REVIEW OF THE QUALITY ACHIEVEMENTS BY FIVE MICROBOARD ORGANISATIONS IN AUSTRALIA

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Report for the National Resource Centre for Circles Of Support And Microboards (COSAM) at Inclusion Melbourne.

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REVIEW OF MICROBOARDS IN AUSTRALIA

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1.0 Introduction and Overview

The National Resource Centre for COSAM contracted with the Consultant to carry out a review (evaluation) of Australian Microboards. The Review focused on four established Microboards, two that have Incorporation status, and two that are in the process of applying for legal incorporation, and a fifth Microboard that was recently established. Formal incorporation is an important, qualifying characteristic of the Microboard structure. The Review was carried out in March-April 2018 in consultation with the two Microboards Australia parent Directors.

Through the COSM, the Consultant made contact with the two parent National Directors and discussions were held about how the Microboards reviews would take place. Two Microboards from WA agreed to participate in the review, and one from Eastern Australia. Two additional groups that were in the process of formalising their Microboards status, one from WA and one from Eastern Australia, also agreed to participate, making 5 groups in total. The two additional groups considered themselves to be Circles of Support pending completion of their incorporation which is regarded as a necessary qualification for a Microboard. The collection of information and the Reviews (evaluations) took place in March/April 2018. Two Reviews took place in the homes of Focal Persons (the person/s with disabilities), one in a (closed) restaurant, and two during the Microboards Australia "UnConvention" that was held over a weekend in March in a location about mid-way between Sydney and Canberra.

The lead person from each Microboard/Circle of Support, Microboards/Circles members, family members, friends, and paid support staff provided information for this Report, based on discussions, the Review, and responding to a questionnaire provided by the Consultant.

Details of the establishment of each Microboard follow.

Microboard One was established in 2007 and Incorporated in 2014. The Stepfather of the Focal Person is the President of the Microboard. The Focal person is a young man who is non-verbal and is described as having a complex disability associated with a sensory processing disorder and both physical and intellectual disability.

Microboard Two was established in 2010 and achieved Incorporation in 2015. The Microboard functions with group leadership and a Chairperson. The Focal Person is described as having an undiagnosed complex disability and a seizure disorder.

Microboard Three was established in 2010 and functions with a Chairperson who is the Focal Person's mother. The Focal Person has autism.

Microboard Four was established as a Circle of Support three years ago and began the process of Incorporation six months ago. The Focal Person has autism and associated disabilities. The Focal Person's mother heads the Circle and is organising the incorporation process.

Microboard Five, currently operating as a Circle of Friends, was recently established. The Focal Person has significant relationship and emotional needs, multiple physical and health impairments, and may also have a mild intellectual disability. This person was the only participant who had no family involvement in the Circle.

The two Circles of Support working on incorporation as Microboards will be referred to as Microboards in this report.

The 3-8 active members in each Microboard consisted of parents, family members, friends, and some ex-support workers. The Microboards were funded through the National Disability Insurance Scheme to employ paid support workers. Some paid staff attended Microboards meetings, but none was permitted to be a formal member.

It is germane to this review that all but one of the Focal Persons had **high or very high support needs**. The level and complexity of support needs provide substantial challenges and contributed significantly to the initial decisions to establish Microboards to address those challenges.

The participants in the Review were asked to identify the major Principles and Achievements of Microboards as a preliminary overview summary.

The major Principles followed by Microboards were described by participants as:
- Person-Centred/Focused
- Self Determination
- Reciprocal Relationships
- Immediate Family Support
- The Vision of Microboards
- Assumed positive capacity

The 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 Focal Persons
- Purchase of a home and motor vehicle for one Focal Person
- Harmonious Boards
- Community involvement
- Support to enable the Focal Person to have the life he/she would like to have
- Development of communication with the Focal Person
- Quality of supports provided
- Establishing a social enterprise

2.0 Review Method

Participants were guided through 21 descriptive criteria drawn from the Individual Supported Living Manual which is described and referenced below. The Manual is based on eight Themes consisting of a total of 21 Attributes. The Themes and Attributes are

described in Appendix 1. The Manual was designed to measure the quality of life experienced by adults with intellectual and developmental disabilities *who were located in individual supported living arrangements in their own homes, and includes adults with high and very high support needs*. Following discussions led by the Consultant on each of the Themes and Attributes, each participant from each Microboard separately rated each of the 21 Attributes, and scored each Attribute between 1 (low) and 5 (high) according to how they perceived the achievement of quality outcomes on each Attribute.

These scores and some basic analysis below describe levels of perceived quality across the eight Themes and 21 Attributes. The scores were also mapped against the National Disability Insurance Scheme (NDIS) Domains and the ILC Activity Outcomes.

Twenty nine people participated in the Reviews with one person being called away during a review which reduced the number of completed Attributes for that person.

2.1 The Individual Supported Living Manual

The primary means of reviewing the Microboards was the use of the Individual Supported Living 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.

