

Centre for Community Child Health



Evaluation of Plumtree Children's Services' *Now and Next* program

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The Centre for Community Child Health is a research group of the Murdoch Children's Research Institute and a department of The Royal Children's Hospital, Melbourne.

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Glossary and definitions

ADHC	Ageing, Disability and Home Care
AHS	Adult Hope Scale - A 12-item measure of a respondent's level of hope.
Book creator	E-book tool used in the program to record goals and document and share child and family progress. This tool is collaborative and incorporates audio and video.
IEP/ILP	Individual education plan/Individual learning plan
IFSP	Individual family service plan
MCRI	Murdoch Children's Research Institute
NANA	<i>Now and Next</i> Alumni who continue to meet face to face and through various technology-based mechanisms in order to inform, support and motivate each other.
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
Now and Next™	An 8-week program developed by Plumtree for families who have a child with a developmental delay or disability.
PCOMS	Partners for Change Outcomes Management System to measure participant outcomes.
Peer facilitator	Trained parents who facilitate the Pictability™ vision setting tool and the <i>Now and Next</i> program. All peer facilitators have been participants in the <i>Now and Next</i> program.
PERMA Profiler	Questionnaire that measures the five pillars of wellbeing (positive emotion, engagement, relationships, meaning, accomplishment), along with negative emotion and health.
Pictability™	A game-like vision-setting tool developed by Plumtree that encourages parents to think about inspiring vision for their child and family and set goals.
PES	Psychological Empowerment Scale - a validated 32 item questionnaire that measures psychological empowerment for parents of children with a disability.
The Centre	Centre for Community Child Health
RCH	Royal Children's Hospital, Melbourne

Executive Summary

Background to the project

Now and Next is a group program developed by Plumtree that helps parents and carers of young children with a disability or developmental delay cultivate skills to achieve positive outcomes for their child, family and self. It teaches families about setting goals and provides them with opportunities to connect with other families to inform, support and motivate each other to aim high and see new opportunities for their child now and in the future.

Plumtree delivered the *Now and Next* program between January 2017 and June 2018 as part of the 'Building Capacity in Families of Young Children with Disability: A Family Leadership Project' which was funded by ADHC, Department of Family and Community Services and the NDIA for an Information, Linkages and Capacity Building (ILC) transition project.

Background and purpose of the evaluation

The Centre for Community Child Health (the Centre) at Murdoch Children's Research Institute (MCRI) was commissioned by Plumtree to undertake a process and outcomes evaluation of the *Now and Next* program. The evaluation looked at data for the 15 *Now and Next* groups that were run between January 2017 to March 2018 and involved 154 families of young children birth to eight years old who have disabilities or a developmental delay.

The purpose of the evaluation was to examine the *Now and Next* program and identify participant outcomes to inform decision-making about the future strategic direction and implementation of the *Now and Next* program. The evaluation used a mix of qualitative and quantitative methods to undertake both a process and outcomes evaluation of the *Now and Next* program. The process evaluation looked at whether the *Now and Next* program had been delivered as intended, if it was reaching the target groups and how participants rated the program. The outcome evaluation looked at participant outcomes, in particular, if participants had achieved their short-term goals, whether participants had become empowered and if participant sense of hope or wellbeing had grown. Data was collected by the program through online surveys at the beginning and end of the program and during the program by the peer facilitators of the *Now and Next* program using a participatory action research approach.

An additional research project undertaken by the Centre for Disability Studies at Sydney University documented case studies of the peer workers. This research is reported separately to the present evaluation.

Findings

The process evaluation found that *Now and Next* program had been delivered to the target group of parents and carers of young children with a disability or developmental delay. The evaluation also found and that the program had been delivered as intended with comprehensive and systematic documentation of the sessions for use by peer facilitators and real-time monitoring of participant feedback incorporated into the program for continuing improvement. Due to the iterative nature of the program, new concepts were tested over the evaluation period. This included delivering the Pictability vision and planning session as a group rather than individually, and trialling new measures to monitor participant outcomes.

The program had high levels of attendance from participants with an average attendance rate across all 15 groups of 79.9% over the eight-week program. The groups had strong levels of participation from culturally and

linguistically diverse families (who made up 59.1% of participants) as well as from fathers (who represented 20.8% of participants).

The evaluation found the program was highly successful in providing all parents with the experience of developing and achieving short-term goals. Data was collected on the goals participants chose to address during the program: A total of 134 child goals, 137 family goals and 117 personal goals were recorded. More than nine in ten participants achieved all three of the goals that they set. Of the thirteen parents that did not achieve all three of their goals, ten achieved two of their goals and three achieved one of their goals.

The evaluation also found that the program was successful in empowering parents and growing participants sense of wellbeing. Matched participant data that was available for a subset of participants showed statistically significant increases in participants' empowerment, sense of hope and wellbeing at the end of the program relative to the start of the program. Other participant measures are indicating that the program is also increasing participants' sense of agency.

Recommendations for further areas of research

Now and Next has a number of unique features that warrant further investigation. Possible research studies include:

- Further trials of the outcomes of the *Now and Next* program in different sites and populations.
- Tracking one or more cohorts of parents over time to see what the long-term effects are, and whether the short-term gains found in the present evaluation are sustained.
- Comparison with other programs and pathways. It would be valuable to compare outcomes for those who enter the NDIS after a *Now and Next* experience with those who go through the standard pathway.
- Determining which of the key features of *Now and Next* are the key ingredients for the effectiveness of the program will require further experimentation and research.
- Exploring the timing of program in relation when parents engage with professionals.

Implications for policy

In contrast to current early childhood intervention services, *Now and Next* focusses on building family capacity using new approaches that are peer-led, provide connection with other families, focus on empowerment, agency and wellbeing and emphasise a whole family approach.

The *Now and Next* program demonstrates the power of parent-to-parent support when properly structured and facilitated. For parents of young children with developmental disabilities, such support can be beneficial in a variety of ways: in helping them clarify their goals for their children, families and themselves; in promoting their personal capabilities to meet these needs; in fostering a positive and constructive approach to the challenges they face; and in contributing to their general well-being. These are goals that early childhood intervention services around the world aspire to, so the *Now and Next* program offers a program for achieving those goals with families who have young children with developmental disabilities or delays. The current evaluation has shown that the program is also effective with non-English speaking groups, suggesting that the program could have widespread potential.

The program could also serve as a template for other forms of parent-to-parent support services. From the evidence of the present evaluation, the key features to include when designing such programs include that they are co-designed with and facilitated by parents, use a structured format addressing the particular challenges the parents are facing at that stage, and are based on positive psychology and strength-based frameworks.

Implications for policy in the NDIS environment

The *Now and Next* program offers a highly promising model that could serve as an adjunct to the existing NDIS pathway or be incorporated into it. At the time they first encounter the NDIS system, parents of young children with developmental disabilities are likely to be at their most vulnerable and unsure of what they need. If parents had experience of the *Now and Next* program before they meet with NDIA or early childhood partners, they would be much clearer about their short- and long-term goals, and much more confident about their ability to achieve at least some of these by themselves. This would equip parents to negotiate service plans that have clear focus on the outcomes they want to achieve, rather than the services that professionals offer.

International implications

Due to the lack of comparable programs internationally, the *Now and Next* program has potential to be trialled and adopted in overseas settings. Whilst outside the scope of this evaluation, it is noted that the *Now and Next* program was trialled in British Columbia, Finland and New Zealand in 2018.

Introduction

Background to the project

In readiness for the introduction of the National Disability Insurance Scheme (NDIS), Ageing, Disability and Home Care (ADHC) funded several organisations to deliver capacity building for individuals under the Getting Prepared initiative 2016-2018. However, none of the projects specifically targeted families of young children birth to 8 years old who have disabilities or developmental delay. Plumtree submitted a successful proposal to the NSW Department of Premier and Cabinet to implement a capacity building project targeting families with children in this age group who have disabilities or developmental delay. The proposal built on the *Now and Next* program, developed by Plumtree in 2015 utilising block funding from ADHC. The *Now and Next* program was designed to deliver services which provide capacity building and decision supports to families who have a young child with disability or developmental delay.

In December 2016, funds were provided by, ADHC, Department of Family and Community Services and the NDIA for an Information, Linkages and Capacity Building (ILC) transition project to Plumtree, in order to deliver the project 'Building Capacity in Families of Young Children with Disability: A Family Leadership Project'. The project commenced January 2017 and finished in June 2018. Project deliverables included:

- Delivering the *Now and Next* program to 150 families in New South Wales.
- Identifying and training 10 family leaders who would receive training to facilitate the Pictability vision setting tool and the *Now and Next* course, as peer workers.
- Building on the evidence base of the *Now and Next* program by researching outcomes using a participatory action research approach.

Background to the evaluation

Funding for research and external evaluation was included and approved as part of the project funding. The Centre for Community Child Health (the Centre) at Murdoch Children's Research Institute (MCRI) was commissioned by Plumtree to undertake a process and outcomes evaluation of the *Now and Next* program. The evaluation looked at the data for groups which were held January 2017 to March 2018. The program continued to be delivered until the end of June 2018, but later groups could not be included due to the timeline of the evaluation.

The purpose of the evaluation was to examine how *Now and Next* program was being delivered and to identify participant outcomes in order to inform decision-making about the future strategic direction and implementation of the *Now and Next* program.

Main evaluation questions

The evaluation involved both process and outcomes evaluation methodologies. Process evaluations examine the way in which a program is delivered, whereas outcomes evaluations look at the *effects* that the program has on recipients of the program. The process evaluation looked at whether the *Now and Next* program had been delivered as intended, if it was reaching the target groups and how participants rated the program. The outcome evaluation looked at participant outcomes, in particular, if participants had achieved their short-term goals, whether participants had become empowered and if participant wellbeing had grown.

The specific questions addressed by process evaluation were:

- Whether the program is reaching the intended target groups.
- Whether the program is being delivered as intended.
- How participants rated the program sessions.

