MICROBOARDS FOR CHILDREN PROJECT

Project Evaluation Report

Report prepared December 2022 for Microboards Australia by:

Dr Sue Taylor
Dr Jo Watson
Associate Professor Angela Dew
Penny Manning

Disability & Inclusion
School of Health & Social Development
Faculty of Health
Institute of Health Transformation
Deakin University

Table of Contents

Acknowledgment of Country

Deakin University acknowledges the Traditional Custodians of our lands and waterways. We pay respects to Elders past, present and emerging. Deakin campuses are built on the traditional lands of the Wadawurrung people of the Geelong region, the Wurundjeri and Boon Wurrung people of the greater Melbourne region, and the Gunditjmara people of Western Victoria.

Deakin is committed to acknowledging, building and sustaining respect and understanding between First Nations and non-Indigenous Australians. Our vision is for a university that values and celebrates diversity – where all students have respect for Aboriginal and Torres Strait Islander knowledges, cultures and values. At Deakin, we see this as a University-wide responsibility. We support Aboriginal and Torres Strait Islander peoples' calls for self-determination, and a 'Voice, Treaty and Truth Telling' through the Uluru Statement from the Heart.

This artwork is painted by proud Wagiman man Nathan Patterson. The artwork is titled 'Learning Together, Growing Together' and represents Deakin's mission to engage meaningfully with reconciliation and treaty-making processes, whilst providing exceptional learning, knowledge-sharing and research opportunities for First Nations peoples. The artwork depicts Deakin as the central meeting place, anchored in the 'present day', with staff and students gathered around it. The other circles represent the past and future, building on Deakin's rich legacy of engaging First Nations students through the NIKERI Institute (formerly the Institute of Koorie Education) and securing a high-quality educational experience that will continue to service our communities into the future. The coolamons up the top represent the gathering of knowledge, and the boomerangs represent students taking this knowledge back to their communities. The gum leaves represent connection to Country.

Microboards for Children Project Evaluation Report

Executive Summary

Background

The United Nations Convention on the Rights of Persons with Disability [CRPD] (United Nations, 2006) is a key international document detailing the human rights of people with disabilities. In response to the Australian government's signing of the CRPD, Australia's disability support systems are increasingly recognising the human rights of people with disability. Despite this, many people with intellectual disability continue to have their right to autonomy denied due to negative stereotyping and perceptions that they lack capacity to make informed choices (Carey et al., 2022; Watson, 2016) and continue to experience high levels of disadvantage and social exclusion (Bigby, 2012). Against this backdrop, Microboards Australia was established by families of people with intellectual disability who wanted their loved ones with disability to live self-determined lives, with a sustained support network of family, friends, and community.

The Microboards model has functioned effectively in Canada and Australia (Microboards Australia, 2016; Stainton et al., 2019). It builds capacity for person-centred, sustainable and responsible support networks to support people with intellectual disability. The model is based on principles of identifying a vision for the future of the person with disability, person-centred thinking, self-determination, and social relationships. Microboards Australia employs facilitators who assist families of people with disability to learn how to embed those principles into their caring and support practices and how to use Microboards systems and resources. Families, friends and others with long-term commitment to the welfare of the person with disability can be guided by facilitators through the formal process of establishing an independent governance structure for a Microboard. Facilitators help the person with

disability and Microboard members to plan and achieve their goals such as coordinating support services, finding employment, or forming and sustaining a social network. As well as supporting the person with disability with systemic advocacy and negotiation, published research suggests that Microboard members can strengthen people's social networks, enhance their communication of will and preference, and improve their coping and life skills (Stainton, 2016).

Microboards Australia obtained an Information Linkages and Capacity-building [ILC] Grant from the Community Inclusion Capacity Development Program of the Australian Department of Social Services [DSS], to build upon the successful Microboards model and adapt it for families with children with intellectual disability and complex support needs. Families of children with disability often have concerns about safeguarding the life of their child into the future when they are no longer able to do so (C. Lee & M. M. Burke, 2020; Microboards Australia, 2016). The Microboards for Children model responds to parental concerns about their child's future wellbeing and support. Research suggests that some families struggle with the power imbalances inherent in the disability support system (Dempsey et al., 2009), and find it difficult to advocate for services, supports and inclusion for their child (Poston et al., 2003). The Microboards for Children model responds to these concerns.

Evaluation

Deakin University's Disability and Inclusion team's Dr Jo Watson, Dr Sue Taylor and Ass Prof Angela Dew, designed and implemented an evaluation of the Microboards for Children Project. The following questions were addressed:

What is the impact of the Microboards for Children Program on focus children, their families, carers and circle members?

What is the value of resources and materials developed as part of the Microboards for Children Project in terms of quality, relevance, accessibility, and useability?

Questionnaires were administered to 42 families who attended Information Sessions about the Microboards for Children Project. Changes in initial understanding about and confidence in the Microboards for Children Project were measured in the questionnaire using a Likert scale to rate families' responses. Semi-structured interviews were conducted with 10 families who participated in

the Microboards for Children Project. Transcribed open-ended interview responses from participants were analysed using thematic analysis.

Findings

Families expressed confidence in the Microboards processes prior to commencement and their positive experiences of the Microboards for Children Project were reflected in analysis of interview data. Themes comprised a global theme and six organising themes.

Global theme:

The Microboards for Children Project provides a reliable framework of support that helps families to strive for an independent, safe, and inclusive adults' life for their child with intellectual disability.

Organising themes:
1. Children with intellectual disability face systematic and interpersonal barriers.
2. Microboards principles form a platform of support and guidance.
3. Microboards resources are helping parents to guide and support their child.
4. Learning to use Microboards principles and processes takes time.
5. Forming their child's Microboard will be a difficult but positive step.

Overall, families found the Microboards for Children principles and processes, and the resources and support provided by the project improved their confidence and ability to support and advocate for their child. Tools and strategies with which to better communicate with their child to plan for their future and to determine their will and preference were contributing to their child's self-determination and improved self-image. The opportunity to learn from the experiences of other parents of children with intellectual disability was especially appreciated by participating families. Although, by the end of the project evaluation, no families had established a Microboard with and for their child, some were in the early stages and others were being supported by the project to plan to do so. Two of the 10 families, who had few informal or formal supports and little social capital were challenged by the prospect of forming a Microboard.

Conclusion

This evaluation report provides evidence of the positive impact on children with intellectual disability and their families of Microboards for Children principles and processes, and the support provided by the project. Families were anticipating the benefits to their child of forming a Microboard and were approaching the task with the support of the project but required more time to do so.

Recommendations

1. That the Microboards for Children Project continues to support the currently participating families who recognise the value to their child of a Microboard until such time as they have a functioning Microboard in place.

2. That Microboards Australia continues to develop its resources for parents of children with intellectual disability and to offer workshops structured around principles of vision and planning, relationships, person-centred thinking and self-determination.

3. That Microboards Australia continues to offer the Microboards for Children Project resources and support to families with children with intellectual disability and complex support needs regardless of their ultimate intention to form a Microboard.

4. That Microboards Australia considers alternative ways of delivering its Microboards for Children material to families with limited opportunity to attend a 2-hour workshop live or on video. These may include workshop summaries, pictorial, or symbolic presentation of information, or by individual sessions with families.

5. That Microboards Australia varies its approach to teaching parents how to use Podio, providing hands-on support when needed.

6. That Microboards Australia structures into the Microboards for Children Project more opportunities for participants to learn from the experiences of other families and from each other, for example through online in-person support groups or online sessions dedicated to group discussion.

7. That the Microboards for Children Project expands its reach and resources to families with children with intellectual disability and complex support needs who have limited social and economic capital. For example, recruiting families through community networks in disadvantaged geographic areas or through migrant support services.