At Curtin University, between 2008 and 2014, with two small grants we developed a framework for measuring and evaluating the quality of individual supported living (ISL) arrangements for adults with intellectual and developmental disabilities (the ISL Manual). Development of the ISL framework assured acceptable levels of content validity by engaging people who had experience and knowledge of individualised living arrangements for adults with intellectual and developmental disabilities. The first version of the Manual was completed in 2010 and tested on a number of ISL arrangements. The Manual was revised in 2017. It consists of 8 Key Themes, made up from a total of 21 Attributes. Each Theme is located in a key domain associated with individual supported living. The focus of the Manual development was on adults with disabilities living in their own homes with individual support. The content of the Themes substantially corresponds to the living situations provided in Microboards and other approaches to supporting adults with disabilities who have high and very high support needs. Based on Article 19 from the United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory, our focus was on *individual supported living* (ISL)*,* which precluded situations that grouped or congregated persons with disabilities.

The methodology for carrying out evaluations involved small teams, members of which received training in the evaluation process, and were led by experienced team leaders. We subsequently were successful, in conjunction with Sydney and Melbourne Universities and a number of NGOs, in obtaining Australian Research Council (ARC) funding to further develop the work. This project was completed late in 2017. It resulted in evaluations of 134 ISL arrangements across WA, NSW, Victoria, and the ACT, based on the ISL Manual and a small number of additional measures. The research project carried out a minor revision of the Manual, published a Final Report on the ARC project, and also examined aspects of the validity of the instrument that confirmed its content validity and reliability. A number of

publications on the development and outcomes of the projects are listed in the References section below.

Following discussion with COSAM at Inclusion Melbourne and further consultation with two of the Australian Microboard leaders, a decision was made to use the ISL Manual as the primary tool for the planned Microboards Review.

2.2 Mapping the ILC Activity Outcomes and NDIS Domains against the Individual Supported Living Manual.

As this Review is closely linked to the NDIS Domains and the ILC Outcomes, it is relevant to examine the relationship between the three sets of outcomes. The following tables indicate the extent to which the ILC Activity Outcomes and the NDIS Outcome Domains address outcomes similar to the ISL Themes and Attributes.

In the Consultant's view, the ILC Activity Outcomes as stated, particularly when they are compared with the NDIS Outcome Domains, will be very challenging for people with disabilities who have *high or very high support ne*eds. In addition, they are not necessarily clear to families or support services. Most of the outcomes are multi-faceted which creates considerable complexity. For example, "Increased shared understanding, experiences, collaboration & leadership" or "Increased connections, relationships & support networks in the community" each includes multiple outcomes with elements that are not necessarily clearly related. Conversely, the NDIS Outcomes Domains are simpler, relatively straightforward, and reasonably understandable and applicable for people with high or very high support needs, and possibly more comprehensible to their family members and support persons.

Tables 1 and 2 map the correspondence between the ILC Activity Outcomes, the NDIS Outcomes Domains, and the ISL Attributes as described in the ISL Manual.

Table 1: Correspondence between ILC Activity Outcomes and ISL Attributes

ILC Activity Outcomes	ISL Attributes
Increased skills & capacity	Attribute 7.3
Increased motivation, confidence & empowerment	Attribute 7.1
Increased self-advocacy, independence, & relationship building	Attributes 1.1, 1.2, 5.1, 5.2, 5.3, 8.1
Increased participation in community life	Attributes 8.2, 8.3
Increased contribution to community life	Attributes 7.2, 7.3
Increased connections, relationships & support networks in community	Attributes 6.1, 6.2, 8.1, 8.2, 8.3
Increased opportunities for active participation & sense of belonging in the community	Attributes 7.1, 7.3
Increased shared understanding, experiences, collaboration & leadership	Attributes 1.1 & 1.2

The NDIS Outcome Domains are more specific and inclusive and there is a clearer correspondence between these and the ISL Manual.

Table 2: Correspondence between the NDIS Outcome Domains and ISL Outcomes

NDIS Outcome Domains	ISL Outcomes
Choice & Control	**Theme 1 - Leadership; Theme 3 - One Person at a Time; Theme 5 - Control.**
Daily Activities	**Theme 2 - My Home,** Attribute 2.2.
Relationships	**Theme 8 - Social Inclusion,** Attribute 8.1, Attribute 8.2.
Home	**Theme 2 - My Home.**
Health & Wellbeing	**Theme 6 - Support; Theme 5** - Control.
Lifelong Learning	**Theme 4 - Planning; Theme 7 – Thriving,** Attribute 7.3.
Work	**Theme 7 - Thriving.**
Social, Community, & Civic participation	**Theme 8 - Social Inclusion.**

The mapping process indicated that there was sufficient consistency across the two sets of principles and the ISL Manual for the Manual to be appropriate for measures of outcomes in Microboards settings. It is also relevant to note, in keeping with the principles of ISL, that some of the Microboards considered here supported an individual with disabilities to live in their own home, that is, they were provided with individual supported living.

3.0 The review processes

Notably, all the Microboards participants provided information generously, freely, and with interest in the process and the relevance of the Review for the development of Microboards.