The outcome evaluation looked at the following participant outcomes:

- The extent to which parent participants achieve the goals they formulated.
- The extent to which parent participants become empowered.
- The extent to which parent participants' wellbeing improved

Report structure

The report outlines the evaluation methodology, including the approach, data sources and limitations of the evaluation. It then provides a description and analysis of the *Now and Next* program including the program logic and analysis of the administrative and program data (process evaluation). An analysis of participants' outcomes is then presented. The discussion section considers the active elements of the program and recommendations for further areas of research. Implications for policy in the NDIS environment are also outlined.

Evaluation methodology

The evaluation used a mix of qualitative and quantitative methods to undertake both a process and outcomes evaluation of the *Now and Next* program. Data sources included a desktop review of *Now and Next* documentation, qualitative analysis of participant feedback and quantitative analysis of program and participant data.

Evaluation approach

This evaluation is underpinned by a participatory evaluation approach that has involved stakeholders of the program in all aspects of the evaluation process. It also employs utilisation focused evaluation to align the purpose and values of the evaluation to those of key stakeholders and ensure that evaluation results are meaningful and will be used.

Ethics

Plumtree have implemented an internal ethics process which provides all participants of the *Now and Next* program with an Information Sheet and Permission Form to gain their informed consent to collect data for research and evaluation purposes. MCRI assessed the evaluation as a Quality Improvement project not requiring RCH Ethics Approval because the primary purpose of this evaluation is to monitor or improve the quality of service delivered by an individual or organisation. The evaluation has been registered on the Policy and Service Development Quality Improvement Register and all protocols relating to Quality Improvement projects have been adhered to.

Evaluation framework

Table 1 outlines the evaluation questions, indicators and data collection tools used in the process and outcome evaluation. Sample sizes for each of the data collection tools is also listed.

Table 1: Evaluation framework

Evaluation question	Indicator/s	Data collection tool and <i>timing</i>	Sample
Process evaluation questions			
Program uptake: Is the program reaching the target groups?	Number of participants from target group. Dropout rate session attendance.	Attendance records. <i>Collected throughout program.</i>	All NN participants (n=154)
Has the program been delivered as intended?	Number of activities and sessions delivered.	Document and agenda review and reflections from program staff.	
How did participants rate the program?	Participant rating – relationship (with facilitator and group); goals and topics; approach or method and overall feedback.	GSRs [PCOMs] Participants’ feedback scales. [Appendix 2] <i>Collected at the end of each session.</i>	NN5, NN6 and NN7 (n=46-31)
Objective 1: Parent participants achieve the goals they formulate			
In what ways did Pictability assist parents set a vision for their child and family?	Parents answer Pictability questions.	Interview questions. [Appendix 1] <i>Collected after the Pictability session.</i>	NN3 and NN7 (n=58)
Did the program support participants’ achieving their goals?	Goals are recorded and scored Agency is discussed and self-scored.	“Mission Control” tool spreadsheet. [Appendix 3] <i>Collected throughout sessions and recorded as soon as goals are achieved. Agency scoring at session 7.</i>	All NN participants (n=154)
What concerns do participants report?	Parents list their concern.	These concerns are then typed up and included in the dataset. [Appendix 3] <i>Collected at session 4.</i>	All NN participants (n=154)
What learning do participants take “moving forward”?	Parents note their learning on posters.	These learning are typed up and included in the dataset. [Appendix 3] <i>Collected at session 8.</i>	NN3 to NN7 (n=143)
Objective 2: Parent participants become empowered			
Are participants growing agency in relation to achieving progress for their children	1. Parents’ reports about their increase in agency scored as a single self-report question.	1. in Group setting and discussion. <i>Collected at session 8.</i>	1. NN4 to NN7 (n=66)
	2. Parents’ reports about their agency before and after program.	2. With AHS following learning about agency (as 1 above). [Appendix 6] <i>Before and after the NN program via online survey.</i>	2. NN7 (n=10)
Are participants feeling empowered as a result of having done the program?	Participants’ feel empowered.	Psychological Empowerment Scale for Families of Children with disability. [Appendix 4] <i>Before and after the NN program.</i>	NN6 and NN7 (n=31)
Objective 3: Parent participants’ wellbeing grows			
Is participants’ wellbeing increased as a result of having done the program?	Participants’ wellbeing scores.	PERMA online questionnaire. [Appendix 5] <i>Before and after the NN program.</i>	NN6 and NN7 (n=22)
What outcomes do participants experience during the program?	Participants’ self-report on individual, interpersonal, social and overall engagement.	Outcome Rating Scale [PCOM]. See Appendix 2 <i>Before each session.</i>	NN5, NN6 and NN7 (n=51-34)

Data collection

Data was collected through online surveys at the beginning and end of the program and during the program by the peer facilitators of the *Now and Next* program using a participatory action research approach. Data was collated in a Google spreadsheet, ensuring that identifiers (such as name) were removed and replaced by a separate code for each participant to ensure confidentiality but to allow individual participants progress to be tracked over the program.

Data related to attendance, participants goals, concern's participants report and learnings participants take moving forward was collected from all groups (n=154). Due to the iterative nature of the program, it trialled and adopted measurements that could capture participant outcomes that program facilitators were observing over the evaluation period. Measurements of empowerment, agency and wellbeing were added to the battery of tests and are only available for a subset of participants. Program impact and participant outcome measures were also introduced during the evaluation period, with a subset of participants completing the Partner in Outcomes Measures Scales (PCOMs) by Duncan and Reese (2015).

Now and Next program

Introduction¹

Recent changes in the disability sector have highlighted the need for families to have well-developed knowledge, skills and capacity in order to take on a greater role in supporting their child who has a disability or delay. The *Now and Next* program provides an evidence-based mechanism and resources to develop the capacity of families who have very young children with disabilities and delays in their development.

The *Now and Next* program provides a greater focus on the role of families in participating as partners in early childhood intervention by engaging them at the earliest possible time. During this early period, families can become intensely focused on gathering information, finding and then engaging services, in an effort to maximize benefit for their child. Many families look to increased therapy services instead of recognizing that the single most significant impact on the child is the family (Mahoney and Perales, 2011). They may take years to see the importance of investing in their own capacity and even then, learning how to do this is an ad hoc process and resources to assist them are scarce. The *Now and Next* program provides a mechanism and resources to engage families at the point of early intervention to:

- Help them develop their inspirational long-term vision for their child;
- Assist them to build skills to achieve positive outcomes for their child and family, whether these families will be eligible for the NDIS or not;
- Benefit child and family well-being;
- Build a sustainable peer-support mechanism.

While some capacity building initiatives are provided by advocacy organisations, these do not specifically target families of young children. By integrating family capacity building activities within early childhood intervention services the *Now and Next* program has shown that targeted, intentional programs can reach this population. It is in the long-term interest of families that they have multiple opportunities for capacity building from the earliest possible point as this will lead to better outcomes for the child and family as a whole.

The *Now and Next* program also cultivates family leadership and peer networks. As defined by Murray (2011), family leadership 'is based on the premise that families are the experts in their own lives and demands that the main function of support agencies is to increase their resilience.' Family leaders are identified throughout the service delivery process and provided with training so that they are able to conduct planning and workshop facilitation as paid peer workers. Building this leadership pipeline is an important and demonstrated mechanism to recruit peer facilitators who will increase family presence and contribute to a stronger peer network for this age group and this has the potential to create the impetus for social movement led by families (Kendrick, 2010).

¹ The introduction was sourced and copied from the 2018 *Now and Next* Evaluation Plan.

Program elements

The *Now and Next* program has 3 elements:

1. An evidence-based **eight-week group program** (2.5 hours each week). This also includes an individual vision and planning session prior to course commencement and an online peer network for the duration of the course. Through this program, families build their agency, family leadership and collective capacity as a group. Between sessions, families interact in the social media space that they create for this purpose, so that they are in touch regularly between sessions. **The 8-week program and vision/planning session is the subject of this evaluation.**
2. The group also serves as a leadership pipeline where families who demonstrate leadership capacity and interest are identified, recruited, trained and employed to fulfil a range of roles including delivery of the group program. Ongoing training and support is provided to the peer facilitators through a number of strategies, both through individual coaching and group learning. The leadership pipeline is outside the scope of this evaluation.
3. Once families have completed the group program, they join the ***Now and Next Alumni (NANA) Network*** which provides an ongoing mechanism for peer support amongst families who now share a common experience and understanding. This process is designed to enhance the impact and sustainability of the outcomes achieved during the original 8-week program. Plumtree is incubating this social movement to harness the collective capacity of families at the earliest possible point in the families' experience. The leadership pipeline is outside the scope of this evaluation. The NANA network is outside the scope of the current evaluation.

Pictability vision and planning session

The program begins with an individual vision and planning session where families use Pictability, a game-like, visual tool that encourages them to think about an inspiring vision for their child and family. Pictability aims to provide a strengths-based planning experience based on positive psychology that enables families to imagine possibilities for their family and child, by including goals that are important to the whole family. This is important as the process is structured so that the family think and plan beyond a focus only on goals for their child. Consequently, families generate a holistic plan which extend their focus to areas other than traditionally early childhood intervention services such as therapy.

During 2018 the program trialled a group Pictability vision and planning session. The reasons for trialling group Pictability was that expanding the program to regional NSW led to the creation of an individual kit which was successful and consequently, adopted as a permanent improvement. The primary benefit of individual kits was that families could keep their own Pictability for subsequent planning opportunities as needed. With each individual having their own kit, it became possible to deliver Pictability in a group environment which offered parents the opportunity to share ideas and make connections.

Eight-week program

The manualised eight-week (2.5 hours each week) program aims at building family agency, leadership and collective capacity as a group. The evidence-based curriculum is rooted in positive psychology and family-centred practice. *Now and Next* uses technology (e-book) and mindfulness exercises to empower families with new knowledge about formulating and achieving goals as well as start fresh conversations with professionals. The program uses gamification to disrupt negative experiences and to deeply engage with families in mindfulness experiences along with fun and collaborative work, which are based on adult learning principles. Between sessions, families interact in the social media space that they create for this purpose. Table 2 provides an outline of content covered in the eight *Now and Next* sessions.