Background

The United Nations Convention on the Rights of Persons with Disability [CRPD] (United Nations, 2006) is a key international document detailing the human rights of people with disabilities . In response to the Australian government's signing of the CRPD, Australia's disability support systems are increasingly recognising the human rights of people with disability. Despite this, many people with intellectual disability continue to have their right to autonomy denied due to negative stereotyping and perceptions that they lack capacity to make informed choices (Carey et al., 2022; Watson, 2016) and continue to experience high levels of disadvantage and social exclusion (Bigby, 2012).

Families of children with intellectual disability often have concerns about safeguarding the life of their child into the future when they will no longer be able to do so (C. Lee & M. M. Burke, 2020; Microboards Australia, 2016). The development of intentional support networks, sometimes called circles of support or Microboards, are internationally recognised as viable ways to support individuals through relationships of trust (Macadam & Savitch, 2015). Microboards have been successfully supporting adults with intellectual disability in Canada and Australia for decades (Microboards Australia, 2016; Stainton et al., 2019). A Microboard is a formal and legally-constituted framework for planning and communication within which a group of people can come together to help formulate, promote and support the individual goals of a person with intellectual disability (Microboards Australia, 2016). Microboards have common features, with an emphasis on facilitated planning; choice and control by the individual with intellectual disability in decision-making; enabling families to share the decision-making and caring load; maintaining focus on the vision of the best life for the individual with disability; and connecting the individual with disability with their community. Microboards facilitate the long- and short-term goal setting of individuals with intellectual disability that ideally begin in childhood (Dezonia, 2009).

Published research indicates families' reluctance to engage in planning for the future of their child with intellectual disability (Kruithof et al., 2021; C. e. Lee & M. M. Burke, 2020). Instead, families are likely to turn to planning when emergencies arise, rather than developing a vision or long term plan for the life of their child with intellectual disability (Lindahl et al., 2019). Against this backdrop, Microboards Australia was established by families of people with intellectual disability who wanted their loved ones with disability to live self-determined lives, with a sustained support network of family, friends, and community.

This evaluation report on the Microboards for Children Project contributes to a small but emerging knowledge base informing the building of circles of support and Microboards for children with disability.

The Microboards for Children Project

In 2020, Microboards Australia received an Information Linkages and Capacity-building [ILC] grant under the Community Inclusion Capacity Development program of the Australian Department of Social Services [DSS] to develop and implement the Microboards for Children model. Microboards Australia partnered with Developmental Disability Western Australia, Inclusion Melbourne, and the New South Wales Council for Intellectual Disability to form a Project Co-ordination Group. Microboards Australia drew on these partnerships to form a Project Advisory Group comprising partner organisations, parents and young people with intellectual disability. The Microboards for Children model was co-designed with the Project Advisory Group to respond to the expressed needs of families with children with intellectual disability. The model comprised a framework of support, resources and planning orientated toward children aged under 18 and their families. The model uses a developmental continuum approach to working towards the principles and strategies for successful transition to a life of autonomy, self-leadership and influence by the child with intellectual disability over their own life (Microboards Australia, 2016).

After mapping the relevance of existing Microboards principles and processes for application to children aged under 18, Microboards Australia worked with the Advisory Group to plan workshop sessions for families that mapped out and mentored them in how to embed Microboards principles into the early years of their child's life. Similarly to the Microboards model that supports adults with intellectual disability, facilitators support and guide families in advocacy for their child and support those who may also wish to establish a Microboard. The co-design group tested and refined a prototype of the Microboards for Children model.

The Microboards for Children Project was designed to support families and carers of children and young people with intellectual disability through a formal network of support that can:

- Safeguard the life of the individual with disability when their parents are no longer able to do so;

- Manage the individual's funding transparently, accountably and with integrity;
- Establish rules of operation of the Microboard;
- and tap into the creativity and networks of Microboard members.

The model offered resources in the form of workshops to help families to develop skills in working with their child to develop a vision for the future. Families were mentored in person-centred thinking and planning, as well as in how to better support their child's choice and control in decision-making. The project also offered a framework to guide families in supporting their child's social relationships. Microboards Australia trained facilitators whose role was to work closely with families as they learned Microboards principles and processes and to help them if they encountered difficulties in areas such as advocacy for their child or communication with their child. New resources tailored to the Microboards for Children model included the Podio platform for information management; a NDIS Fact Sheet and information to help children and young people with intellectual disability to understand what Microboards can do formatted in easy English and graphics.

Key principles embedded in the model are:

- Vision and Planning, to guide decision-making so that children with intellectual disability can envision a good life;
- Relationships, embedded in the Vision and upheld by belief that relationships are possible for all children with intellectual disability;
- Person-centred thinking to make it easier to discover and respond to the preferences of children with intellectual disability; and
- Self-determination to increase the sense of choice and control by children with intellectual disability.

Four online workshops of 2 hours each were presented by Microboards Australia, attended by families and facilitators. Workshops focused on each of the four Microboards for Children principles. Workshop formats positioned each principle within the Microboards for Children model, explained its relevance and how it might be put into practice, and demonstrated relevant tools and resources. Each workshop provided time for group discussion. Workshops were recorded and available for families who were unable to participate live, or who wished to review the material after the workshops.

Evaluation process

Microboards Australia contracted Deakin University's Disability and Inclusion Team's Dr Jo Watson and Associate Professor Angela Dew to conduct an evaluation of the program. The evaluation sought to identify effective aspects and outcomes of the Microboards for Children Project. The focus of the evaluation was on participant knowledge, attitudes and outcomes for focus children, their families and circle members. The evaluation was designed to provide insights into best practice in terms of how families can understand and embed Microboard principles during childhood and the organisational strategies necessary to develop and support them.

Deakin researchers adopted a participatory action research approach to evaluating the project, aligning with the project's co-design methodology. A team of three co-researchers, young people with lived experience of their own Microboard, worked with the researchers. It was agreed that the evaluation would use both survey and interview data and would evaluate resources developed as part of the Microboards for Children Project using a critical appraisal tool.

Evaluation questions

The evaluation addressed the following questions:

What is the impact of the Microboards for Children Program on focus children, their families, carers and circle members?

What is the value of resources and materials developed as part of the Microboards for Children Project in terms of quality, relevance, accessibility, and useability?

Ethics approval

The original evaluation design centred on semi-structured interviews with children and young people who, along with their parents and carers, were interested in having their own Microboard. However, concerns on the part of the Deakin University Human Research Ethics Committee (DUHREC) about the vulnerability of potential young participants with intellectual disability and communication access support needs in an interview setting led to a change in approach. Instead, the evaluation proceeded

by interviewing participating families of the children and young people in the project. Deakin researchers considered that families exploring Microboards were motivated by safeguarding the best interests of their child and would most likely play key roles with them in deciding on the efficacy of a Microboard in their circumstances. The evaluation received clearance from the Deakin University Human Research Ethics Committee (DUHREC) (2021-142) on 29th July 2021. See Appendix 1 for DUHREC letter of approval and Appendix 2 for Plain Language Information Sheets and Consent Forms.

Evaluation Method

Reflecting best practice, the formative evaluation method provided input into the Microboards for Children Project while it worked with families, to allow iterative changes to be made from lessons learnt during the evaluation period. This approach added value to the work of Microboards Australia's co-design group and allowed flexibility and responsiveness in the ongoing development of the Microboards for Children model. Researchers worked closely with Microboards Australia, the co-design group and co-researchers to refine evaluation objectives and to design surveys and interview questions. This final report demonstrates the impact of the project at its conclusion.