The process of gathering information about the Microboards involved the following processes.

a. In WA, the Consultant met separately with each of the three groups, two in the Focal Person's home and one at a (closed) restaurant. The Consultant distributed a form that described the 21 Attributes and then led a discussion on each Attribute with the group members. Following each discussion, participants scored each Attribute on a scale of 1 to 5 by marking the form. Participants were encouraged to write brief comments alongside any of the Attributes. Each review took between 2 and 3 hours.

b. In regard to scoring:
   Scores of 1 indicated that the particular Attribute was "Not Addressed".
   Scores of 2 meant the Attribute was "Not Developing".
   Scores of 3 meant the Attribute was "Developing".

Scores of 4 meant the Attribute was "Strong".
Scores of 5 meant the Attribute was "Optimal".

c. In addition, a brief set of questions was left with group members and they were requested to return their comments to the Consultant.

d. The reviews of the two Eastern Australian Microboards took place separately during a Microboards Australia "UnConvention" at a location roughly half way between Sydney and Canberra. This meeting involved over 20 participants, including persons involved with the two groups who agreed to participate in the review. The process described above was repeated with the two groups during the "UnConvention".

e. It is a reflection on the positive, inclusive culture of Microboards that for all 5 reviews, the focal person was present throughout, as were the parents, other family members, and support workers.

4.0 Outcomes

The Outcomes section of this report:
- Examines the scores from the reviews of the Themes and Attributes from the ISL Manual that are detailed in Appendix 2.
- Comments on aspects of how the Microboards participants worked together during the reviews and during the "UnConvention", including some very impressive talks given by four parents. Some parents meticulously described ways that were particularly appropriate and effective in the day-to-day responses to their sons. The Consultant observed that the parents and other family members and friends interacted with the Focal Persons with great sensitivity and understanding, including occasions when some processes were time consuming.
- Provides a brief overview of a document that describes the *Rules of* Association for one of the Microboards.

4.1   Quality Outcomes from ISL Manual Themes and Attributes

The Tables below draw from Appendix One in which Tables 1a to 1d provide the Sum and Average scores for:
- Each of the 5 Microboards
- Each of the 8 Themes
- Each of the 21 Attributes

The following Table 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.

ATTRIBUTES SCORING 4 OR MORE	AVERAGE SCORE	RANGE OF SCORE
3.1 Arrangement is developed around the person.	4.7	5-3
4.1 Planning focuses on the person.	4.6	5-4
4.2 People close to the person involved in planning.	4.5	5-4
5.1 Person & those close control person's life.	4.4	5-3
2.2 Person does normal things done in the home.	4.3	5-3
5.2 Self-determination for person is central.	4.3	5-3
5.3 Person & those close have control of arrangement.	4.2	5-3
6.1 Supports flexible & adapt to changes in needs.	4.2	5-3
1.1 Arrangement based on clear vision & strong ideas.	4.1	5-3
3.2 Arrangement does not group people with disability.	4.1	5-4
6.2 Variety of supports in place to suit person.	4.1	5-3
2.1 Person has secure tenure in their home.	4.0	5-3
2.3 Person's home reflects who person is & their likes.	4.0	5-3
7.1 Person's lifestyle & wellbeing are improving.	4.0	5-3

COMMENTS

Attributes that scored 4 or more:

The two top scoring Attributes (3.1 and 4.1) clearly reflected the priority emphasis on the Focal Person in the Microboards. In all the Consultant's contact with the members of the 5 Microboards, there was a clear and compelling focus and priority on the Focal Persons and their needs.

The second, third, and fourth top scoring Attributes (4.1, 4.2, and 5.1) reflected an emphasis on planning and the importance placed on the involvement of support people. During the UnConvention, there were frequent comments from participants reinforcing the vital role of the Microboards members – family, supporting friends, and support workers. The Consultant had contact in various activities during the Review at which people previously employed as support workers participated, some as Microboards members.

Attributes, 5.2 and 5.3 focus on self-determination.

Other Attributes given priority include the importance of flexibility and variety of support, avoidance of congregation of people with disabilities, the importance of "vision", security of tenure and the importance of "home", and improved lifestyle and wellbeing.

The following Table lists Attributes that scored less than 4.

ATTRIBUTES SCORING LESS THAN 4	AVERAGE SCORE	RANGE OF SCORES
1.2 Key people provide the leadership to set up and continue the relationship.	3.5	5.3
7.2 The person has valued roles.	3.6	5.3
8.2 The person has a rich social network.	3.6	5.3
7.3 There are many opportunities for growth and development.	3.8	5.3
8.3 The person takes part in the community.	3.8	5.3
4.3 The person's future is central to planning.	3.9	5-3
8.1 The person has close and long-lasting relationships.	3.9	5.3

COMMENTS

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 disabilities 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 with averages 4 or over and less than 4 that mapped directly onto NDIS Outcome Domains (in BOLD below) included:

Scored 4 or more
- **Choice & Control** (Attributes 5.1, 5-2, 5.3, 2.1).

- **Daily Activities** (Attribute 2.2)

- **Relationships**: Relationships referred to people who are "close" to the person (Attributes 4.2, 5.1, 5.3). Two Attributes that focus on relationships scored less than 4 (8.1 and 8.2). These attributes focus on close and long-lasting relationships and rich social networks.

