them to establish and maintain a Circle of Support or a Microboard. The evaluation is also designed to assist organisations that undertake Circles of Support and Microboards work to:

1. Foster a culture of continuous improvement and data collection that facilitates effective COSAM work
2. Undertake data collection, analysis and reporting activities that ensure they use evidence-based models of practice and produce evidence-based practice material
3. Develop and use a benchmarking framework for the operational implementation of their Circles and/or Microboards work, and
4. Build an evidence base that demonstrates how their activities can valuably contribute to the NRCCOSAM.

Method

Two organisations agreed to be part of this review: Belonging Matters and UnitingCare Queensland. The evaluation comprised key activities including: development of program logic and evaluation template; data collection; interviews, data analysis and report.

Findings

Table 2 summarises the process for setting up a Circle of Support and outcomes.

Table 2: Analysis of Process and Outcomes

	Belonging Matters	Uniting Care Queensland
Process / Steps	<ol style="list-style-type: none"> 1. Introductory workshop to inform and decide if Circles are appropriate, covering: <ol style="list-style-type: none"> a. What is a Circle (called a network)? b. How networks can be useful c. Values underpinning the Building Community Networks (BCN program) d. What is required to establish and maintain a network e. What it takes to support a person to have an inclusive life 2. People who wish to move to the next step submit an expression of interest 3. Once accepted, a pre-meeting takes place including: <ol style="list-style-type: none"> a. facilitator meets with the person and family to answer questions and obtain a 	<ol style="list-style-type: none"> 1. Identify the need to form a circle as the next step in a person's life (the right time the right circumstances) using a set of conditions as a guide to an individual's readiness including: <ol style="list-style-type: none"> a. people are dissatisfied with how the service system works b. people are dissatisfied with their service arrangements c. people want to exercise more choice and control over their lives d. people recognise that service providers don't have all the answers

	<p>clearer picture of the person and their circumstances</p> <p>b. identification of 4 or more supporters (family, friends, allies) who might become network members</p> <p>4. Facilitator facilitates 6 meetings over a 12 month period. The COS can continue as requested by the focus person/family. The first couple of meetings with the network members:</p> <p>a. Develop, clarify and record the person's vision for their life (which informs the purpose for, and guides the network)</p> <p>b. Discuss the roles within the network</p> <p>5. The future meetings focus on development and achievement of the goals aligned to the vision</p> <p>6. At the commencement of each year the Circle establishes a plan based on what the person would like to do/achieve. This is reviewed at the end of each year.</p>	<p>e. people are willing to step away from providers who won't listen or work with them to have greater choice and control.</p> <p>2. Develop a vision based on what people want/need, now and into the future.</p>
<p>Outcomes</p>	<ul style="list-style-type: none"> ▶ Moved into own house ▶ Left day centre ▶ Joined local activities (gym, yoga, cooking and art classes) ▶ Established a microbusiness ▶ Paid work ▶ Work experience ▶ Learnt to use public transport ▶ Volunteer roles (conference presenter, local AFL club and F1 GP). Assistant swimming coach, dog walking assistant, Royal show exhibitor ▶ Education: attended TAFE courses ▶ Increased friendships ▶ Established online banking and bank accounts. 	<ul style="list-style-type: none"> ▶ Supporting and safeguarding decision making and choice ▶ Home and community roles, based on interests, skills and strengths ▶ Positive, unpaid relationships with community members ▶ Home life that reflects the norms that other citizens value.

Conclusions

Belonging Matters

Belonging Matters' (BM) *Building Community Networks (BCN)* program is a highly organised, well-documented Circles program based in Melbourne. BCN currently supports twelve individuals and their families on their pathway to achieving significant, valuable outcomes that enable them meaningfully to participate socially and economically in their communities and society. BM's work is deeply grounded in Social Role Valorisation, personalisation, supported decision making and social inclusion principles and values. It uses capacity building approaches to ensure that the capability of both the individual and the network continuously grows over time.