Table 2: Overview of eight-week program

Session 1:	Introduction. Visioning session to define family goal, child goal and personal goal. Focus on setting family goal and ‘creating memories’ mindfulness exercise.
Session 2:	Setting long-term child goals. Setting short-term child goals to match what we want to achieve in the future, with small steps to mark and celebrate progress.
Session 3:	Identifying our signature strengths and using them to achieve our goals. Reviewing progress on child goals.
Session 4:	Circle of Control – Circle of Influence (“Letting go worries” data), i.e. discussion of what participants need to ‘let go’, because of the things and events that cannot be controlled to focus on what can be influenced.
Session 5:	Understanding the mind-shift we experience as we become empowered. Setting long-term personal goals and short-term personal goals to match what we want to achieve in the future, with small steps to mark and celebrate progress.
Session 6:	Working with Professionals – partnership models with professionals, agency, roles and responsibilities.
Session 7:	Wellbeing and flourishing – what matters and the importance of self-care.
Session 8:	Recapping what we learnt and reviewing our next steps (“Moving forward” data).

Program development

Now and Next has been co-designed with families and has evolved over time. To understand the development of the program, *Now and Next* has developed a numbering system by which cohorts are numbered to track different iterations of the program and provide a way in which to test, embed and track learnings. A total of 19 different groups have been run (from NN1 to NN7) with 274 participants.

Figure 1: *Now and Next* cohorts and timeline

Cohort	NN1	NN2	NN3	NN4	NN5	NN6	NN7
Timing		August 2016	Term 1, 2017	Term 2, 2017	Term 3, 2017	Term 4, 2017	Term 1, 2018
Group characteristics	Evaluation period						
Number of groups (total participants)			4 groups (n=60)	3 groups (n=37)	3 groups (n=22)	3 groups (n=17)	2 groups (n=18)
Groups run in community languages			Vietnamese		Arabic, Korean	Vietnamese	
Regional groups						Hunter	
Delivery characteristics			Group format of 8 sessions trialled and adopted				
Now and Next sessions	individual sessions						
Pictability vision & planning session	individual - facilitated by professional	Individual - facilitated by peer worker					Group session
Outcomes Measurement					Agency		
					PCOMS		
						PERMA	
						Empowerment	
							Adult Hope Score

The first cohort, NN1, piloted general ideas in a format known to the early intervention sector: a staff meets with a parent in the parent’s house to get to know the family and child in their natural environment. Parents commented about their experience as being very positive, but they still reported feeling of isolation to the staff they were working with. After a year of the NN1 format, a group format of 8 sessions lead by staff was trialled (NN2). The program reported that parents attending this group were visibly thrilled about meeting other parents, reported a feeling of community and noted that they provided significant peer support to each other. Some parents even reported these meetings as “life-changing”.

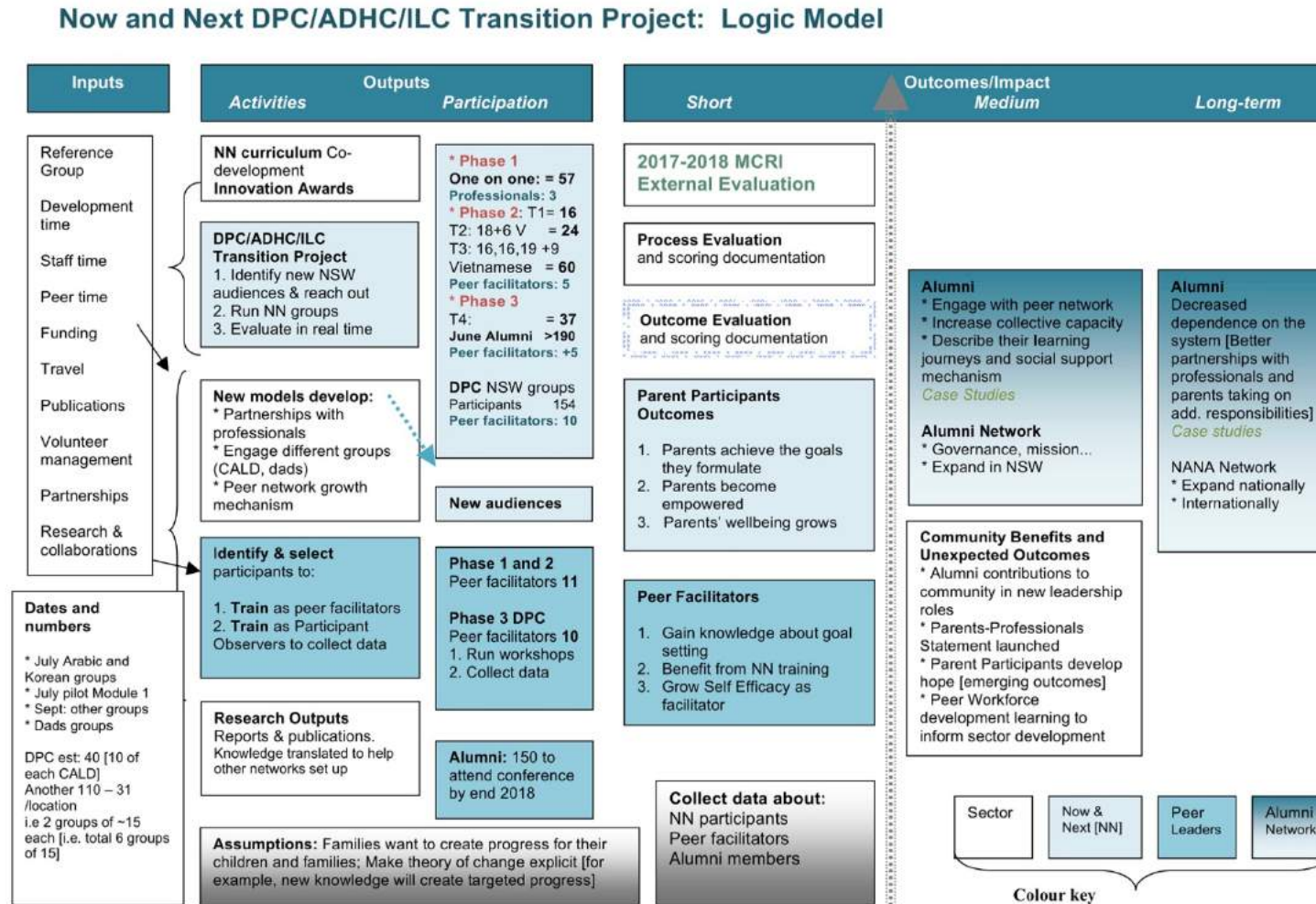
A significant shift in the program was to extend the concept of peer support to include capacity building and provide parents with the opportunity lead the program as peer workers. Between August 2016 and June 2017, some 194 families participated in the program, which was led by both peer family facilitators and professionals. When the program was offered in early 2017, it was led solely by peer facilitators.

Other concepts that were tested over the evaluation period included delivering the Pictability vision and planning session as a group rather than individually, developing a Pictability kit which would be owned by families, program sessions were improved using co-design with the peer facilitators, expanding the program to regional NSW, and trialling new measures to monitor participant outcomes. Measurements of empowerment, agency and wellbeing were added to the battery of tests over the evaluation period.

Program logic

A program logic was developed in August 2017 (Figure 2) which describes the project inputs and outputs (activities and participation) and short, medium and long-term outcomes. For the purposes of this evaluation, only the short-term outcomes will be included and measured.

Figure 2: Now and Next Program Logic



Process Evaluation

Findings from process evaluation are based on information collected from a desktop review of program documentation and reflections from key stakeholders.

Program uptake: Is the program reaching the intended target groups?

Over the evaluation period (January 2017 to March 2018), 154 parents and carers participated in 15 *Now and Next* groups. More than half of participants (59.1%) were from culturally and linguistically diverse (CALD) backgrounds. CALD participants spanned 30 different ethnic backgrounds, with higher participation rates noted for the following CALD groups: Vietnamese (11.0%), Chinese (9.7%) and South Korean (5.2%). Of these participants, 122 were female (79.2%) and 32 were male (20.8%). Engagement of fathers grew at Alumni events. Fathers represented 30.8% of participants at the NANA conference in 2017 and 31.3% of participants at the NANA conference in 2018.

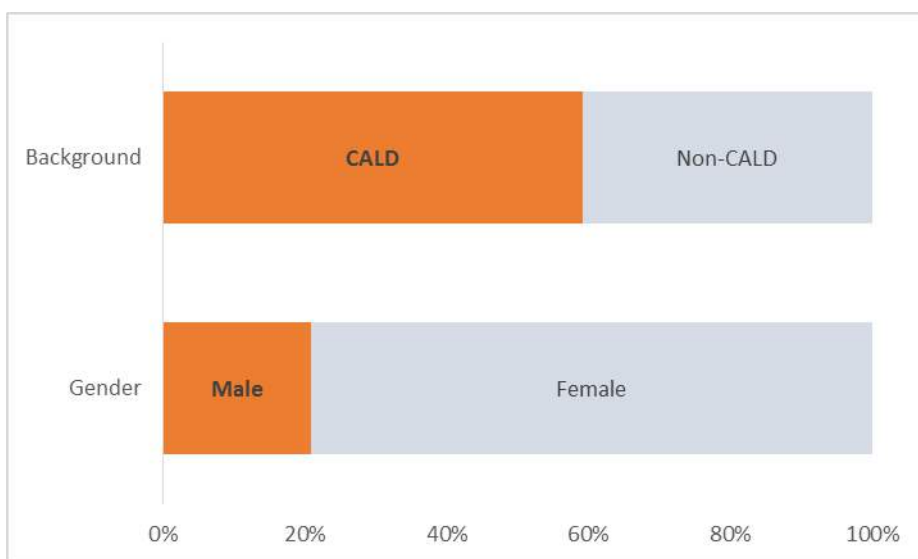


Figure 3: Participants by gender and ethnic background (n=154)

The 15 *Now and Next* groups varied in size, between 19 and 4 participants, with a median of 11 participants. Other group characteristics were:

- Four groups were run in community languages including: Vietnamese (2), Arabic (1) and Korean (1). The remaining 11 groups were run in English, but were attended by families from a range of CALD backgrounds.
- The Korean speaking group was a pilot that ran for four weeks. The other 14 groups ran for 8 weeks.
- One group was run in the regional area of Hunter region. The other 14 groups were run in metropolitan Sydney at Plumtree Children’s Services in Marrickville. Groups were offered on a range of days and evenings - typically, a weekday, a week night and a Saturday.