- **Home**: Four Attributes that scored well were about the Focal Persons doing normal things in the home (2.2), not being in congregate settings (3.2), security of tenure (2.1), and how home reflects who the person is (2.3).

- **Health & Wellbeing**: Attribute 7.1 addressed Lifestyle and wellbeing.

Scored less than 4
- **Lifelong Learning**: Three Attributes reflect aspects of learning and development (7.3, 8.3, and 7.2) and scored less than 3.9.

- **Work**: A number of Attributes incorporate work and all scored less then 4.

- **Social, community, & civic participation**: Attribute 7.1 is relevant to this Domain and scored 4. Attributes 7.2, 8.2, and 8.3 were all relevant to participation and scored less than 4.

Attributes with averages approaching 4.0 that mapped directly onto ILC Activity Outcomes (in BOLD below) included:

Increased skills and capacity;
7.3 Many opportunities for growth & development.   3.8

Increased motivation, confidence and empowerment to act;
Increased self-advocacy, independence and relationship building;
8.2 Person has a rich social network.   3.6

Increased participation in community life;
8.3 Person takes part in community.   3.8
7.2 Person has valued roles.   3.6

Increased connections, relationships & support networks in the community;
8.1 Person has close & long-lasting relationships.   3.9
8.2 Person has a rich social network.   3.6
4.3 Person's future is central to planning.   3.9

Increased opportunities for active participation & increased sense of belonging in the community;
7.2 Person has valued roles.   3.6

Increased shared understanding, experiences, collaboration & leadership;
1.2 Key people provide leadership to set up & continue.   3.5

5.0 Some insightful and valuable contributions by Microboard family members, friends, and support workers.

Attendance at the Microboards UnConvention over two days and nights provided a valuable opportunity to understand more about how the Microboard participants responded to the needs of the participants with disabilities.

Two young men with disabilities and high/very high support needs attended the event. They were accompanied by their parents, other family members, friends, and support workers. Everyone responded to the young men with warmth, great sensitivity, and a depth of understanding that was exceptional. The event ranged from formal discussions and presentations, discussions about relevant issues, and social time. The young men were a part of these events. There were many examples of warm and trusting relationships between the young men and other participants, including support workers and friends.

Four parent leaders of Microboards gave presentations during the event. They addressed Supported Decision Making, Social Safety, and Medical Emergency Planning. All presentations were very relevant and strong. Medical Emergency Planning addressed issues associated with medical emergencies and the particular risks for people with significant disabilities. The address explored the expression of pain by people with disabilities and the complications that often occur around communication, particularly in circumstances that are challenging and may be perceived as threatening. The presentation was accompanied by a handout that clearly and sensitively outlined constructive responses to medical or related experiences that may be perceived as threatening. A similar confidential handout had been prepared by the mother of one of the young men. It was entitled "Strategies for Success" and focused on issues of communication in the context of autism. This was a well-developed and valuable account of response to a complex disability.

My conclusion to listening to the presentations is to reinforce the importance of providing opportunities for experienced, knowledgeable *family members* to provide forms of training that focus on the knowledge and understanding that develop from being a family member of a person with high support needs. My reflections on this issue, after many decades in disability, are shaped very much by the current dearth of adequate preparation and training in the disability sector at a time of increasing and complex demands on support workers.

A third example of leadership was a detailed response to the Microboards Self Review by the mother of a young man with high support needs that followed the 8 Themes of the ISL Manual framework. His Microboard was established in 2010 and, as his mother wrote: "…in the eight years since, (he) has continued to grow in a manner I could not have dreamed about, particularly in the area of communication…". His achievements have included paid employment for a day a week and volunteering to work in two other establishments. After living in his home since 2011, in 2017, the young man secured a loan to purchase his own home and the Microboard serves to ensure his finances are well managed to enable him to continue servicing his debt.

The importance of **work-related** activity for people with high or very support needs is a crucial innovation. Referenced below (Appendix A, #9) is a recently published paper recounting the experiences of parents who have established remunerated employment for their sons who have high or very high support needs after having decided against the options of sheltered workshops or adult day centres.

These few observations reflect well on the strengths and potential of Microboards and also affirm the capacities of the families involved and the great value that accrues from family, friends, and support persons.

6.0 Vela Microboards Australia: Rules of Association – Dan the Man's Clan Inc

Based on Vela Microboard Association of British Columbia, in 2010 "DTMC Inc." was approved as an Association under an Australian State Incorporation Act. The Rules of Association laid out the legal requirements for a Microboard to be established and set out details of how it should operate. The Rules provided both the Plain English objectives and the Legally Agreed objective of DTMC Inc.

Appendix 4 lists the "legally agreed objects of DTMC Inc". The more expressive elements of the objectives are described below.