Surveys

The Microboards for Children Project commenced with an initial Information Session for families interested in joining the project. Attendees of this initial Information Session were asked to complete a survey asking specific questions about what they had learnt and their interest in joining the project.

Subsequently, Microboards Australia conducted two follow-up Information Sessions for families who expressed an intention to join the Microboards for Children Project. Attendees were asked by Deakin researchers to complete surveys before and after the Information Session to assess what they had learnt about the Microboards for Children Project.

Interviews

Thirteen families joined the Microboards for Children Project and of those 10 consented to participate in the evaluation via semi-structured interviews. Interviews were conducted between October 2021 and October 2022 with 10 families participating in the first round and 8 in the second round. Two families were unable to participate in a second interview because of their family circumstances. Interviews with participants were conducted using an online audio-visual platform. Participating families were widely dispersed throughout Australia and one family was located overseas.

Co-researchers

Co-research roles were designed for young people with intellectual disability and complex communication access needs with their own lived experience of a Microboard. The co-research

method was intended to build the research skills of young people with intellectual disability and also to better consider in research findings the perspective of young Microboards users. Three young adults known to Microboards Australia expressed their interest in working as co-researchers with Deakin University researchers. Co-researchers resided in Western Australia and Victoria.

Co-researchers Penny Manning, Eli Dickenson and Peter Hall were briefed by the researchers on evaluation methods, and they advised on the wording of surveys and participant interviews. One of the co-researchers, Penny Manning, expressed an interest in being involved in the interviews with participating families of children with intellectual disability. Penny is an accomplished communicator using a Grid Pad 10s speech generating device with which she uses Pragmatic Organisation Dynamic Display (PODD). To facilitate interviews Deakin researchers provided an interview guide and instructions for Penny's communication partners to program the questions into her AAC device.

Evaluation participants

Respondents to the initial survey were 8 families providing care and support to a child with intellectual disability and who were interested in learning about the Microboards for Children Project.

Respondents to the follow-up survey were families who intended to join the Microboards for Children Project. Forty-two respondents completed the pre-Information Session survey and twenty-two the post-Information Session survey.

Interview participants were 10 families (10 mothers and 1 father) who joined the Microboards for Children Project and agreed to participate in the evaluation. The ages of their child with intellectual disability ranged between 3 years and 18 years. The children lived with intellectual disability, some with conditions such as autism or anxiety, and one child lived with Alfi's syndrome. Most had complex communication access needs and either communicated using augmentative and alternative communication (AAC) systems or used embodied forms of communication that their families understood. One child lived with hearing impairment and communicated using Auslan. 5 of the 10 families had other children without disability and one family had another child with autism. Co-researcher Penny Manning was involved in conducting 16 of the total 18 interviews with families. All interviews were audio-recorded and transcribed using a professional transcription company.

Data analysis

The initial survey and the pre- and post- Information Session survey responses were measured using Likert-scales. For example, participants were asked in the pre-Information Session survey how much they knew about Microboards. Responses could range between 'I know nothing' with a numerical value of 0, up to 'I know a lot' with a numerical value of 4. The same question was asked in the post-Information Session survey, again with possible responses ranging between 'I know nothing' up to 'I know a lot' and the same numerical values. The results are discussed below.

Data analysis of the interview transcripts was commenced during the first round of data collection, using inductive and deductive thematic analysis (Braun & Clarke, 2022) to identify emerging themes. Co-researcher Penny Manning participated in a data analysis workshop based on Deakin researchers' initial analysis, providing valuable insights drawn from her experience as a young person with intellectual disability and complex communication access needs who has her own Microboard. Data analysis produced subcategories and themes which were tested and developed further by focused questioning in the second round of interviews. The summative data was synthesized to report on project deliverables.

EVALUATION FINDINGS

Surveys

Initial Survey

The initial survey was designed to discover what respondents had learnt about the Microboards for Children Project before they decided whether to join. Respondents were recruited from Microboards Australia's networks within the community of families with children with intellectual disability. The survey explored their confidence in using Microboard principles and processes and their interest in setting up a Microboard for their child in the future. Of 8 respondents, 3 lived in Western Australia, 2 Victoria, 1 in NSW, 1 in Queensland and 1 overseas.

Tables 1 to 4 provide the Likert-scale responses to questions on respondents' knowledge about Person Centred Thinking, which is foundational to the Microboards for Children model (Table 1); their levels of comfort about others being part of the life of their child (Table 2); and their levels of confidence in developing a positive vision for their child and in setting up a Microboard (Tables 3 & 4).

Table 1: Knowledge about Person Centred Thinking

Answer	
Nothing	5
A little	1
A lot	1
Did not respond to this question	1
Total	8

Table 2: Comfort about Others Being Part of the Life of the Child and Helping them to Make Decisions

Answer	
I am not comfortable at all	1
I am somewhat comfortable	4

I am comfortable	2
I am very comfortable	1
Total respondents	8

Table 3: Levels of Confidence in Developing a Positive Vision for the Future of the Child

Answer	
I am not confident at all	1
I am confident	3
I am very confident	4
Total respondents	8

Table 4: Levels of Confidence in Setting up a Microboard or Circle

Answer	
I am not confident	2
I am a little confident	2
I am confident	2
I am very confident	2
Total respondents	8

Participants' responses indicate they came to the Information Session knowing little about person-centred thinking, and that whilst they were tentative about engaging with Microboards for Children principles and processes they were positive about the future of their child or young person. Half of the respondents felt confident about setting up a Microboard.

Vision for the future

Participants were invited to complete the sentence 'In the future I envisage the child I support living ....'. Participants responses reflected a diverse array of vision.

'independently with a friendship group and people she feels connected to'

'happily, independently, doing work she loves, contributing in ways that light her up, with a lovely partner and surrounded by friends and family. I see her well supported to have the agency to curate a life she loves, and that offers her expansion and safety'

'a happy life filled with purpose and meaningful activities'

'her life as she chooses'

'independently in her own home, with strong connections to friends, family and community. She is known and loved and has the same life opportunities as her siblings. She has valued roles in community and enjoys a life of purpose and meaning of her choosing. She is a lifelong learner and persists at her goals and has a sense of self-worth'

Responses indicated families interested in the Microboards for Children Project wanted their child to live an inclusive and connected life as they moved towards adulthood.

.

Follow-up Information Session (pre and post surveys)

Respondents to before and after in two follow-up Information Sessions about Microboards for Children principles and processes were asked to complete a survey to gauge whether the Information Session they attended had helped them to learn about Microboards for Children. Of 42 respondents to the Pre-Information Session survey, the majority (24) lived in Western Australia, 7 in Victoria, 6 in NSW, 4 lived overseas and 1 lived in Queensland. The majority (34) lived in a city, whilst 8 lived in a large or small country town. Twenty-seven respondents were the parent of the child, 1 was another family member and 13 were either carers or family friends who had a role in the life of the child. Results indicated interest in Microboards for Children extended beyond Western Australia, where Microboards Australia is based, and was widely dispersed. Although the majority lived in cities, respondents' living environments were likely to offer differing levels of support for families and their child with intellectual disability.

Table 5 provides the Likert-scale responses to a question about how much respondents knew about Microboards for Children before and after the follow-up Information Session they attended.

Table 5: Knowledge about Microboards for Children

Answer	Pre-Information Session (42 respondents)	Post Information Session (22 respondents)
I know nothing	5 (11.9%)	1 (4.5%)
I know a little	10 (23.8%)	2 (9%)
I know something	12 (28.5%)	6 (27.2%)
I know quite a lot	5 (11.9%)	12 (54.5%)
I know a lot	10 (23.8%)	1 (4.5%)

Table 6 provides the Likert-scale responses to a question about how much respondents knew about person-centred thinking before joining the follow-up Information Session.