- 11 groups had a mix of male and female participants, with the remaining four groups having all female participants.

Participation rates

The *Now and Next* program is run over 8 sessions. More than eight in ten participants attended five or more sessions. The average attendance rate across all 15 groups was 79.9%. Average attendance at individual groups varied between 62.5% and 94.5%.

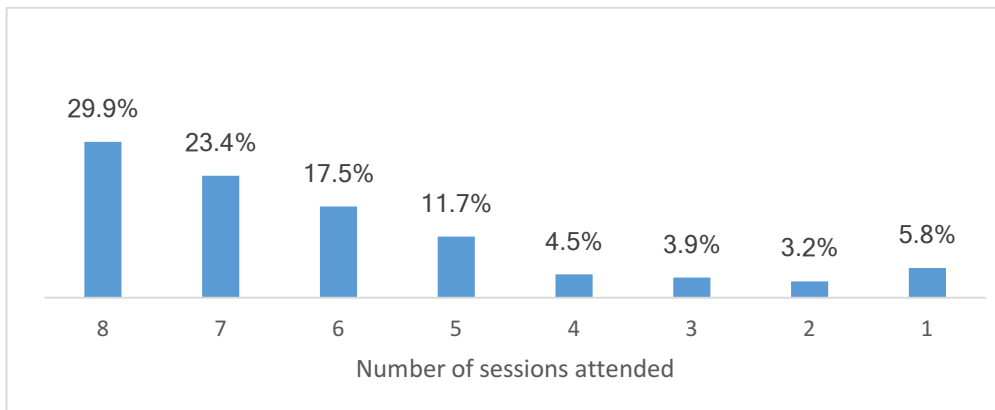


Figure 4: Number of sessions attended (n=154)

Has the program been delivered as intended?

Plumtree delivered the *Now and Next* program between January 2017 and June 2018 as part of the ‘Building Capacity in Families of Young Children with Disability: A Family Leadership Project’. During this period, it was proposed that the *Now and Next* program would be delivered to 150 families and that sites could be distributed in a range of areas in NSW. The evaluation found and that the program had been delivered as intended, and highlighted the following:

- Due to the iterative nature of the program, new concepts were tested over the evaluation period. This included delivering the Pictability vision and planning session as a group rather than individually, and trialling new measures to monitor participant outcomes.
- Three regional areas were targeted to run the *Now and Next* program: Hunter (Hunter Prelude), Dubbo (Orana Early Childhood Intervention) and Lismore (Summerland). All three organisations engaged and agreed to host a group in Term 4, 2017. Plumtree provided support to advertise and recruit participants from their regions. Only the Hunter group had sufficient recruitment numbers to proceed with hosting *Now and Next* in term 4 2017.
- The *Now and Next* program has been delivered by Peer facilitators only since the beginning of 2017. Ongoing training and support is provided to the peer facilitators through a number of strategies, both through individual coaching and group learning. *Now and Next* have engaged the Centre for Disability Studies at Sydney University to undertake research into the experience of peer facilitators and the efficacy of the use of peer facilitators in aiding service provision at Plumtree. This will be available in later in 2018.

How did participants rate the program?

For each session of the program, participants from NN5 to NN7 groups (n=57) completed the Partner in Change Outcome Measures (PCOMs). Participants' ratings provided facilitators with feedback so that they could tailor support to suit their needs during the program. PCOMs uses two brief scales:

1. The PCOM scales administered **before** the session begins is called the "Outcome Rating Scale" (ORS) and measures participants' perception of the **programme effectiveness**. The results of the ORS are discussed below and again in: Outcomes for participants - Parent Participants' Wellbeing Grows.
2. The PCOM scales administered **after** the session ends is called "Group Session Rating Scale" (GSRS) and it measures **session feedback**.

How *Now and Next* uses PCOMS to monitor participant progress

PCOM measures are analysed in real time, so that the program can bring issues up with participants as they are reported. For instance, if a participant's scores decreased on one of the ORS items, the program coach would discuss with facilitators how to approach the participant to discuss with them what they need and how *Now and Next* can provide this - or alternatively, they may need the facilitator to refer them to other agencies. Likewise, if a participant's scores decreased on one of the GSRS items, the program coach would discuss with facilitators what might have occurred during the session to explain the score and how to remedy for the next session.

As part of their Professional Development, facilitators are trained to:

1. Follow participants' ORS to ensure they are indeed showing an **increasing trend** session after session; and
2. Closely **monitor potential decreases in ORS** - if a participant's outcome decreases two sessions in a row, this was the signal to talk to this participant individually.

Facilitators were required to review results during the session if possible or immediately after the session as part of their debriefing. Facilitators would then follow up with any of the participants if needed as soon as possible but before the next session.

PCOMs provides a fast and structured way of embedding participant feedback into the program. The protocol of the PCOMs aims to keep participants engaged, however, it is noted that data is only collected from those that are present in the group who will generally have a higher level of engagement.

Outcome Rating Scale (ORS)

At the beginning of each session, participants rate (on a scale of 1 to 10) how they feel in relation to their participation in the group on four levels: individual level (personal wellbeing); interpersonal level (family, close relationships); social level (work, school, friendships); and overall (general sense of wellbeing). Table 3 summarises the average ORS scores for each session. It shows that scores generally increased, session after session, over the course of the program, with the exception of session 5 where scores decreased slightly, then increased for the remainder of the program.

Table 3: Average ORS for each session (measuring participants' perception of programme effectiveness)

Groups/Sessions	Pre-Session PCOM survey results				
	Individually	Interpersonally	Socially	Overall	Total
Session 1 (n=51)	6.5	6.3	5.6	6.7	26.8
Session 2 (n=48)	7.0	6.7	6.8	7.3	27.9
Session 3 (n=47)	7.4	7.4	7.0	7.5	28.9
Session 4 (n=42)	7.6	7.8	8.0	8.0	31.0
Session 5 (n=37)	7.7	7.6	7.8	7.8	31.0
Session 6 (n=42)	8.1	8.1	8.0	8.2	32.5
Session 7 (n=29)	8.4	8.2	8.2	8.5	33.2
Session 8 (n=34)	8.6	8.6	8.4	8.6	34.3

At the end of each session, participants used the Group Session Rating Scale (GSRS) to rate (on a scale of 1 to 10) how they felt about: their relationship (with the facilitator and the group); the goals and topics that were part of each session's program; the approach or method used in each session; and an overall feedback score. Table 4 summarises the average GSRS for each session. It shows that scores generally increased, session after session, over the course of the program, with the exception of session 5 and 6 where scores decreased slightly, then increased for the remainder of the program.

Table 4: Average GSRS for each session (measuring participants' session feedback)

Groups/Sessions	Post-Session PCOM survey results				
	Relationship	Goals and Topics	Approach or Method	Overall	Total
Session 1 (n=46)	9.0	8.5	8.4	8.7	34.7
Session 2 (n=44)	9.0	9.0	9.0	9.0	36.1
Session 3 (n=43)	9.2	9.1	9.2	9.2	36.7
Session 4 (n=41)	9.4	9.2	9.3	9.4	37.2
Session 5 (n=37)	9.2	9.1	9.3	9.4	35.8
Session 6 (n=42)	9.1	9.1	9.3	9.1	36.5
Session 7 (n=31)	9.6	9.5	9.5	9.5	37.2
Session 8 (n=34)	9.5	9.5	9.5	9.6	38.1

The process evaluation found that *Now and Next* had been delivered to the target group. The evaluation also found and that the program had been delivered as intended with comprehensive and systematic documentation of the sessions for use by peer facilitators and real-time monitoring of participant feedback incorporated into the program for continuing improvement. The next section looks at participant outcomes.

Outcomes for participants

The outcome evaluation looked at three sets of participant outcomes that *Now to Next* was designed to achieve: the extent to which parent participants achieve the goals they formulated, the extent to which parent participants become empowered, and the extent to which parent participants' wellbeing improved. The focus on participant outcomes differs from many initiatives that emphasise service outcomes.

Objective 1: Parent participants achieve the goals they formulate

Through participation in the Now and Next program, parents are supported to 1) learn about formulating and 2) achieve goals for their child, their family and themselves.

Did the program support participants' achieving their goals?

The *Now and Next* program supports parents to formulate and achieve goals for their child, their family and themselves. Parents learn how to break down long-term aspirational goals into short-term achievable objectives through a coaching approach. Goal setting processes used in the program include:

- Individual visioning session using Pictability to help families to see new possibilities and set goals. Previous research has shown that although families are encouraged to set family goals, they prioritise child goals. The Pictability process deliberately leads families to select a goal for themselves, their family and their child, thus creating a balance from the start through a design approach. At the conclusion of the visioning activity, peer facilitators assist participants to understand how to link a goal for their child to an outcome. Parents are engaged in active learning mode about setting and achieving goals.
- In group sessions, families are invited to work on one goal for themselves, one for their family and one for their child to help them to experience success through targeted and achievable pathway thinking and a coaching approach. Each session starts with small group discussions reflecting on the participants' progress towards achieving their goals. They allow participants the opportunity to review their goals, strategise in depth, and celebrate each goal achieved.
- Families are provided with tools and strategies to support goal achievement such as the Goal 2 Action template and identifying and using character strengths.

The program was successful in providing all parents with the experience of developing and achieving short-term goals. Table 5 provides summary data on the goals participants chose to address during the program. A total of 134 child goals, 137 family goals and 117 personal goals were recorded. More than nine in ten participants achieved all three of the goals that they set. Of the thirteen parents that did not achieve all three of their goals, ten achieved two of their goals and three achieved one of their goals.