The Plain English Objectives of the DTMC Association are:
   a) All attention is on D. (the focal person), to get to know him and help him when he needs it.
   b) All members staying around D. and hanging out together. Get active and have fun with D.
   c) To be a representative for D., even if that means not doing anything. Make sure we always ask D. before we do anything.
   d) Look out for possibilities. Think outside the box. D. to have an exceptional, enviable life. The kind of "I want some of that" life.
   e) D. to be considered the same as everyone else. Treated the same way everyone else wants to be treated. Group's aim is to help D. experience a great, totally involved life as a young man.
   f) To help D. with un/structured activities in all aspects of his life, being aware of what he wants and what he's comfortable with.
   g) Be aware of D.'s health and act accordingly.
   h) Don't rip off D. Keep all profits within the DTMC group and be only used in support of issues that may lead to direct benefit to D.

Both the formal and informal versions of the Rules of Association seek personal commitment to the Focal Person, careful address of the person's needs including health care, and promote a lifestyle that is appropriate to the person's stage in life. The objects addressed issues around income and property, which would be considered as particularly challenging given the Focal Person's high support needs, however, the Rules of Association clearly identify these issues and do not overlook access to "the good life".

It is relevant to add that D. has purchased his own home, no doubt supported by the existence of DTMC Inc. and its capacity to influence the commercial market, and also that D. has part-time, paid employment.

7.0 Conclusions:

Parents and family members have played a critical role in the development of disability services and support in Australia (and other Western countries) since the 1950s. In response to the exclusion of their children from access to education, employment, social participation, and positive living situations, the non-government sector in Australia (and many other international contexts) grew from a small base in the late 1940s to a large and effective parent/family movement. It is appropriate to state that disability reform in those early decades was driven *substantially* by parents. Parent groups in jurisdictions across Australia established NGOs that provided day activity centres, sheltered workshops, hostels, and some institutions. Victoria is a case in point. In the 1970s and early 1980s, most mid-sized country towns in Victoria had their own NGO that provided day activity centres and hostel accommodation. In Melbourne, there were many well-established NGOs. It was common to hear from parents how their efforts were to maintain their sons and daughters

at home rather than surrendering them to the extensive, deleterious system of Victorian large institutions.

There is ample evidence that the parent/family movement and parent leadership in disability has undergone a major shift in perspective and purpose. The reasons for this include the fact that members of the original parent movement have aged or passed on, leaving the management of NGOs essentially to the managers. In addition, there have been very significant developments in disability theory that have successfully challenged the theories behind much of the damaging 20th Century disability practices. Positive examples of this include various social theories including Normalisation, Social Role Valorisation, and the Social Model of disability, each of which has contributed in one way or another to international Covenants such as the UN Convention of the Rights of Persons with Disabilities and the UN International Classification of Functioning, Disability and Health, the latter of which essentially adopted the social model of health.

At the same time that these high order reforms were developing, movement was occurring at the level of practical policy. In Western Australia for example, Local Area Coordination (LAC) was established around 1990 and linked to a systematic ongoing program of training, and LAC's were permitted to provide direct funding to families. Some institutional closures began in the 1970s and other reforms such as individual supported living and small business enterprises (both referenced below) began to explore small, focused employment for adults with disabilities and high/very high support needs to challenge the preoccupation of some disability policy and practice that promotes congregation of people with disabilities. The emergence of Circles of Friends and Microboards in the 1990s, associated with MAPS, PATH, and PIN, identified ways of supporting the inclusion of people with disabilities in schools, work, and communities. Both approaches placed considerable importance on the roles of parents, family members, friends, and support persons who have shared values and commitments.

This exercise in exploring the qualities and outcomes of Microboards provides some important conclusions. Some findings from the Attribute scores do 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.

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

2. The lower attribute scores again reflected the challenges of high/very high support needs. These scores were loaded onto 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 that 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.

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

4. 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 Microboads purposes and strategies.

5. 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.

6. All the Focal Persons had high or very high support needs. Supporting each person was clearly challenging and rested strongly on the commitments and skills of participants.

7. It was very moving to spend time with each Microboard and to see how committed participants were to each person with disabilities and to observe the depth of understanding they showed.

8. The connection between Circles of Friends and Microboards is strong and sensible, enabling experience 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.

9. The knowledge and understanding of the parents who presented seminars during the Microboards UnConvention was very impressive. They have an important role in engaging in training and related activities.

10. To conclude, I strongly recommend that consideration be given to developing appropriate curricula focused on Microboards, similar initiatives, and related concepts. This comes from the Consultant's concern that 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.

I am very grateful to the Focal Persons, family members, friends, and support workers for their willingness to share so much with me, and to COSAM for enabling me to carry out the Review.

APPENDIX 1: Individual Supported Living Manual – Themes and Attributes

Theme 1   **Leadership**
        Attribute 1.1: The arrangement is based upon a clear vision and strong ideas.
        Attribute 1.2   Key People provide the leadership to set up and continue the arrangement

Theme 2   **My Home**
        Attribute 2.1: The person has secure tenure in their home.
        Attribute 2.2: The person does normal thinks people do in their own home.
        Attribute 2.3: The person's home clearly reflects who the person is and what he or she likes.

Theme 3   **One Person at a Time**
        Attribute 3.1: The arrangement is developed around the person.
        Attribute 3.2: The arrangement does not group people with disabilities.