Table 6: Knowledge about person centred thinking

Answer	Pre-Information Session (41 respondents)	Post Information Session (22 respondents)
I know nothing	8 (19.5%)	0
I know a little	8 (19.5%)	2 (9%)
I know something	12 (29.2%)	7 (31.8%)
I know quite a lot	8 (19.5%)	12 (54.5%)
I know a lot	5 (12.1%)	1 (4.5%)

Table 7 provides the Likert-scale responses to a question about how hopeful respondents were about their child having a strong social network in the future.

Table 7 Hopefulness about future social networks for their child

Answer	Pre-Information Session (42 respondents)	Post Information Session (22 respondents)
I am not very hopeful	2 (4.7%)	0
I am a little hopeful	6 (14.2%)	0
I am somewhat hopeful	7 (16.6%)	5 (22.7%)
I am hopeful	13 (30.9%)	9 (40.9%)
I am very hopeful	14 (33.3%)	7 (31.8%)
Did not respond to this question	0	1

Table 8 provides the Likert-scale response to a question about how much respondents thought their child could participate in decisions about their future.

Table 8 Extent of expectations about child's decision-making in the future

Answer	Pre-Information Session (41 respondents)	Post Information Session (22 respondents)
Not at all	2 (4.8%)	1 (4.5%)
A little	6 (14.6%)	2 (9%)
Some	3 (7.3%)	4 (18.1%)
Moderate	7 (17.07%)	0
A lot	11 (26.8%)	8 (36.3%)
A great deal	12 (29.2%)	7 (31.8%)

Analysis of survey data considers the reduction in number of respondents from 41-42 to 22 between the pre- and post- surveys. Knowledge about Microboards for Children and person-centred thinking increased from 34.7% and 31% respectively before the Information Sessions to 59% after the Information Sessions. Responses suggest that after the Information Sessions participants felt more positive about their child's social networks and decision-making in the future.

Table 9 provides the Likert-scale responses to a question about whether respondents will contact Microboards Australia to find out more about how they can support respondents and their child.

Table 9 Intention to contact Microboards Australia to find out more

Answer	Post Information Session (22 respondents)
Yes	13
I will think about it	9
No	0

This indicates that respondents were encouraged by what they learnt at the Information Sessions, and many intended to follow-up with Microboards Australia.

Social Map

Friends, some family, some teachers (e.g., dance teachers)
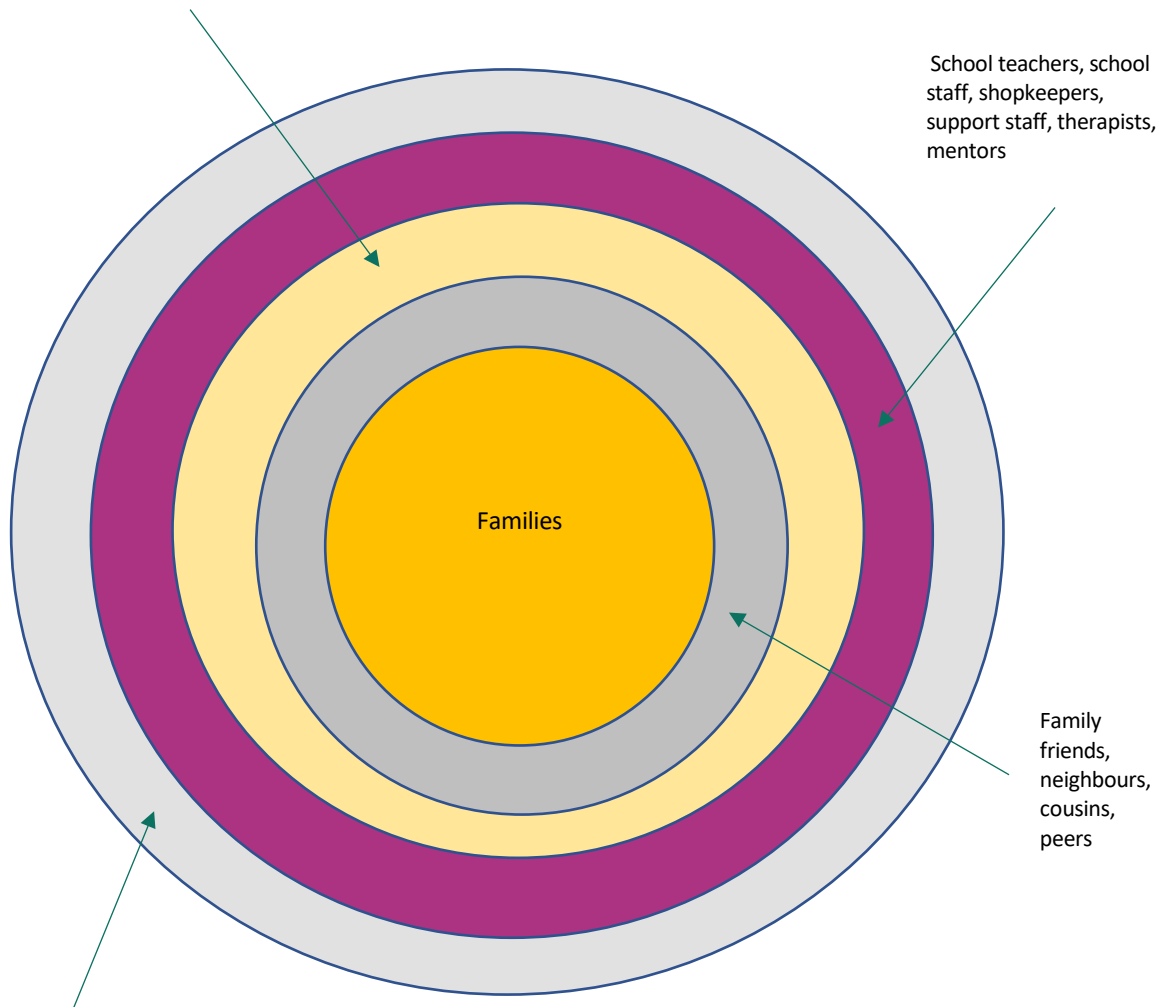
School teachers, school staff, shopkeepers, support staff, therapists, mentors

Families

Family friends, neighbours, cousins, peers

Health Professionals & Communities

Families' perceptions indicate the importance to children with intellectual disability of their family relationships, and suggests that, regardless of age differences, their social networks outside the home are largely adults with whom they interact regularly, such as school teachers, support staff and therapists. The outer circles representing casual social interactions, for instance with neighbours or in the community, are likely to be less accessible to them.

Participant Interviews

Analysis of interview data produced six themes reflecting the experiences of families participating in the Microboards for Children Project.

Global theme:

The Microboards for Children Project provides a reliable framework of support that helps families to strive for an independent, safe, and inclusive adults' life for their child with intellectual disability.

Organising themes:
1. Children with intellectual disability face systematic and interpersonal barriers.
2. Microboards principles form a platform of support and guidance.
3. Microboards resources are helping parents to guide and support their child.
4. Learning to use Microboards principles and processes takes time.
5. Forming their child's Microboard will be a difficult but positive step.

Theme 1: Children with intellectual disability face systemic and interpersonal barriers

Families participating in the Microboards for Children Project commonly experienced structural barriers, especially in education systems. Families experienced challenges with schools restricting their child's participation and their child experiencing exclusion from school social networks. School decisions about what was taught in their child's class, teachers' misunderstanding of their child's abilities, meetings with school and clinical staff about their child's future, were all raised by parents as ongoing sources of stress and frustration.