The life domains that inform each individual's vision align well with NDIS Outcome Domains and ILC Outcomes. Data from existing networks indicates that most individuals are achieving significant outcomes across a range of domains. There are demonstrably positive changes in areas like employment, living arrangements, study and lifelong learning, volunteering, contributing to and leading their communities, life skills and health and fitness.

Uniting Care Queensland

UnitingCare Queensland (UCQ) disability services Practice Framework is a robust base upon which UCQ potentially can build a systematic approach to delivering contemporary, individualised disability support services. This review has identified that Disability Leadership Unit (DLU) staff seem to have a deep understanding of how to implement the Practice Framework and are doing so with good effect in the lives of several individuals who have highly complex support needs. Authorising the DLU to have a greater role in leading this process more broadly across UCQ's Disability Services would seem to be an important next step.

Within the context of the DLU's work with individuals who have complex support needs, Circles of Support are seen as mechanisms that can enable and safeguard the individuals' rights to make decisions and choices about their own lives and support arrangements. They are not a means to this end rather than being an end in themselves. Consequently, UCQ's approach to supporting the development of Circles of Support is small-scale, organic and emergent rather than being program-based or program driven.

This level of individualisation and responsiveness is a great strength of UCQ's approach to Circles of Support in terms of individuals and their lives. However, in the context of individualised funding and the NDIS, the challenges of systematising and costing this approach creates numerous challenges. There is merit in considering whether this approach can co-exist alongside a more systematised, 'program style' approach to Circles of Support in a way that might add value to both approaches.

The data that was collected and analysed demonstrates that in the cases discussed, the DLU's approach is proving to be highly effective in enabling some individuals with complex support needs to live expansive lives connected to their communities where they are making meaningful and valued contributions. The outcomes being achieved for these individuals are significant for those individuals. They are also strongly aligned to the Objectives and Principles of the NDIS Act, the NDIS Outcome domains and ILC Outcomes.

Professional Evaluation - Emeritus Professor Errol Cocks

Aim

To undertake an evaluation of Australian Microboards. The evaluation focused on five established Microboards, two that have incorporation status, and two that were in the process of applying for legal incorporation, and a fifth newly established Microboard. Formal incorporation is an important, qualifying characteristic of the Microboard structure. The evaluation was completed in March-April 2018 in consultation with the two 'Microboards Australia' parent-Directors.

Method

The primary means of reviewing the Microboards was using the Individual Supported Living ISL Manual (2nd Edition) that consists of an evaluation scale and describes methodologies that can be used to carry out evaluations of the quality of supported living environments. The scores were also mapped against the National Disability Insurance Scheme (NDIS) Domains and the ILC Activity Outcomes. All Microboards participants provided information generously, freely, and with interest in the process and the relevance of the evaluation for the development of Microboards.

The process of gathering information about the Microboards involved a 2-3 hour meeting with the members of the selected Microboards. This meeting included discussion and scoring of the 21 Attributes from the ISL Manual. In addition, a set of questions was left with group members and they were requested to return their comments to the Consultant. Twenty-nine people participated in the meetings and included focus people, parents, family members, friends, and some ex-support workers.

Findings

Participants in the Review were asked to identify the major Principles and Achievements of Microboards as a preliminary overview summary, and were described as:

- ▶ Person-Centred/Focused
- ▶ Self Determination
- ▶ Reciprocal Relationships
- ▶ Immediate Family Support
- ▶ The Vision of Microboards
- ▶ Assumed positive capacity

Major Achievements of Microboards were described by participants as:

- ▶ Achieving paid employment in the community
- ▶ Increasing friends with shared interests
- ▶ Building knowledge and skills of people around the focus person
- ▶ Purchase of a home and motor vehicle for one focus person
- ▶ Harmonious Boards
- ▶ Community involvement
- ▶ Support to enable the focus person to have the life they would like to have
- ▶ Development of communication with the focus person

- ▶ Quality of supports provided
- ▶ Establishing a social enterprise.

Table 3 lists attributes with average scores of 4-4.7. A cut-off score of 4 was arbitrarily chosen as incorporating 80% or better quality achievement. Fourteen of the 21 Attributes obtained scores of 4 or more.