Theme 4   **Planning**
        Attribute 4.1: Planning focuses on the person.
        Attribute 4.2: People close to the person are involved in the planning.
        Attribute 4.3: The person's future is central to the planning.

Theme 5   **Control**
        Attribute 5.1: The person and those close to him or her have control over the person's life (if appropriate).
        Attribute 5.2: Self-determination for the person is central to arrangement.
        Attribute 5.3: The person and others close have control of the arrangement.

Theme 6   **Support**
        Attribute 6.1: Supports are flexible and adpt to changes in person's needs.
        Attribute 6.2: A variety of supports are in place to suit the person.

Theme 7   **Thriving**
        Attribute 7.1: The person's lifestyle and well-being are improving.
        Attribute 7.2: The person has valued roles.
        Attribute 7.3: There are many opportunities for growth and development.

Theme 8   **Attribute 8.1: The person has close and long-lasting relationships.**
        Attribute 8.2: The person has a rich social network.
        Attribute 8.3: The person takes part in the community.

APPENDIX 2: Sum and Average Scores for Themes and Attributes

Tables 1a to 1d provide the Sum and Average scores for:
- Each of the 5 Microboards
- Each of the 8 Themes
- Each of the 21 Attributes

Note that for Themes 1 to 3 there were 29 respondents.
For Themes 4-8 there were 28 respondents as one person was called away.

TABLE 1a: SCORES FOR THEMES & ATTRIBUTES – Sum & Average Scores

MICRO-BOARD	Theme 1: Leadership		Theme 2: My Home		
	1.1 Clear vision & strong ideas	1.2 Key people provide leadership	2.1 Secure tenure in the home	2.2 Normal things done in own home	2.3 Home reflects the person
A.	29 & 4.1	29 & 4.1	33 & 4.7	32 & 4.6	24 & 4.0
B.	15 & 3.8	16 & 4.0	10 & 2.5	13 & 3.3	16 & 4.0
C.	25 & 4.2	22 & 3.7	20 & 3.3	26 & 4.3	4.0 & 4.8
D.	32 & 4.6	24 & 3.4	34 & 4.9	32 & 4.6	28 & 4.0
E.	19 & 3.8	18 & 3.6	20 & 4.0	23 & 4.6	24 & 4.8

TABLE 1b: SCORES FOR THEMES & ATTRIBUTES – Sum & Average Scores

MICRO BOARD	Theme 3: One Person at a Time		Theme 4: Planning		
	3.1 Developed around the person	3.2 Does not group people with disabilities	4.1 Planning focuses on the person	4.2 People close are involved in planning	4.3 Person's future is central in planning
A.	32 & 4.6	12 & 4.0	31 & 4.4	32 & 4.6	32 & 4.6
B.	19 & 4.8	18 & 4.5	19 & 4.8	16 & 4.0	13 & 3.3
C.	29 & 4.8	29 & 4.8	27 & 4.5	25 & 4.2	23 & 3.8
D.	31 & 4.4	34 & 4.9	29 & 4.8	29 & 4.8	27 & 4.5
E.	25 & 5.0	25 & 5.0	24 & 4.8	24 & 4.8	18 & 3.6

TABLE 1c: SCORES FOR THEMES & ATTRIBUTES – Sum & Average Scores

MICRO BOARD	Theme 5: Control/Influence			Theme 6: Support	
	5.1 Person & those close have control over life	5.2 Self-Determination is central	5.3 Person & those close control arrangement	6.1 Supports are flexible & adapt to needs	6.2 Variety of suitable supports in place
A.	31 & 4.4	31 & 4.4	30 & 4.3	29 & 4.1	28 & 4.0
B.	17 & 4.3	18 & 4.5	15 & 3.8	17 & 4.3	15 & 3.8
C.	28 & 4.7	27 & 4.5	27 & 4.5	27 & 4.5	27 & 4.5
D.	25 & 4.2	22 & 3.7	23 & 3.8	24 & 4.0	25 & 4.2
E.	22 & 4.4	23 & 4.6	23 & 4.6	21 & 4.2	21 & 4.2

TABLE 1d: SCORES FOR THEMES & ATTRIBUTES – Sum & Average Scores

MICRO BOARD	Theme 7: Thriving			Theme 8: Social Inclusion		
	7.1 Lifestyle & wellbeing better	7.2 Person has valued roles	7.3 Growth & Development	8.1 Close & lasting Relationships	8.2 Rich social networks	8.3 sTakes part in community
A.	30 & 4.3	28 & 4.0	29 & 4.1	34 & 4.9	33 & 4.7	34 & 4.9
B.	15 & 3.8	12 & 3.0	12 & 3.0	9 & 2.3	12 & 3.0	12 & 3.0
C.	25 & 4.2	21 & 3.5	23 & 3.8	23 & 3.8	19 & 3.2	22 & 3.7
D.	22 & 3.7	20 & 3.3	22 & 3.7	22 & 3.7	20 & 3.3	20 & 3.3
E.	20 & 4.0	20 & 4.0	19 & 3.8	22 & 4.4	17 & 3.4	19 & 3.8