Table 5: Overview of goal achievement during the program

	Family goals	Child goals	Personal goals
Goal achievement %	95.4%	96.3%	95.7%
Number of goals achieved	131	129	112
Number of goals did not achieve during program	6	5	5
Total number of goals ²	137	134	117

² Goals were not recorded for all 154 participants due to inconsistency in how goals were recorded by peer facilitators in resulting in incomplete records (and one group ran for four sessions only and did not work on personal goals). One of the learnings from NN3 groups was that it was difficult for peer facilitators to record goal descriptions and the extent to which participants worked on their goals and achieved them. From NN4 the program devised the

Child Goals

When parents articulate goals for their children, Peer Facilitators position them within the context of the three categories core to the *Early Years Learning Framework for Australia* (2009), and consistent with the NDIS Outcomes framework (2015): 'being', 'becoming', and 'belonging'.

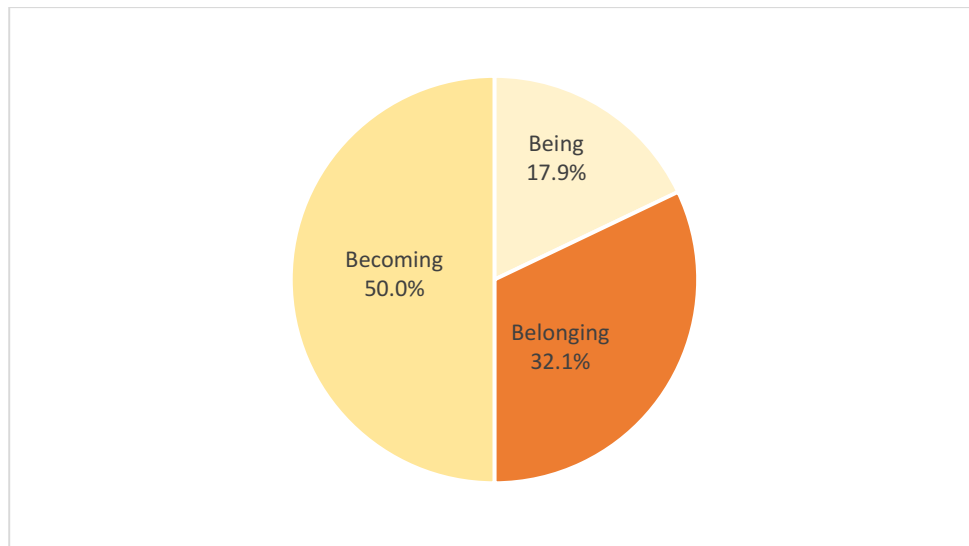


Figure 5: Long-term child goals (n=134)

Being, including health and wellbeing, represented 17.9% of all child goals. An example of a long-term goal was to *increase fine motor skills* with the corresponding short-term goal of *one-on-one time on Thursday and Saturday working on activity book*. Nearly all (95.8%) short-term goals related to being were achieved during the program.

Becoming, including independence, personal care, decision-making and changes, represented half (50%) of all child goals. An example of a long-term goal in this area was *dress independently* with the corresponding short-term goal of *pulling down top, pulling pants up*. Nearly all (95.5%) short-term goals related to becoming were achieved during the program.

Belonging, including participation in family and community life and routines, represented 32.1% of all child goals. A long-term goal would be to *participate actively in his preschool/school life* with the corresponding short-term goal being to *take photos of his new preschool for social story book*. Nearly all (97.7%) short-term goals related to belonging were achieved during the program.

'Mission Control', an online tool into which facilitators recorded both the participants' initial goals and later their achievement, to ensure the data was recorded.

Family Goals

Participants formulated three main types of family goals: spending quality time together; building family relationships; and increasing family wellbeing.

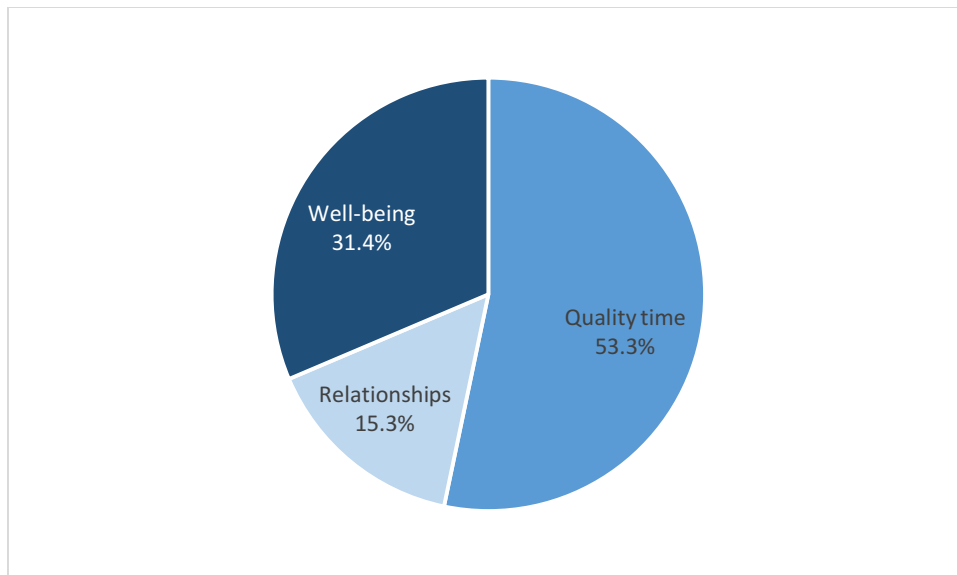


Figure 6: Family goal categories (n=137)

Goals related to spending quality time together represented 53.3% of all family goals. Long-term goals related to quality time included connecting as a family, spending enjoyable time together and taking time for family outings and holidays. Examples of short-term goals related to quality time included: *scheduling a family activity once a month* and *playing a fun activity as a family once a week after dinner*. Nearly all (96.0%) short-term goals related to quality time were achieved during the program.

Increasing family wellbeing represented 31.4% of all family goals. Long-term goals related to family wellbeing included: health of the whole family and cultivating an interest in sport. Examples of short-term goals related to family wellbeing included: *buying fresh vegetables to cook* and *going for a weekly walk as a family*. Nearly all (95.6%) short-term goals related to family wellbeing were achieved during the program.

Building family relationships represented 15.3% of all family goals. Long-term goals related to family relationships included improving relationships between siblings, building stronger parent-child connections. Examples of short-term goals related to family relationships included *create an activity that all 4 boys can play together* and *Jonas and daddy to plan a day out that is enjoyable to both of them*. All short-term family relationship goals were achieved during the program.

Personal Goals

Participants formulated three main types of personal goals: increasing personal wellbeing; increasing fitness; and goals related to career.

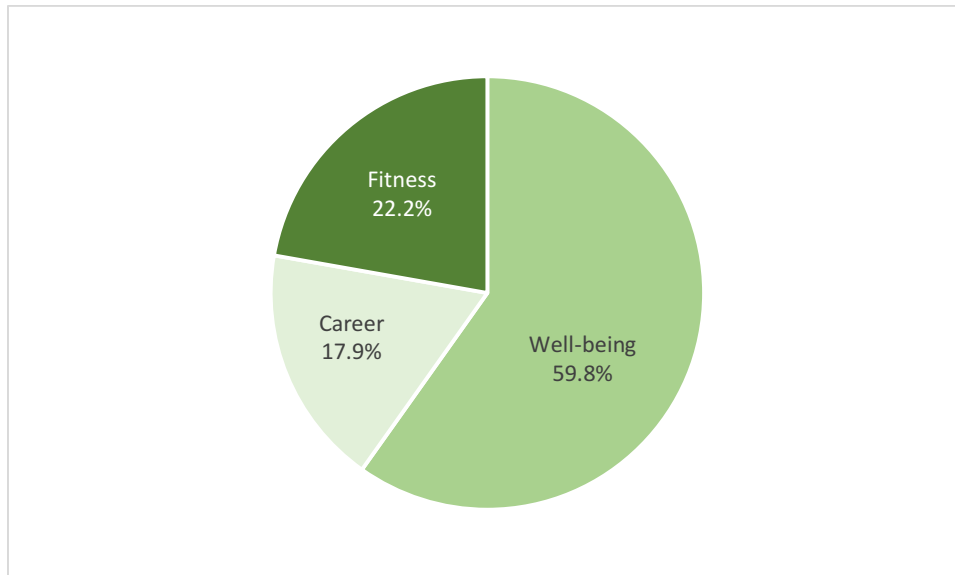


Figure 7: Long-term personal goals (n=117)

Wellbeing goals represented 59.8% of all personal goals. Long-term goals related to wellbeing included: parents making time for themselves and getting more sleep. Examples of short-term goals related to wellbeing included: *going to bed at 10pm, 3 nights a week* and *organising care to allow “me time” once a week*. Nearly all (98.6%) short-term goals related to wellbeing were achieved during the program.

Fitness goals represented 22.2% of all personal goals. Long-term goals related to fitness included getting fit and doing more exercise. Examples of short-term goals related to fitness included: *spending 10 minutes a day on physio exercises* and *one swim or walk a week*. The majority (84.6%) of short-term goals related to fitness were achieved during the program.

Career goals represented 17.9% of all personal goals. Long-term goals related to career included: returning to work, finding a better job and studying or retraining. Examples of short-term goals related to career included: *make a list of jobs and industries to work in* and *to research short courses in art therapy*. All (100%) short-term goals related to career were achieved during the program.

In what ways did Pictability assist parents set a vision for their child and family?

Participants (n=41) from 6 groups in the NN5-NN7 cohorts were asked to provide feedback about how they found the Pictability vision and planning session.