Table 3: Summary of Highly Achieved Microboard Attributes

Attributes Scoring 4 or more	Average Score	Range of Scores
Arrangement is developed around the person.	4.7	5-3
Planning focuses on the person.	4.6	5-4
People close to the person involved in planning.	4.5	5-4
Person and those close control person's life.	4.4	5-3
Person does normal things done in the home.	4.3	5-3
Self-determination for person is central.	4.3	5-3
Person and those close have control of arrangement.	4.2	5-3
Supports flexible & adapt to changes in needs.	4.2	5-3
Arrangement based on clear vision & strong ideas.	4.1	5-3
Arrangement does not group people with disability.	4.1	5-4
Variety of supports in place to suit person.	4.1	5-3
Person has secure tenure in their home.	4.0	5-3
Person's home reflects who person is & their likes.	4.0	5-3
Person's lifestyle & wellbeing are improving.	4.0	5-3

The two top scoring clearly reflected the priority emphasis on the focus person in the Microboards. In all 5 Microboards, the consultant found there was a clear and compelling focus and priority on the focus person and their needs.

The following Table lists Attributes that scored less than 4.

Table: Summary of Moderately Achieved Microboard Attributes

Attributes Scoring less than 4	Average Score	Range of Scores
Key people provide the leadership to set up and continue the relationship.	3.5	5-3
The person has valued roles.	3.6	5-3
The person has a rich social network.	3.6	5-3
There are many opportunities for growth and development.	3.8	5-3
The person takes part in the community.	3.8	5-3
The person's future is central to planning.	3.9	5-3
The person has close and long-lasting relationships.	3.9	5-3

Attributes with lower average scores draw attention to some of the key challenges faced by Microboards. Most of these challenges reflect the difficulties associated with young adults with disability who have high or very high support needs. For example, they include the challenges to promote and achieve valued social

roles, increased community participation, and the development of more extensive social networks. Relationships and a future focus were borderline issues based on the review.

Attributes Mapped to NDIS Outcome Domains

Attributes with averages 4 or over that mapped directly to NDIS Outcome Domains included:

- ▶ Choice & Control
- ▶ Daily Activities
- ▶ Relationships: Relationships referred to people who are “close” to the person. Two Attributes that focus on relationships scored less than 4. These attributes focus on close and long-lasting relationships and rich social networks.
- ▶ Home: Four Attributes that scored well were about the focus person doing normal things in the home, not being in congregate settings, security of tenure, and how home reflects who the person is.
- ▶ Health & Wellbeing

Attributes that scored less than 4 that mapped directly to NDIS Outcome Domains included:

- ▶ Lifelong Learning
- ▶ Work
- ▶ Social, community & civic participation

Attributes with averages approaching 4.0 that mapped directly onto ILC Activity Outcomes included:

- ▶ Increased skills and capacity - many opportunities for growth & development (3.8).
- ▶ Increased motivation, confidence and empowerment to act; Increased self-advocacy, independence and relationship building – person has a rich social network (3.6)
- ▶ Increased participation in community life - person takes part in community (3.8) and person has valued roles (3.6)
- ▶ Increased connections, relationships & support networks in the community - person has close & long-lasting relationships (3.9), person has a rich social network (3.6), and person’s future is central to planning (3.9)
- ▶ Increased opportunities for active participation & increased sense of belonging in the community - person has valued roles (3.6)
- ▶ Increased shared understanding, experiences, collaboration & leadership - key people provide leadership to set up & continue (3.5)

Conclusion

The evaluation of the qualities and outcomes of Microboards provides some important conclusions. Findings from the attribute scores reflect the challenges of high and very high support needs. Notably, the self-review methodology meant that the outcomes were derived from the scores determined by the participants themselves.