APPENDIX 3: Attributes Average Scores, Highest and Lowest Scores

THEME & ATTRIBUTES	AVERAGE SCORE	HIGHEST SCORE	LOWEST SCORE
Theme 1: Leadership			
Attribute 1.1	**4.1**	**5**	**3**
Attribute 1.2	**3.5**	**5**	**3**
Theme 2: My Home			
Attribute 2.1	**4.0**	**5**	**3**
Attribute 2.2	**4.3**	**5**	**3**
Attribute 2.3	**4.0**	**5**	**3**
Theme 3: One at a Time			
Attribute 3.1	**4.7**	**5**	**3**
Attribute 3.2	**4.1**	**5**	**4**
Theme 4: Planning			
Attribute 4.1	**4.6**	**5**	**4**
Attribute 4.2	**4.5**	**5**	**4**
Attribute 4.3	**3.9**	**5**	**3**
Theme 5: Control			
Attribute 5.1	**4.4**	**5**	**3**
Attribute 5.2	**4.3**	**5**	**3**
Attribute 5.3	**4.2**	**5**	**3**
Theme 6: Support			
Attribute 6.1	**4.2**	**5**	**3**
Attribute 6.2	**4.1**	**5**	**3**
Theme 7: Thriving			
Attribute 7.1	**4.0**	**5**	**3**
Attribute 7.2	**3.6**	**5**	**3**
Attribute 7.3	**3.8**	**5**	**3**
Theme 8: Social Inclusion			
Attribute 8.1	**3.9**	**5**	**3**
Attribute 8.2	**3.6**	**5**	**3**
Attribute 8.3	**3.8**	**5**	**3**

APPENDIX 4: The Legally Agreed Objectives of DTMC Inc are

a. To solely serve the needs of D.
b. That each Association member makes a personal commitment to establishing and maintaining a relationship with D.
c. As needs indicate, to actively and respectfully advocate in all areas of D.'s life.
d. With D., explore all options available to best serve his social, emotional and physical needs.
e. To assist/ensure D. lives a lifestyle that is as typical as possible of other citizens of the same age, gender and cultural situation and that he will be treated with respect and dignity, experiencing the same rights as other citizens.
f. To plan, acquire, and/or deliver all cultural, social, religious, recreational, vocational and residential programs for D. with consistent respect for his wishes, interests, and strengths.
g. Monitor D.'s health care needs.
h. The property and income of DTMC Inc shall be applied solely towards the promotion of the objects or purposes of DTMC Inc and no part of that property or income may be paid or otherwise distributed, directly, to members of the association, except in good faith in the promotion of those objects or purposes.

APPENDIX 5: NDIS Outcomes Domains and ILC Activity Outcomes

NDIS Outcome Domains

a. Choice & control
b. Daily activities
c. Relationships
d. Home
e. Health & wellbeing
f. Lifelong learning
g. Work
h. Social, community & civic participation

ILC Activity Outcomes

a. Increased skills and capacity
b. Increased motivation, confidence and empowerment to act
c. Increased self-advocacy, independence and relationship building
d. Increased participation in community life
e. Increased contribution to community life
f. Increased connections, relationships & support networks in community
g. Increased opportunities for active participation and increased sense of belonging in community
h. Increased shared understanding, experiences, collaboration and leadership

APPENDIX 6: WRITTEN COMMENTS BY PARTICIPANTS DURING THE REVIEW PROCESS

The house arrangement was based around **A** – those who come and live in the house are asked if **A** wants it to happen.

We set goals at the beginning of each year.

On our Board we have friends and family that love **A**.

A's team are awesome. We are all flexible and adapt very quickly. One of our paid workers couldn't take **A** to the Fringe one night so I stepped in and took him.
A has a great relationship with all the people he meets. He has a great social network. He goes out a lot with his friends. **A** is a public speaker and goes and talks in the community.

Although other people with disabilities live with **A**, it is <u>always</u> done in consultation with **A** and **A** wants them and has a personal relationship with them.

The unpaid support could be spread more evenly, e.g., more friends taking **A** out. I speak mainly for myself. Giving house mates a break and less hours of paid staff.

A has strong social/emotional roles. He has valued work in the community. I think there are other roles **A** would like to play in the community that we need to get better at supporting.

Family (parents) remain the leaders for now, but others take ownership in the space and beyond to an extent. His home is owned. He does everything in his own home except chores – he is developing here. More stimulation and structures to support independence in Isaac would help.

Everyday planning takes time as well – cannot just be future oriented.

B is loved.

Support has become more and more focused on empowerment, individualised and innovative.

Does not have a sustainable group of his own friends his age – yet – but support network that cares.

B clearly identifies the place he lives in is his home.

We collaborate on leading more and more – (it) was just Mum at the start.

Mum and Dad still live there so (home) is not quite optimal for a young man.

We are working towards planning for what happens when parents can't support **B**.

We employ our own staff to have complete control.
We saw the need to help.

Perhaps by necessity, family members have strong influence on direction of **B's** life. Hopefully, arrangements will allow other Microboard members to take stronger positions in future.

As **B** has high support needs, I feel a lot of energy is spent on organisational matters. As a new Microboard member without prior support history with **B**, I find it difficult to obtain timely, quality information that helps me to make Board decisions.