Families were protective of their child and the impact upon them of systemic and interpersonal barriers.

Participant 5: '… *there's sometimes only so much as a parent that you can bash your head against a brick wall or make the school your enemy, and you need to bring them on the journey with you … but every time I've approached it at school, I have very much hit a brick wall and I don't know how to get through the wall.*'

Families also talked about the difficulties of their child's life transitions such as shifting from primary to high school, leaving school, the transition from child health into adult health services, as well as employment and housing systems.

Participant 6: *'I'm getting to that point in my life where I've been doing this for 18 years, and it's like, oh god, I've got another – we've still got accommodation, we've still got a job to – we've still got those two big milestone things up ahead of us, and it's like, oh god, I just – one thing at a time, but yeah'.*

Parents were also challenged by managing their child's behaviour, their own social isolation, lack of support in caring for their child, constantly being the main or only support, their child's dependence upon them, and the need to protect their child from harm or isolation.

Participant 1*: 'some antisocial behaviour is, probably anger at other people, resentment, where breakdowns don't get repaired or get forgotten about'.*

Parents acknowledged their lack of confidence and self-doubt.

Participant 1: *'I'm the one that sabotages a lot of things out of my fears'.*

Theme 2: Microboards principles form a platform of support and guidance

As outlined above, the Microboards for Children's workshops were structured around principles of vision and planning, relationships, person-centred thinking and self-determination. The workshops guided participant families towards understanding how to support their child to have an independent, safe and inclusive life in the future.

Participant 1*: 'I think the conversations with Microboards about … person centred and putting the person first and human rights that's making me smarter and more thoughtful about things … So the vision and the planning I'm doing for Microboards is completely front of mind in dealing with everyday situations'.*

The Vision Statement

Developing a vision statement is foundational to the Microboards for Children model and

forms a point of reference for families in terms of developing and sustaining social networks, planning with their child or young person and supporting them to explore choices. Some families already had a vision for their child.

Participant 1:' I don't think the vision has changed'

Others without a firm vision appreciated the value of developing one.

Participant 6: things like when we did the vision statement towards the very early part of the project, have been really useful.

Participant 8: I'm really passionate about maintaining that inclusive life and there are times when that becomes more challenging, but I think that it's really important to have that overarching vision

Participants spoke of their vision statements reflecting priorities for their child to be part of their community, to have choice and control over their lives, to be safe, to contribute to their community and experience fulfilment, and to have a meaningful life.

All participant families have used their vision statement as a basis for planning, to negotiate inclusion and to help people to know their child. Families also used their child's vision statement as an advocacy tool.

Participant 2: *'you've got to state your claim, put your flag in the ground and say "this is the vision and we are not going to accept less than that" '.*

Relationships

Relationships are core to the Microboards for Children Project, driven by the belief that a full range of relationships is possible for the child and supported by tools such as relationship mapping. Their child's friendships were of greatest concern to participants, who struggled to find a balance between initiating and supporting friendships and allowing the space for spontaneous social interactions, whilst keeping their child safe. Many parents expressed their own lack of self-confidence.

Participant 1:' *I was too scared to initiate the play date because I was worried about embarrassment or not me personally, but you know, I was trying to protect my daughter'.*

Participant 10: *It takes so much facilitation, like so much me putting myself out there, me being that annoying character who is constantly texting the other parents and going "hey, how about we get the kids together for this or that".*

Data from the second round of interviews suggests that families were gaining confidence and were often buoyed by hearing others' experiences.

Participant 6: '*We're making progress. We're not making huge progress, but we're certainly making progress. … if I had to prioritise all the aspects of the Microboard that's [social networks] probably the biggest drawcard for us'.*

Others were hoping that the Microboard structure would broaden opportunities for their child's social networks.

Participant 10: *I'm hopeful that once she has a Microboard, that that will be some of the by-product, that some of her Microboard members will start widening her circle.*

Person-centred thinking and self-determination

Some families were using person-centred principles prior to joining the Microboards for Children Project. Exposure to the Microboards for Children Project planning frameworks and communication tools raised participants' awareness of how to better support their children to communicate their wishes and make choices. Families learnt strategies from the project for communicating with their child to support and explore their choices, and the benefits of enhancing their sense of control and self-determination.

Participant 8: *'So, using talking mats to try and express his interests, his priorities, what he likes, what he doesn't like, giving feedback, that sort of thing … So, we're working a lot more with talking mats. We've got a long way to go, but it will work. He was able to indicate preferences on issues and stuff and it's like, oh, far out'.*

With their parents' support some children were having a big say in their own plans to move schools, leave school, go to university, take on new activities and more.

Participant 3: *'So she was so involved in it. I mean, it's her plan. There was no mistake. Everything about it was her and she was directing it all, which was amazing'.*

Participant 10: '*I think it's probably just become even more clear that what she wants to do, and the direction she wants to head – like, she just told the university lecturer that what she really wants to do is study astrophysics, and they went okay, sure, let's help you make that happen'.*

However, some parents had ongoing struggles engaging their child in person-centred planning.

Participant 9: It's a bit challenging at times because it's really hard to get him engaged in things. And I think one of the other challenges that I find is that he is reluctant to talk about personal things like this with anyone other than me.

Theme 3: Microboards resources are helping parents to guide and support their child

Families reflected positively on the benefits of access to project resources and support.

Participant 1: '*the talks that we've been having, the seminars for the parents, have been very practical and useful and they've come with - with tools, with resources to put things in place. That's invaluable too because …it's such a wonderful gift to be given something that works; a format, a template that works already… then the mentorship; I - I can't tell you how helpful that is to send a quick email and, "Oh, how would I sort this out, or what could I do for this, or, I've run into a little glitch, or I'm not confident about something" and just have wise counsel on tap'.*

Despite the challenges of using the Podio app, those participants who learnt how to use it found it extremely valuable for sharing clinical information, tracking their child's progress in communicating with their AAC device, preparing for assessments, keeping track of current friendships or emerging possibilities for social networks, for communicating with support workers and many other tasks.

Participant 8: *'it was really lovely this time [in an assessment] to actually have really clear data as to what – you know, when we were asked the questions about how many words [my daughter is] saying or where we're at in each of the poles on that assessment tool to be able to really have clear information around what that is'.*

Participant 10: *'The resources have been amazing … they're resources that I don't think I would have found on my own. But I don't get enough time to really stop and think, like, what sorts of things will be helpful, and then go down the right rabbit hole to find where they might be.*

Theme 4: Learning to use Microboards principles and processes takes time

Many of the participants had other children in their family, some had few formal or informal supports, and a small number were sole parents. Although all participants were positive about the benefits of Microboards for Children many felt they needed more time to make the most of what the project offered them and their child. Participants appreciated the wealth of expertise available to them and the practical support provided by Microboards for Children Project facilitators, Microboards staff and Jacquie Mills, the Microboards Australia Director.

Theme 5: Parents learn by listening to others

Participants spoke of the isolation they experienced as parents of a child with intellectual disability, and how stimulating and reassuring it was to have the opportunity as part of the project to hear other parents' experiences. It was especially encouraging for them to hear and see examples of young people with their own Microboard, such as co-researcher Penny Manning, and the sons and daughters of members and staff of Microboards Australia. For some parents, this aspect of the project, and the prospect of future networking with other parents, was a highlight.

Participant 8: *'the other really positive thing that Microboards have done is continued to share examples of what it looks like, and I would like probably more opportunities to connect a little bit more with the other families'.*

Theme 6: Forming their child's Microboard will be a difficult but positive step

Most families were positive in their intentions and their child's intentions of forming a Microboard with the assistance of the Microboards for Children Project. Some families have taken the first steps.