The high attribute scores reflected:

- The importance of being person-focused
- The key roles played by family and the support persons
- The priority given to self-determination which was also borne out by various comments that gave precedence to determining what the focus person wanted or needed, and acting on that
- Support was flexible and there was a variety of support persons with different backgrounds and experience
- The issue of security of tenure in each focus person's home was clearly valued

The lower attribute scores again reflected the challenges of high/very high support needs. These scores corresponded to the most challenging aspects including community participation, long-term planning, friendships, and valued roles. It was also possible to observe during the various review processes indicates there had been progress in each of these areas, however it is reasonable to conclude that the relatively low scores meant participants were acknowledging that there was more to be done.

Microboards (and Circles of Support) reflects the emergence of the parent/family movement that aims for family members with disability to live valued lives.

Four of the Microboards in the review were essentially governed by family members who had brought together a group of friends and support workers who clearly participated in and shared the explicit values that underpinned the Microboards purposes and strategies. One Microboard in this review had little family involvement, however the Microboard members were essentially "filling a gap" and had engaged in a process that valued the person and aimed for her full inclusion.

All the focus people had high or very high support needs. Supporting each person was clearly challenging and rested strongly on the commitment and skills of participants.

The connection between Circles of Support and Microboards is strong, enabling experiences of Circles to essentially achieve similar outcomes but not necessarily with the provision of incorporation. One possible benefit of incorporation may be providing a continuing structure in the event that some members, including parents, are unable to continue in those roles.

The knowledge and understanding of the parents is very impressive and they have an important role in engaging in training members and related activities.

Consideration should be given to developing appropriate curricula focused on Microboards, similar initiatives, and related concepts. There is a dearth of focused training for different groups of people concerned with this area. Training is needed to promote and support these ideas that are wholly consistent with the aims of the NDIS.

References

Academic Research – La Trobe University

- 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., Donnelly, 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.

Professional Evaluation - Dr Leighton Jay, Sotica

- Kuhn, L. 2009. *Adventures in Complexity: For organisations near the edge of chaos*. Triarchy Press: Axminster, UK
- Westley, F., B. Zimmerman and M.Q. Patton. 2006. *Getting to Maybe: How the World is Changed*. Random House: Canada.

Professional Evaluation - Emeritus Professor Errol Cocks

- Cocks, E. & Boaden, R., (May, 2009). *The Personalised Residential Supports Project*. Final report of the PRS Project, CRDS (Curtin University of Technology).
- Cocks, E., & Boaden, R. (2010). A quality framework for personalised residential supports for adults with developmental disabilities. *Journal of Intellectual Disability Research*, 55(8), 720-731. doi:10.1111/j.1365-2788.2010.01296.x
- Cocks, E., Williamson, M., & Thoresen, S. (2011). *Individual Supported Living Manual*. CRDS, School of Occupational Therapy and Social Work, Curtin University.
- Cocks, E., Thoresen, S., Williamson, M., & Boaden, R. (2014). The Individual Supported Living (ISL) Manual: a planning and review instrument for individual supported living arrangements for adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 58(7), 614-624. doi:10.1111/jir.12059
- Isaacson, N., Cocks, E., & Netto, J. (2014). Launching: The experiences of two young adults with intellectual disability and their families in transition to individual supported living. *Journal of Intellectual & Developmental Disability*, 39(3), 270-281.
- Cocks, E., Thoresen, S. H., O'Brien, P., McVilly, K., Thomson, A., Gadow, F., Crosbie, J. and Prain, M. (2016). Examples of individual supported living for adults with intellectual disability. *Journal of Intellectual Disabilities*, 20, 100-108. doi:10.1177/1744629516629854.
- Cocks, E., & Thoresen, S. (2017). *Individual Supported Living Manual (Revised)*. Bentley: Curtin University.
- Cocks, E., Thoresen, S., O'Brien, P., McVilly, K. (July, 2017). *Quality & outcomes of individual supported living (ISL) arrangements for adults with intellectual and developmental disabilities*. Report, School of Occupational Therapy & Social Work, Curtin University.
- Cocks, E., Thoresen, S., Jackson, R., & Thomson, A. (February, 2018). *Small business enterprise models of employment for persons with intellectual disabilities and high support needs*. BCEC Research Report No. 9/18.