Significant effort are always being made to develop **B's** social inclusion. It has not reached a stage where it can grow naturally.

C's Microboard is currently changing but they listen to what **C** is communicating if he likes or dislikes the ideas and they have set out jobs.

C has the choice to add or remove what he wants in his house. **C** says yes to how he likes his house.

C has a choice of who he hangs out with and when and how long. **C** is not being forced o spend time …?

C is in the room and meeting when planning. He has a choice to say no I don't like this or yes I do like this or I need more information.

C has the control/influence – his Microboard or others are there to assist. They can't fully take over and not allow **C** to have a choice.

He has a vast variety of support. He has friends, family, paid, Microboard fellow employees. Has a variety of people around him – spending time with him and helping him or mentoring him through life.

We are always looking to give ideas that would improve **C's** life.

C has a normal mortgage like everyone else. His house reflects his personality and his interests.

Random variation in NDIS funding limits our control of the arrangement having funded creation of a vision now cutting back resources to implement.

A lack of peers but other parts of social network developing very well. Involvement in community is good but huge amount of work for a small result but hopefully will become more self-sustaining.

Mo provides vision and ideas now being consolidated in Microboard constitution.

Microboard being incorporated to disperse leadership among Board members.

NDIA funding changes affect the ability of the Microboard to implement control.

Further training required for formal/informal supports.

As members of C's Microboard

    a. We are focused on C., maintain a personal relationship with him, and walk alongside him in fun and hard times. We value his friendship, enthusiasm, determination, interest in the world around him and his quiet sense of humour.
    b. We support C.'s decision making, to help him determine his wants and needs, and to advocate to meet them.
    c. We help C. have a meaningful life filled with work, friends, fun and family.
    d. We act to support C.'s physical health and mental wellbeing.
    e. We strengthen C.'s connection with community.
    f. We oversee the engagement and performance of his support structure.
    g. We foster C.'s independence and positively plan for his future.
    h. We guide our decision making using the principles of Microboards Australia and Vela Microboards.

APPENDIX 7: BIO – Emeritus Professor Errol Cocks BA, MPsych, PhD

My engagement in the disability sector began in 1970.
I retired from Curtin University in October 2017.

Academic Qualifications

- Teacher's Certificate, Claremont Teacher's College (1963)
- Bachelor of Arts (Psychology), University of WA (1969)
- Master of Psychology (Clinical), University of WA (1974)
- Doctor of Philosophy (Education), The University of Queensland (1996)
- Awarded the title of Emeritus Professor by Curtin University in December 2017 for service to disability and the University.

1964-1986: INVOLVEMENT IN DISABILITY SERVICES– Located in Government disability services with major clinical and administrative responsibilities.

Western Australia and Victoria 1964-1986:

- 1964-1970 – Teacher and Guidance Officer in schools and the Guidance and Special Education Branch, WA Education Department.
- 1971-1980 – Senior Clinical Psychologist, Deputy Superintendent, WA Division for the Intellectually Handicapped.
- 1980-1983 – Director, Mental Retardation Division, Health Commission of Victoria.

1986-2018: ACADEMIC & RESEARCH ROLES - Located in Universities in WA, the UK, and the United Arab Emirates.

Western Australia 1986-1998:

- Associate Professor and Director, Centre for Disability R&D, Edith Cowan University.

United Kingdom 1998-2001:

- Joint appointment as:
    - Professor, Clinical Psychology & Learning Disabilities, Centre for Clinical Psychology & Healthcare Research, University of Northumbria
    - Senior Consultant Clinical Psychologist and R&D Lead, Northgate & Prudhoe National Health Service (NHS) Trust.
- External Examiner for the MA/Graduate Diploma courses in Learning Difficulties at Keele & Manchester Universities, UK.

United Arab Emirates 2002-2004:

- Professor, College of Family Sciences, Zayed University, Dubai, UAE.

Curtin University 2005-2017:

- Professor, School of Occupational Therapy, Social Work, & Speech Pathology, Faculty of Health Sciences, Curtin University.
- Director, Centre for Research into Disability and Society, 2010-2012.

Publications, Research, & Consultancy

Authored/co-authored over 100 publications on disability in international academic journals, books, three disability Ministerial Reports for Ministers of Health in WA & Victoria, & completed approximately 80 research/contract/technical reports in disability issues for a range of government bodies including the ARC, Health, Community Services, Disability, Employment & Training, Foreign Affairs & Trade, & NGOs. Provided disability consultancy & training in Australia, the UK, USA, the UAE, Korea, Indonesia, China, & the OECD. Primary roles in the closure of 3 large disability institutions in WA & Victoria & the redevelopment of a substantial number of other disability organisations.

Current principal disability interests:

- Individual supported living
- Disability employment
- Disability health

APPENDIX 8: References

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3. Cocks, E., Williamson, M., & Thoresen, S. (2011). *Individual Supported Living Manual*. CRDS, School of Occupational Therapy and Social Work, Curtin University.

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6. 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.

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8. Cocks, E., Thoresen, S., O'Brien, 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.

9. 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.