Participants reported that they found the Pictability vision and planning session a useful and enjoyable experience. It was widely reported that the visuals and sorting cards had expanded participants thinking and increased the range of goals they considered. One participant commented: *I was able to imagine many things through visuals to set goals.*

Some participants reported that Pictability process had prompted them to choose goals they might not otherwise have considered. One participant commented: *Would not normally have so many goals for myself in the past, but realise that self-care is important.* Two other participants reported they were very surprised at the end when selecting their goal to work on, that they didn't choose speech therapy which is their biggest priority. A number of participants reported that the Pictability process had enabled them to think clearly about what they want to achieve and to prioritise their goals. One participant commented: *This has been good in clarifying goals instead of the endless stream of things that need to get done, narrowing down is helpful, feels more achievable ... it's more concrete.*

Participants were asked if they had ever participated in other types of goal planning sessions. Less than half (41.5%) of participants reported that they had been involved in another type of planning session. The majority of planning sessions that participants had been involved in related to NDIS, early childhood intervention (ECI) or other early childhood professionals. Other types of planning sessions reported were financial and personal development.

Participants who had been involved in NDIS planning reported varying levels of satisfaction with the process. One participant commented that it had provided *valuable information on how to best approach and plan for NDIS access/ application.* Other participants commented that the process had been okay or that they had not been happy with the process. One participant commented: *it was a nightmare... we struggled with goal setting.* Participants who had been involved in planning with ECI or other early childhood professionals were generally positive about the process, but some identified issues such as lack of a clear plan on how to achieve goals. One participant commented: *Lots of talking, it can be hard to pin things down.* Participants that reported that the planning sessions were useful relayed that they had set small achievable goals and/or had reflected on their child's needs, interests, challenges and interests.

Participants who had been involved in a NDIS, ECI or individual development planning session reported they had chosen goals related to their child's physical development, social skills, self-direction skills, executive function and behaviour. Participants reported that some goals had been achieved and some had not. Where the goals related to professional intervention, some participants commented that they had received limited feedback from professionals about whether the goals had been achieved

Some participants were asked about the three most important things that you are hoping to achieve from *Now and Next*. Participants reported that they wanted strategies for planning and achieving goals with their family that help them focus on what is important for them. They were also keen to learn from other people and hear about their experiences. Participants also talked about wanting to become better parents, improve their relationship with professionals and deal with difficulties more effectively. Participants also listed a number of specific goals they hoped to achieve for their child.

Earlier Pictability feedback was collected from participants (n=17) in NN3 groups run in Term 1, 2017. Participants were asked to rate two statements about Pictability on a scale of (1=Lowest to 6=Highest) and provide comments.

More than three in four participants (76.5%) reported that the Pictability experience had helped them understand how to set a vision for their family. Participants reported that they found the process enjoyable and helpful in identifying and setting goals. Comments from participants included:

Pictability was the first time I had really thought about goals for my child, family and myself. So it was an invaluable experience.

It seemed more tangible to visualise them.

I enjoyed being able to set goals. But then work out what goals were more important than others was important.

Feedback provided by a facilitator on one mum's experience with Pictability highlighted how the process could help parents focus on the good things that are happening in their life, rather than focussing too much on what their child may not be doing.

A few participants expressed reservations about the Pictability visioning planning session, in particular, that it was unclear what they were doing. One participant found the process overwhelming:

The Pictability experience caused more anxiety for me. Seeing all the goals that my child has to achieve in such a short space of time (12 months) was very overwhelming³.

Nearly all participants (94.1%) reported that they understand the difference between long-term and short-term goals. Comments from participants included:

It was a bit of a hard concept to grasp at the start. But breaking it down to an 8-week short term goal with regular reviewing helped.

I now understand that breaking down our long-term goals into short term goals gives us a sense of achievement instead of just feeling like we are plateauing. We notice the smaller improvements all the time.

What concerns do participants report?

As part of the fourth session of the program, participants write down a concern that worries them on a small note. These concerns are brainstormed by the group and ideas are shared on how to address these concerns, including, what aspects they can influence and what is outside of their control. For instance, worrying about a child's level of independence in the future can be addressed by understanding what part of their independence parents can invest in as they grow up.

Many of the concerns related to **how their child will adjust to adulthood**. Parents wanted their children to be able to enjoy a happy, regular life and be accepted by others. They worried about whether their child would be happy, independent and have friends and/or a family of their own. Whether their child would be able to find work or have a career was also of concern. Many parents expressed concerns about who would look after their when they were elderly or had passed away.

Parents also expressed more immediate concerns about their child's health and wellbeing. These included worries about physical health and development including whether they would be able to communicate or be

³ Instructions to this part of Pictability were amended as a result of this comment to make it clear that parents design their long-term vision on the first board and later choose 3 goals to work in the short term

toilet trained. Issues related to their child's social skills or behaviour in public were also mentioned. Many parents worried about whether their child would make friends and whether they would be bullied.

Parents expressed worries about how other family members were coping with the pressure of their situation. Some worries related to their partner's physical or mental health. How siblings were coping was also discussed. Issues related to extended family were also mentioned.

Parents also had concerns about how they were coping and whether they would have the stamina to manage their situation long-term. This included feeling that they weren't being a good parent and feeling angry and frustrated at their child's behaviour. Some parents worried about the loss of their sense of identity and not having time to do things they enjoy or connect with friends. Some parents felt regret at how they had handled the situation, or worried that it was something they had done that had caused the situation they were in.

Some families expressed concern about the NDIS and whether the NDIS package would be what they need. Another parent reported their concern at life changing decisions being made on their behalf. Other worries included financial and work-related problems, problems with neighbours and coping with traffic.

What learning do participants take “moving forward”?

Participants from 13 of the 15 groups (n=143) reflected in group discussion on how they would use their learnings from *Now and Next* in the future.

Participants reported that they would continue to use goal setting strategies including setting small goals, focussing on signature strengths to achieve goals and celebrating small steps towards the goal. Advocating for their child with professionals and carers was also mentioned. Some participants talked about the importance of looking after themselves and asking for help and support.

The tools and strategies that participants reported they would use when they meet an obstacle included:

- Thinking about signature strengths and using PERMA to get over the obstacles and get planning to make change for the better outcomes.
- Persistence and thinking about the motto 'never give up'.
- Breaking the problem or situation down into smaller manageable steps and making a plan using the 5 windows goal- to-action templates.
- Focusing on the present and what is within your control including stepping back and observing the situation and not thinking too much about the future.
- Applying Circle of Control/ Influence.
- Taking time out.
- Talking with your support network and connecting with people who understand including family, friends, the *Now and Next* Alumni and professionals.
- Keeping a positive attitude such as finding the positives, reflection on what you have achieved, using humour and positive self-talk.

Participants were asked how they would use their **agency** in the next month. Participants talked about being more proactive and assertive as their child's advocate including being clear on outcomes they want to achieve for their child. Participants mentioned setting up specific meetings with their child's specialists or educators to talk about their child's strengths, challenges and goals and how to manage transitions (ie. into a mainstream school). Participants also talked about managing and coordinating the professionals they were involved with to

get better results and ensure that information was shared between them to enable better collaboration. Planning and reviewing goals and using the 5 windows goal-to-action approach were also mentioned.

Participants reported a range of ways that they would share their learnings from *Now and Next*. Participants said they would encourage others to do the program and share their knowledge and experience with their family and friends. Participants were keen to use strategies from the program with their family, particularly, around setting goals. Some participants wanted to share learnings such as the five windows approach with their school or pre-school. Other participants wanted to adopt a more positive and confident attitude with their family and friends and help others that need help.

Participants reported a number of ways in which they would continue to use their e-book. Participants reported they would use the e-book to collaborate with services including for NDIS planning and goals. Other uses included as an organising tool for their child's goals, reports and medical records and recording services and support networks. Documenting their child's achievements, milestones and events was also reported including writing a diary, saving photos and videos and creating a history of learning. Using the e-book as an educational tool by creating social stories and visual e-books for learning was also mentioned. Participants also reported they would use the e-book to set new goals and focus on them.

Participants were asked how they would institute Goal-to-Action as a habit. Participants talked about the importance of setting goals, keeping the goals simple and achievable, writing them down and discussing the goals with spouses, friends and family. Many participants talked about the 5-window structure to plan, act and achieve goals, with some reporting they would teach children how to problem-solve and plan using 5-windows approach. Documenting the goals in e-book was also mentioned.

Participants reported they thought the Alumni Network would help them by providing social connection, social support and a way to share information. Participants talked about wanting the Alumni to provide a sense of belonging so they feel like we are not alone but part of a "village". The Alumni was seen as a place to share knowledge and experience and get ideas and advice, and support and understand one another. Participants also hoped the Alumni would help them focus, provide direction and inspiration and help them to keep on top of goals by checking in with others and providing a source of positive affirmation.

Participants reported what they would contribute to the Alumni Network by sharing their experience, knowledge and information (about services, resources, events, self-care and wellbeing). Participants were also keen to stay in touch with Alumni friends and to track each other's progress through social media and provide positive feedback and thoughts.

Objective 2: Parent participants become empowered

Through growing their empowerment and sense of agency, parents learn to create the outcomes they want for their children and families

Are participants growing agency in relation to achieving progress for their children?

Adult Hope Scale (AHS)

Hope levels were measured at the start and the end of the *Now and Next* program in an online survey. Participants were asked to describe their levels of hope using the AHS, a validated 12 item questionnaire (Snyder, Irving, & Anderson, 1991). Participants respond to each item using a 10-point scale ranging from definitely false to definitely true.

The AHS measures Snyder's cognitive model of hope (1994, 2002) which defines hope as a positive motivational state that is based on an interactively derived sense of successful **agency** (goal-directed energy), and **pathways** (planning to meet goals).

The AHS was introduced in 2018 and completed by two NN7 groups (n=10). Eight participants (80%) recorded gains in both agency and pathway, with the remaining two participants recording slight declines in agency and pathway. Figure 2 shows the average score before and after the program. The average gain for agency was 1.6, pathway 1.9 and adult hope score 1.8.