Participant 10: *'Yeah, she [my daughter] has decided that she would like to set up a Microboard. We … haven't done as many steps towards that as we would have hoped by this point, but it's also [my daughter's] first year out of school, and so it's been really busy, and lots of change happening, so yeah, she really does want to have a Microboard for herself, and I think it would be enormously useful, but we're not very far along in getting that happening'.*

Perceived challenges were finding the time to learn how to set one up and finding the right people to join the Microboard. Microboards for Children facilitators helped families to identify people with a long-term interest in supporting their child, as well as think about the mix of skills and personalities that might be needed. Facilitators also advised families on formal Microboards structures. Families envisaged their role in a Microboard would at first remain central to the decision-making with their child or young person, but that over time they would withdraw and entrust the Microboard with the responsibility.

Participant 10: '*She [my daughter] has agreed that I would be on it. She'd be the more important person on it, but I would be allowed to be there but both our hope … is really for me to start pulling back a bit more in all aspects of her life. So, the microboard would then fill some of the roles that I currently do'.*

Biggest challenges

PODIO

Microboards Australia customised an online information management system produced by Citrix, called Podio. Podio can help families to store information about their child with intellectual disability such as their daily routines, their preferred activities, their social networks, their medical information, and their vocabulary. Information can include recorded videos or audio recordings that can be used to train support workers. Families can customise

Podio to their needs and they can authorise access to the information by other family members, disability support workers and school teachers. Most families were initially challenged about learning to use Podio. Many put off learning how to set it up and use it.

Participant 3: *'I guess just the vastness of it is still a bit, it's not intimidating, it's just that I know there are so many possibilities.'*

Participant 9: *'learning a new programme was a little bit challenging for me.'*

Some participants delegated the work of setting up and using Podio to their child's support worker.

Participant 1:*' [my child's support worker] has supported me to feel okay that a lot of the work entering details into Podio really isn't a mum's job and I shouldn't feel guilty not adding that to my daily tasks.'*

Participant 10: '*I think with Podio, as much as the facilitators were really good at talking [partner] and I through it online, like remotely, for me, it would be – it would be better the way I work, for someone to actually be here, for someone to come over and – yeah, help me do it, and maybe having a support worker there at the time, to say here, show them as well.'*

Another family was concerned about Podio's status as a hosted platform, that could potentially be withdrawn by the host and all data lost. Eventually by the end of the evaluation all families were using Podio, but some knew they were not using it to its full potential.

Participant 3: '*So yeah, it's a work in progress but I believe Podio is always a work in progress.'*

Limited Time

Some participants did not have as much time as they would have liked to participate in all Microboards for Children workshops or to learn from the resources and tools provided.

Participant 5: *'I find them* [workshops] *sometimes a bit long because I am, as I said, time-poor so to sort of sit and listen to it for an hour and a half or whatever.'*

These families would occasionally watch recordings of the workshops, but not always. They felt they learnt more from listening to other parents speak about their own experiences in workshops rather than from viewing workshop material when they could access those discussions.

Participant 2: *'I'm finding the meetings actually pretty helpful like just hearing how other parents are going and the kinds of things that they're doing and trying.'*

Participant 8: '*it's been really good to actually hear little snippets of other families, so having that lived experience of Jaquie and Jo and other people who are running the project but also other people who are like now in the project with young children so I think that's been really powerful.'*

As both the end of the evaluation and the final stages of the project approached, families reflected on how much more they could learn from the Microboards for Children Project.

Participant 8:'*I think I've got lots of learnings still to do in this space and still building my understanding around it, and I think as I said too lots of unlearning myself as well*.'

Setting up a Microboard

Two participants expressed doubts about their capacity to form a Microboard for their child, reflecting challenges facing single-parent families with few informal supports, time constraints and limited social networks. Their challenges were not as much related to the knowledge about how to do it, with which facilitators could help, but rather to their own social capital and time, which may have been compromised by caring for their child with intellectual disability.

Participant 5: *'In terms of actually a Microboard for* [my son] *… I don't know how you would make one happen and I don't know that they* [Microboards Australia] have *got any magic, you know, unless there was a group of people in Australia who sort of said, "We're interested in doing a Microboard" and they just assign them to families.'*

Participant 9: '*I think we all need to talk more about how to engage people in the Microboards model for people who are a little bit at times reluctant to engage*'.

Participant 7: '*The people – so, like, his cousin and his aunty – I can't see them stepping up to that sort of detail anytime soon.'*

These parents were concerned about their children's future, especially the prospect of them moving into adult disability systems.

Participant 9: '*I'm terrified. If I can be entirely honest, I am so terrified. I mean it's only a year and a half away that he will be eligible to apply for DSP* [Disability Support Program].'

Composite case study

The following case study demonstrates the complex challenges facing families with a child with intellectual disability and complex communication needs and the support and resources the Microboards for Children Project has been able to offer.

Emma

Emma is aged 15 with two siblings. She has an intellectual impairment, complex communication access needs and autism. Emma was experiencing challenges with school inclusion and with forming school friendships, and Emma was experiencing anxiety when at school. She and her family made the decision to change to home schooling, using Microboards for Children person centred planning principles to do so.

'I think one of the things we did especially about formal planning was once we'd consulted with Emma, and she was happy and made the decision about home schooling.'

They were strengthened in their decision by Emma's vision statement.

'I'm really passionate about maintaining that inclusive life and there are times when that becomes more challenging, but I think that it's really important to have that overarching vision.'

The family used a Microboards for Children relationship mapping tool to revisit Emma's social networks and develop strategies for friendships in the local area. They initially struggled to understand how to use Podio, but now they find it invaluable. They use Podio to keep track of possible friends and activities that Emma is interested in.

'Yeah, I think that Podio increases the power of that tenfold just by having someone who's kind of done that framework for you. You are not having to build everything from scratch …'

Podio was also helping Emma and her family to share information with support workers, to track her progress and to find the information they need for Emma's assessments.

'… that was the thing that was of really high value to us, and the communication log has been a really – my daughter's communication this year, her growth in her communication has been the most significant that it's been …'

Emma's choice and control in her life is improving.

'… the most successful thing, certainly that we've personally experienced of late, is the decision-making, allowing her to make the decisions and choices.'

Emma's family especially valued the opportunity to learn from the lived experience of other families involved in the Microboards for Children Project and from the experience of Microboards for Children staff. They intended to start setting up a Microboard for Emma but were cautious about losing parental control. They perceived a Microboard to be a good alternative to guardianship and intended to link the Microboard with a trust fund.

'I know that for a person like Emma with an intellectual disability if we don't leave instructions, she's at risk of being given guardianship even if she doesn't want it. I have grave concerns about that, so that makes us very committed to Microboards Australia.'

Emma's family wanted their role in the Microboard to be at first be central, but they were hoping that Emma's siblings would eventually be part of it. Microboards for Children facilitators were helping them to develop ideas on who they might ask to join the Microboard. They were looking forward to seeing Emma becoming more autonomous and enjoying her life independent of them. They expected that they would need to continue to draw on the support of Microboards Australia and other families in the project.

Discussion

The evaluation sought to discover the impact of the Microboards for Children Project on participating families and, by proxy, their children with intellectual disability. All participating families initially expressed their hopes for their child in terms of self-determination, fulfilment, inclusion and happiness in their present and future lives. The Microboards for Children Project offered families and their children resources, support and a formal structure that could help them to work toward this future. Participants demonstrated that two key aspects of the project helped them and their child with disability to envisage and take steps toward this future. The first of these are the Microboards for Children principles and processes. The second is the support provided by Microboards Australia in the form of online workshops, tools such as relationship mapping and Podio, and the guidance of Microboards for Children facilitators and senior Microboards Australia staff.