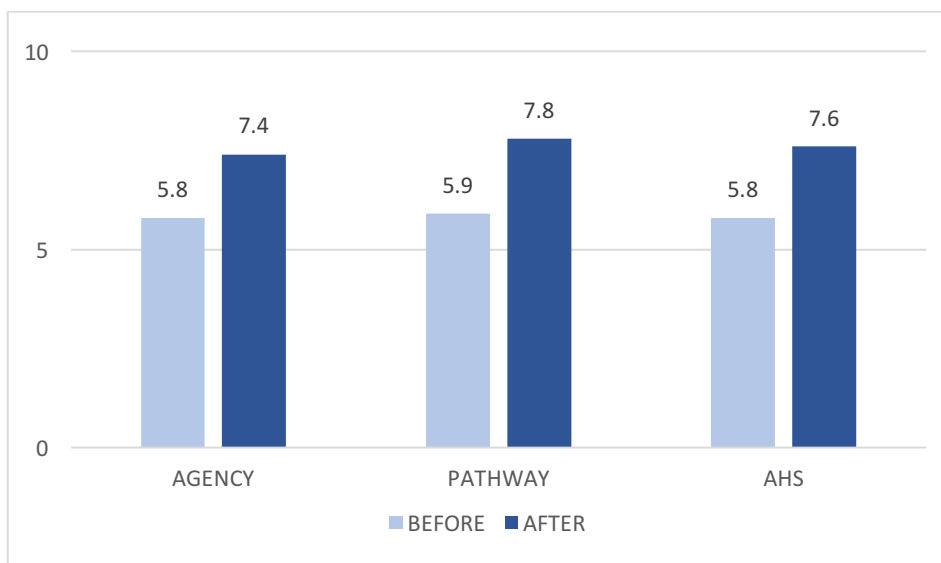


Figure 8: Average Adult Hope Scale Scores Before and After *Now and Next* Program (n=10)

Even though this is a relatively small size sample (n=10) there were statistically significant increases in agency and pathway. A paired samples t-test was used to compare pre and post program agency scores. The difference between agency scores at the start of the program (M=5.8, SD=1.1) and end of the program (M=7.4, SD=1.7) was significant; $t(9)=2.6$, $p=0.03$. A paired samples t-test was used to compare pre and post program pathway scores. The difference between pathway scores at the start of the program (M=5.9, SD=1.3) and end of the program (M=7.8, SD=1.4) was significant; $t(9)=3.3$, $p=0.009$.

Agency

In session 6 of the program, participants are asked to reflect on their sense of agency by completing the following question: “Before *Now and Next* I thought achieving my child’s goals were% up to me, and% up to professionals (total 100%). After the *Now and Next* program I know that achieving my child’s goals are% up to me!”

This question was completed by participants in the NN4 to NN7 cohorts (n=66). The average agency reported by participants before *Now and Next* was 58.8% which increased to 83.2% by the end of the program (Figure 9). Nearly all participants 93.9% reported increased agency after the program. A paired samples t-test was used to compare parent reported sense of agency before and after *Now and Next*. The difference parent reported sense of agency at the start of the program (M=58.57, SD=22.23) and end of the program (M=84.36, SD=16.3) was significant; $t(66)=8.38, p=0.0001$. On average, participants reported a 24.3% gain in agency.

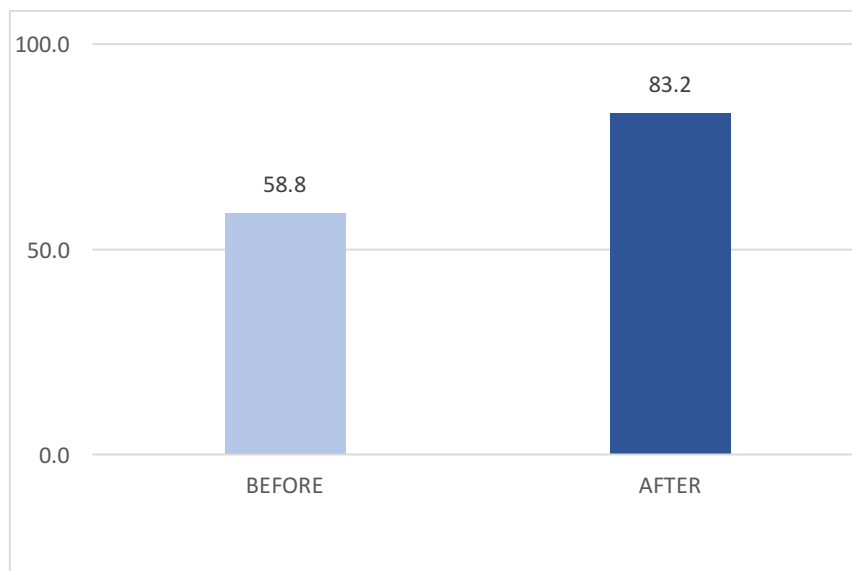


Figure 9: Average Agency reported Before and After *Now and Next* Program (n=66)

Are participants feeling empowered as a result of having done the program?

Psychological Empowerment Scale

Parent empowerment levels were measured at the start and the end of the *Now and Next* program in an online survey. Participants were asked to describe their levels of empowerment using the Psychological Empowerment Scale (PES), a validated 32 item questionnaire (Akey, Marquis & Ross, 2000). The PES measures psychological empowerment for parents of children with a disability, defined as a dynamic process involving interactions between people and their daily social contexts that produces changes in individual lives and environments (Akey, Marquis & Ross, 2000).

The PES was introduced in July 2017 and data was collected from six *Now and Next* groups (n=46). There was pre and post program data available for 31 of the 46 participants. Of the 31 participants who completed the PES before and after the program, 25 (81%) reported higher parent empowerment at the end of the program relative to the start of the program. A paired samples t-test was used to compare pre and post program PES scores. The difference between PES scores at the start of the program (M=12.5, SD=14.5) and end of the program (M=23.1, SD=17.7) was significant; $t(30)=2.7$, $p=0.01$. The average gain in empowerment on the PES was 10.6 points.

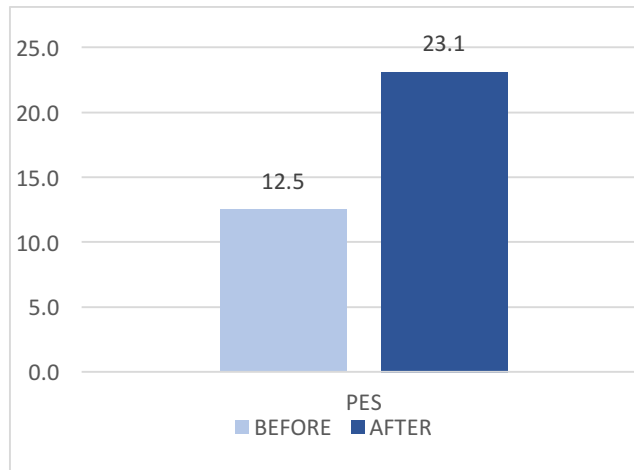


Figure 10: Average Psychological Empowerment Scale Scores Before and After *Now and Next* Program (n=31)

Objective 3: Parent participants’ wellbeing grows

Through participation in the Now and Next program, parents grow their wellbeing as expressed by the Positive Psychology PERMA theory.

The PERMA profiler is a general measure, developed for adults, which measures flourishing in terms of five key domains: positive emotion, engagement, relationships, meaning, and accomplishment, following Dr Martin Seligman's PERMA wellbeing theory (Seligman, 2012). It includes measures on five additional domains including health, happiness optimism, negativity and loneliness (see **Appendix 5** for more information). The PERMA profiler provides an overall wellbeing score (average participants’ scores on the five key domains and one item assessing happiness), and a secondary direct self-report measure of general wellbeing. All items are measured on a scale from 0 (not at all) to 10 (completely).

Participants from five *Now and Next* groups (n=22) completed the PERMA profiler in an online survey to measure wellbeing levels before and after the program⁴. A paired samples t-test was used to compare participants’ overall wellbeing PERMA scores before and after the *Now and Next* program. The difference between overall wellbeing scores at the start of the program (M=6.4, SD=1.5) and end of the program (M=7.5, SD=1.5) was significant; $t(21)=4.0, p<0.001$. The average gain in overall wellbeing on the PERMA was 1.1 points. Figure 11 provides a comparison of participants’ average scores in the five PERMA key domains before and after the *Now and Next* program. It shows that on average, participants reported increased positive emotions, engagement, relationship, meaning and achievement after the program.

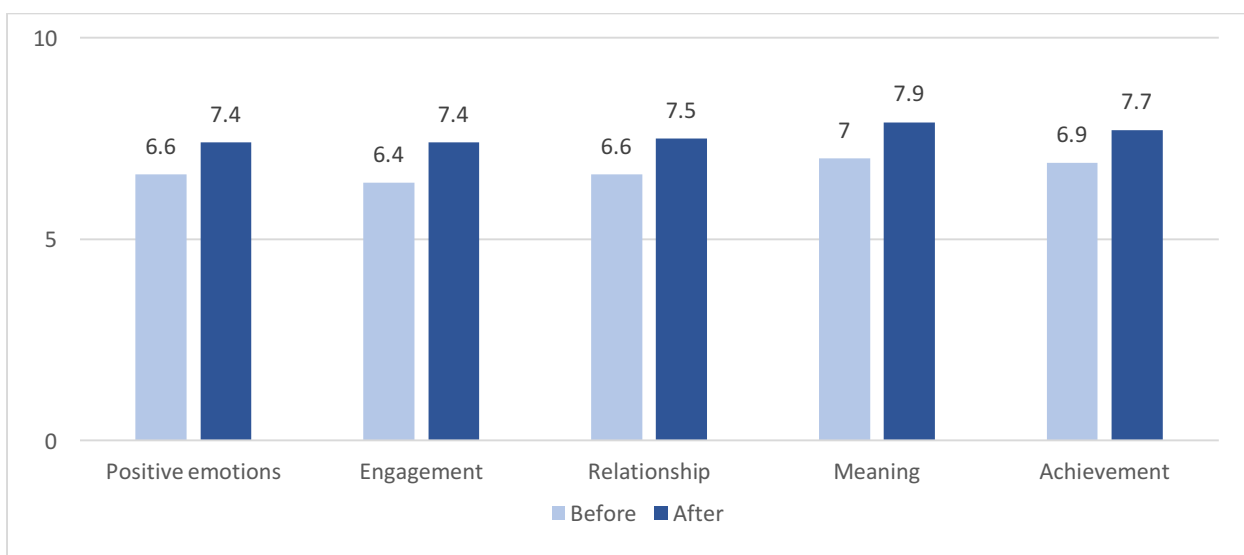


Figure 11: Average PERMA Score Before and After *Now and Next* Program (n=22)

Figure 12 provides a comparison of participants’ results on the additional PERMA measures before and after the program, including health, happiness, optimism, negativity and loneliness. It shows that on average, participants’ health, happiness and optimism increased, while their negativity and loneliness decreased. Note: ‘Ladder’ refers to participants’ responses from zero to 10 on the following item: “On which step of a ladder

⁴ The five groups had a total of 35 participants, however, pre and post program data was available for 22 of the 35 participants.

would you say you personally feel you stand at this time?” as a direct self-report measure of general wellbeing. On average, participants rated themselves 1.3 points higher on this item after the program.