Families were geographically widespread and came to the project with differing skills and challenges. The Information Sessions provided most families with confidence in the Microboards for Children Project and what it could offer them and their child. There is evidence in evaluation data that participating parents and their children gained value from learning how to develop a vision statement and using it to assert their child's strengths and to advocate for inclusion. Families were particularly challenged by the difficulties of establishing and maintaining their child's social networks, even more so as they supported their child to transition between schools or leave the school system altogether. One of the project's strengths therefore was in guiding families through relationship mapping and understanding how they and their child could better grow their social networks and feel safe. All families indicated they wanted to help their child to explore choices and increase their sense of control. There was evidence that the project's person-centred philosophy, planning frameworks and communication tools facilitated dialogue between families and their child that encouraged steps toward greater independence.

Whilst there was no obligation on families to establish their own Microboard with and for their child, most families came to appreciate the value of the Microboard structure and processes. Most participants expressed an intention to form a Microboard with and for their child in the future because of the safety and consistency of vision it offered their child as they grew into adulthood. Parents were encouraged by hearing stories of others' experiences of Microboards and by the support offered by the Microboards for Children Project to lay the foundations for a Microboard. Some families had

commenced forming the Microboard structure with assistance from project facilitators, but all needed more time as the evaluation ended. For some families, their limited access to social and economic capital meant they could put little time into learning about Microboards principles and processes and they had little hope of creating a Microboard. These are families whose children's voices are less likely than others to be heard as they transition into adulthood. There needs to be scope within the Microboards for Children Project to respond more specifically to the needs of children of families with lower social capital such as those from other cultures or experiencing economic constraints.

Conclusions/Future Directions

The project aimed to demonstrate the value of a Microboard in safeguarding the life of the child with intellectual disability and complex support needs by building the capacity and skills of families, their child, and others in their lives over time. This evaluation report provides evidence of the positive impact of Microboards for Children principles and processes and the support provided by the project for children with intellectual disability and their families. Evaluation findings suggest that families less well-resourced with formal or informal supports, with limited time and few family or social networks struggled to keep up with the project and instead gained most benefit from hearing about their peers' experiences. Although at the conclusion of the project no participants had formed a Microboard for their child, it is likely that most will do so soon, except for those with limited social or family networks.

Recommendations

1. That the Microboards for Children Project continues to support the currently participating families who recognise the value to their child of a Microboard until such time as they have a functioning Microboard in place.

    This recommendation builds on the benefits acknowledged by participating families and responds to their need for more time to put in place a Microboard with and for their child.

2. That Microboards Australia continues to develop its resources for families of children with intellectual disability and to offer regular workshops structured around principles of vision and planning, relationships, person-centred thinking, and self-determination.

This recommendation acknowledges the quality and consistency of resources offered to families by the project and encourages continued work with the Co-Design Group to further develop resources.

3. That Microboards Australia continues to offer the Microboards for Children Project resources and support to families with children with intellectual disability and complex support needs regardless of their ultimate intention to form a Microboard.

   This recommendation recognises that, whilst the Microboards for Children principles and processes are extremely helpful to families with children with intellectual disability and complex needs, not all families will use the knowledge gained from participating in the project to form a Microboard.

4. That Microboards Australia considers alternative ways of delivering its Microboards for Children material to families with limited opportunity to attend a 2-hour workshop live or watch a video. These may include workshop summaries, pictorial or symbolic presentation of information, or by individual tutorials with families.

   This recommendation considers the difficulties of full participation in the project expressed by families experiencing time pressures.

5. That Microboards Australia varies its approach to teaching parents how to use Podio, providing hands-on support when needed.

   This recommendation reflects participants' feelings of inadequacy and delayed learning of Podio.

6. That Microboards Australia structures into the Microboards for Children Project more opportunities for participants to learn from the experiences of other families and from each other, for example, through online in-person support groups or online sessions dedicated to group discussion

This recommendation builds on participants' enthusiasm for this aspect of the project and expressed desire for more such opportunities.

7.   That the Microboards for Children Project expands its reach and resources to families with children with intellectual disability and complex support needs who have limited social and economic capital. For example, recruiting families through community networks in disadvantaged geographic areas or through migrant support services.

This recommendation considers the pressures for some families to create an inclusive future for their child with intellectual disability and the difference that the Microboards for Children Project could make for these children and families.

References

Bigby, C. (2012). Social inclusion and people with intellectual disability and challenging behaviour: A systematic review. *Journal of Intellectual & Developmental Disability*, *37*(4), 360-374. https://doi.org/10.3109/13668250.2012.721878

Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, *9*(1), 3-26. https://doi.org/10.1037/qup0000196

Carey, E., Ryan, R., Sheikhi, A., & Dore, L. (2022). Exercising autonomy—The effectiveness and meaningfulness of autonomy support interventions engaged by adults with intellectual disability. A mixed-methods review [https://doi.org/10.1111/bld.12464]. *British Journal of Learning Disabilities*, *n/a*(n/a). https://doi.org/https://doi.org/10.1111/bld.12464

Dempsey, I., Keen, D., Pennell, D., O'Reilly, J., & Neilands, J. (2009). Parent stress, parenting competence and family-centered support to young children with an intellectual or developmental disability [Article]. *Research in Developmental Disabilities*, *30*(3), 558-566. https://doi.org/10.1016/j.ridd.2008.08.005

Dezonia, K. (2009). Microboards: an option in life span supports. *The Exceptional Parent*, *39*(11), 30.

Kruithof, K., Ijzerman, L., Nieuwenhuijse, A., Huisman, S., Schippers, A., Willems, D., & Olsman, E. (2021). Siblings' and parents' perspectives on the future care for their family member with profound intellectual and multiple disabilities: A qualitative study. *Journal of Intellectual & Developmental Disability*, 1-11. https://doi.org/10.3109/13668250.2021.1892261

Lee, C., & Burke, M. M. (2020). Future Planning Among Families of Individuals With Intellectual and Developmental Disabilities: A Systematic Review [Article]. *Journal of Policy & Practice in Intellectual Disabilities*, *17*(2), 94-107. https://doi.org/10.1111/jppi.12324

Lee, C. e., & Burke, M. M. (2020). Future Planning Among Families of Individuals With Intellectual and Developmental Disabilities: A Systematic Review. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(2), 94-107. https://doi.org/https://doi.org/10.1111/jppi.12324

Lindahl, J., Stollon, N., Wu, K., Liang, A., Changolkar, S., Steinway, C., Trachtenberg, S., Coccia, A., Devaney, M., & Jan, S. (2019). Domains of planning for future long-term care of adults with intellectual and developmental disabilities: Parent and sibling perspectives. *Journal of Applied Research in Intellectual Disabilities*, *32*(5), 1103-1115. https://doi.org/https://doi.org/10.1111/jar.12600

Microboards Australia. (2016). *What is a Microboard?* Retrieved 15/03/2022 from http://microboard.org.au/what-is-a-microboard/

Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, *41*(5), 313-328.

Stainton, T. (2016). Supported decision-making in Canada: principles, policy, and practice. *Research and Practice in Intellectual and Developmental Disabilities*, *3*(1), 1-11. https://doi.org/https://doi.org.10.1080/23297018.2015.1063447

Stainton, T., Morris, R., Perry, L., & Bahadshah, Z. (2019). The Impact of a Community Microboard Program on Social Capital of Persons with Intellectual and Developmental Disabilities. *Journal of Intellectual Disability Research*, *63*(7), 850-850.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved 27/04/2018 from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Watson, J. (2016). Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability. *Laws*, *5*(1), 6. https://www.mdpi.com/2075-471X/5/1/6

Memorandum

		cc:
To:	Dr Joanne Watson	
	School of Health & Social Development	
	B	
From:	Deakin University Human Research Ethics Committee (DUHREC)	
Date:	29 July, 2021	
Subject:	2021-142	
	Microboards for Children Evaluation	
	Please quote this project number in all future communications	

DUHREC considered the application for this project at its meeting held on 10/05/2021 and found it to comply with the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).

DUHREC has granted approval for Dr Joanne Watson, School of Health & Social Development, to undertake this project from 29/07/2021 to 29/07/2025.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Human Research Ethics Unit immediately should any of the following occur:

·   Serious or unexpected adverse effects on the participants
·   Any proposed changes in the protocol, including extensions of time.
·   Any events which might affect the continuing ethical acceptability of the project.
·   The project is discontinued before the expected date of completion.
·   Modifications are requested by other HRECs.
·   Any complaints are received by the research team, an external HREC or, in the event of overseas research, an external complaints contact. In the case of overseas research, the local complaints contact should be aware that, where appropriate, they can directly contact DUHREC if they are unable to resolve a complaint or would like assistance in resolving a complaint.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).

Please note: if you have indicated that your project will be conducted while COVID-19 restrictions are in place, approval has been granted in line with the current restrictions. It is the responsibility of the principal investigator to remain aware of any changes to the restrictions and in the event that such changes make the approved research non-compliant with the restrictions, to either seek approval for a further modification to the project, or postpone the research until the restrictions are lifted.

Human Research Ethics Unit
research-ethics@deakin.edu.au
Telephone: 03 9251 7123

Human Ethics - Deakin Research Integrity
Tel 03 9251 7123
research-ethics@deakin.edu.au

Melbourne Burwood Campus,
221 Burwood Highway, Burwood, VIC 3125
deakin.edu.au

1

Deakin University CRICOS Provider Code: 00113B

APPENDIX 2

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: *Participant*

Plain Language Statement

Date: 24 August 2021

Full Project Title: Microboards for Children Evaluation

Principal Researcher: Dr Jo Watson

Associate Researcher(s): Associate Professor Angela Dew, Dr Sue Taylor

Microboards Australia is sending this information to you on behalf of Deakin University researchers.

Who is doing this evaluation?

Dr Joanne Watson, Associate Professor Angela Dew and Dr Sue Taylor are evaluating the Microboards Australia 'Microboards for Children' project. Jo, Sue and Angela are part of Deakin University's Disability and Inclusion team. They all have a lot of experience doing evaluations and research with people with disability.

A group of co-researchers with disability will help Jo, Sue and Angela with the evaluation.

Purpose of the research

Deakin University is evaluating the Microboards for Children project. The aim is to see whether learning about a Microboard/Circle of Support principles and processes will help children with disability to reach their goals.

What will it mean for you to be involved?

If you choose to participate in the evaluation, the Deakin researchers and co-researchers will talk with you online or by telephone three times for about 1 hour each time. The first time will be at the start of the project, and the second one will be half way through and the third will be at the end. With your permission we will audio-tape these interviews and have them transcribed into a written format.

The researchers will ask you and your children questions about your involvement in the Microboards for Children project.

If you are a child at the center of a Microboard, the researchers will ask you questions about whether the Microboard has made your life better, and if so in what way. Children will have a family member present during the interviews.

Plain Language Statement & Consent Form Children with Microboards
[2021142]: version n1: [13.04.21]

If you are a family member, the researchers will ask you questions about your expectations, attitudes, experience, and knowledge of the Microboards for Children project. If someone is unable to give consent on their own, a person who knows them well will decide whether or not they will participate on their behalf.

Risks **and potential benefits**

Participating in this evaluation is up to you. The researchers don't think being involved in the evaluation will upset you.But if you do become upset, they will give you the names and numbers of people who can help. You can stop the interviews at any time or take a break. You can decide not to answer certain questions. If you decide you want to participate but then you change your mind about it later, that is ok too. You just have to let the researchers know. You do not have to explain why.

Benefits to the wider community

This evaluation will provide Microboards Australia with information about the Microboards for Children project. This information might mean future Microboards are offered to children with disability and their families and show what might make Microboards for children work better.

Privacy and confidentiality

Any information collected will be kept on password-protected computers, which only Jo, Sue and Angela can use. The information is stored according to Deakin University policy on a Microsoft Teams group which only Jo, Sue and Angela have access to. No child or other participant will be identifiable through this researchor reports on it. We will replace your name with a made-up name so people won't know it is you. Only Jo, Sue and Angela will know who you are and be able to match this to your made-up name.

Withdrawal

Participation is voluntary. You can withdraw from the evaluation at any time.

Complaints

This evaluation has been approved by the Human Research and Ethics Committee of Deakin University. If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

> The Human Research Ethics Office, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 03 9251 7129, research-ethics@deakin.edu.au

Please quote project number [2021-142].

How to get in touch with the researchers

Thank you for thinking about taking part in this evaluation. If you would like to ask questions about being

Plain Language Statement & Consent Form Children with Microboards
[2021142]: version n1: [13.04.21]

involved you can contact: Jo Watson joanne.watson@deakin.edu.au Phone: 03 9251 7189

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Children Participants

Consent Form

Date: 24 August 2021

Full Project Title: Microboards for Children Evaluation

Reference Number: v1

I have read, or have had read to me, and I understand the attached Plain Language Statement.

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of the Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details, including where information about this project is published, or presented in any public form.

Participant's Name (printed) …………………………………………………………………………

Signature ……………………………………………………………… Date …………………………

Please return to:
Dr Jo Watson joanne.watson@deakin.edu.au Phone: 03 9251 7189

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Family member participants

Third Party Consent Form

(To be used by parents/guardians of minor children)

Date: [to be added]

Full Project Title: Microboards for Children Evaluation

Reference Number: v1

I have read, or have had read to me, and I understand the attached Plain Language Statement.

I give my permission for .... (name of participant)
to participate in this project according to the conditions in the Plain Language Statement.

I have been given a copy of Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details or the identity and personal details of the person for whom I am providing consent, including where information about this project is published, or presented in any public form.

Participant's Name (printed) …………………………………………………

Name of Person giving Consent (printed) ……………………………………………………

Relationship to Participant: ……………………………………………………

Signature …………………………………………………………   Date …………………………

Please return to:
Dr Jo Watson joanne.watson@deakin.edu.au Phone: 03 9251 7189

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Family members of children with microboards

Consent Form

Date: [to be added]

Full Project Title: Microboards for Children Evaluation

Reference Number: v1

I have read, or have had read to me, and I understand the attached Plain Language Statement.

I have been given a copy of Plain Language Statement and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details or the identity and personal details of the person for whom I am providing consent, including where information about this project is published, or presented in any public form.

Participant's Name (printed) …………………………………………………

Focus Child's Name: …………………………………………………

Signature …………………………………………………   Date …………………………

Please return to:
Dr Jo Watson joanne.watson@deakin.edu.au Phone: 03 9251 7189

PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Participants

Withdrawal of Consent Form

(To be used for participants who wish to withdraw from the project)

Date:

Full Project Title: Microboards for Children Evaluation

Reference Number: v1

I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT affect my relationship with Deakin University *or Microboards Australia.*

Participant's Name (printed) ………………………………………………….

Relationship to Focus Child (child, family member, community member): ……….……………………………………

Signature ……………………………………………………………….Date ……………………

Please email this form to:

Dr Jo Watson joanne.watson@deakin.edu.au Phone: 03 9251 7189