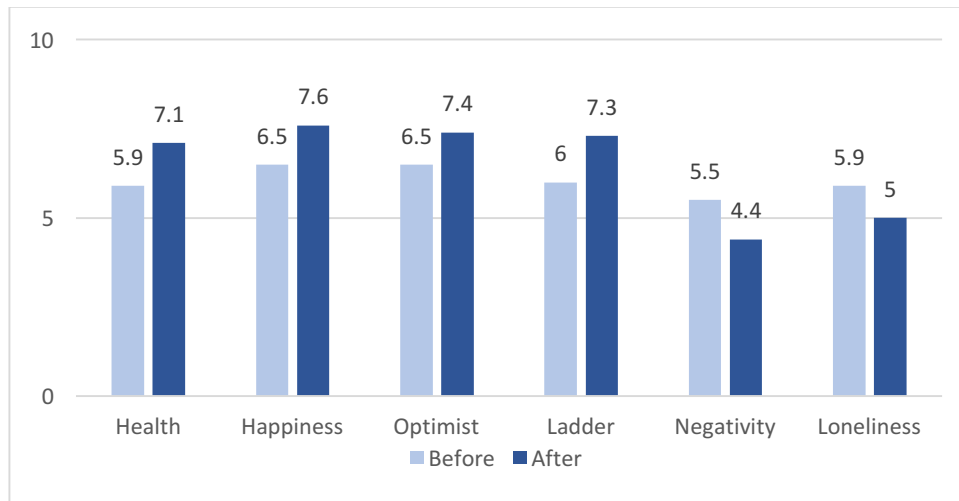


Figure 12: Average Other Wellbeing Measures Before and After *Now and Next* Program (n=22)

Outcome rating scale (ORS)

Participants from NN5 to NN7 completed the ORS. At the beginning of each session, participants rate (on a scale of 1 to 10) their feeling of wellbeing in relation to their participation in *Now and Next* on four levels: individual, interpersonal, social and overall. Figure 13 shows the average ORS scores for the first and last session of *Now and Next*. It shows that participants report a greater sense of wellbeing on all four levels: the individual (personal wellbeing); interpersonal level (family, close relationships); social (work, school, friendships); and overall (general sense of wellbeing). It should be noted that a smaller sample of participants completed the ORS in session 8 compared to session 1⁵.

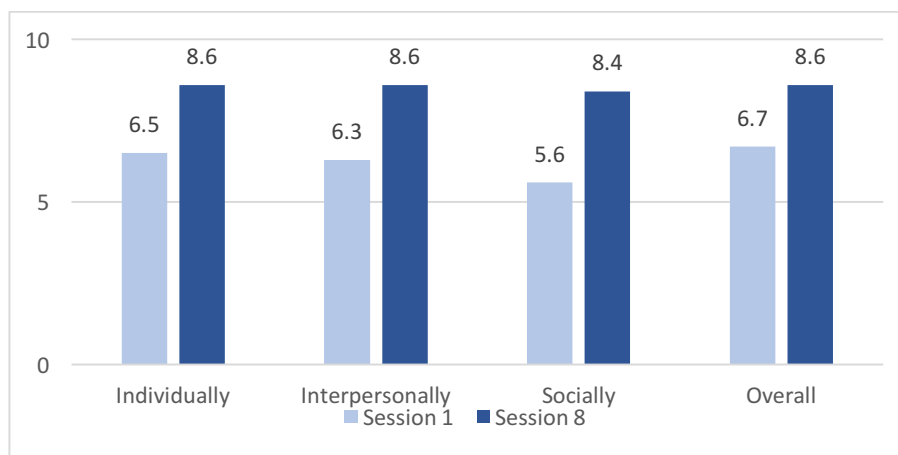


Figure 13: Average ORS Before and After *Now and Next* Program (session 1 n=51, session 8 n=34)

⁵ The smaller sample of participants in session 8 was due to the Korean group running as a four-week program (6 participants) and missing data from one NN5 group (8 participants).

Discussion

This evaluation has shown that the *Now and Next* program was highly successful in providing parents with the experience of formulating and achieving short-term goals for their child, their family and themselves. **These goals were generated through a vision-setting process completed by the family rather than a planning process directed by professionals.** More than nine in ten participants achieved all three of the goals that they set. The program was also successful empowering parents and building their sense of agency and growing participants' sense of wellbeing.

The focus on three sets of goals – for the child, the family as a whole, and for the parents themselves – is a strong feature of the *Now and Next* program. Although hard data is lacking at this stage, anecdotal evidence indicates that the majority of goals being identified through the NDIS planning process for young children are child-focused, and there is little or no focus on the all-important family and parental goals. Even under the previous ECI service models, there was a tendency for child-focused goals to predominate. The *Now and Next* program clearly shows that parents regard family and personal goals are just as important – and as achievable – as goals for their children.

A key issue that arises is how to ensure that knowledge learnt during the program continues to be used by families and how to enhance the impact and sustainability of the outcomes achieved during the original eight-week program.

In terms of **pathways from the program**, *Now and Next* have developed two ongoing mechanisms to ensure ongoing support and capacity building for families:

- the *Now and Next* Alumni (NANA) Network which provides an ongoing mechanism for peer support amongst families who now share a common experience and understanding (outside the scope of the current evaluation).
- a leadership pipeline where families who demonstrate leadership capacity and interest are identified, recruited, trained and employed to fulfil a range of roles including delivery of the group program (outside the scope of this evaluation).

There are no specific pathways from the program to professional early childhood intervention services. Participants were in various stages of the early intervention pathway ranging from no diagnosis, recent diagnosis or post diagnosis. Families self-selected into the program and there was no screening other than a check that they spoke English well enough to participate in the program. The *Now and Next* team does not formally refer families to any professional services. Informal referrals might occur during the program when families raise issues about working with professionals or ask for recommendations of professional services which are responded to by other participants and peer workers during group discussions. It was reported that families are encouraged to set small achievable goals to work on during the program that do not require involvement from professionals. It is envisaged that the Goal to Action template which participants use to set goals during the program can also be used as a coaching tool to engage with professionals after the program.

In terms of **entry or referral points to the *Now and Next* program**, the program runs parallel to whatever else is happening for the family and is offered to families regardless of whether they are receiving professional services or not. Some families in the program might have a team of professionals working with them for their child whereas some might have a child who is very young or might not require a lot of professional support. Whether there are particular benefits for parents in attending a *Now and Next* program before they become involved with professional services is a question for future research.

The *Now and Next* program and resources provide a well-documented and comprehensive package that makes the program portable to other settings and organisations. The program is comprehensively documented in a facilitator manual to allow seamless facilitator delivery. Participant feedback mechanisms are built into the program delivery and program slides to ensure that participant outcomes are measured consistently. Some program measures provide immediate feedback to facilitators on how participants are tracking. The Pictability resource provides parents with a creative, engaging and hands on tool to help them through the process of building a vision for their family. The *Now and Next* program uses well-designed visuals and themes to enhance participants' understanding of course content and key concepts. Further research is needed to find out what is needed to enable different agencies and jurisdictions to adopt the *Now and Next* program. Issues to be addressed include what kind of support would peer facilitators in other settings need, and what kind of adaptations might be needed to enable different populations to adopt the program.

What are the active ingredients of the program?

While this evaluation indicates that *Now and Next* is effective in achieving a number of important outcomes for parents, what it does not show is what the active ingredients in the intervention are, that is, the key features of the program that make the difference.

There are a number of unique features of the *Now and Next* program that are candidate key ingredients. These include:

- *Parent-to-parent contact.* The program provides group sessions that allow parents to meet and build supportive networks with other parents. Not all parents want or need to build new support networks, but many do, and this is an additional positive side effect.
- *Provision of a structured sequence of sessions.* This is not just a parent support process, but a purposeful and planned training approach, that systematically seeks to build parental skills and confidence using the scientific evidence from Positive Psychology.
- *Parent as facilitators.* The only other example is the Empowering Parents Empowering Communities (EPEC) parenting program where parents who have done the program are trained as facilitators. As in the EPEC case, what is powerful about this approach is that the facilitators are from the same background or have had the same experiences as the participants. This helps them understand and respect the responses of participants and also helps them set more realistic goals.
- *The use of a positive psychology framework* to encourage families to imagine possibilities for their family and child.
- *The focus on parents' long-term hopes as well as short-term goals.* Acknowledging and respecting parent's hopes is important, particularly at this early stage.
- *The focus on achievable short-term goals.* Parents of young children with developmental problems may feel overwhelmed and unable to see what they can do to make improvements in their lives or that of their children. Helping them look for what they might be able to do.
- *The focus on three sets of goals – for the child, the family as a whole, and the parents themselves –* rather than focusing solely on goals for the child.
- *The use of specially designed tools* such as Pictability which provides a creative/experiential and engaging process to help parents with goal setting and building a vision for their family.

- *Encouraging parents to think in terms of outcomes rather than services or therapies.*
- *Encouraging parents to solve goals through their own actions, rather than automatically deferring to or looking for help from professionals. The program encourages families to build positive partnerships with professionals and reinforces the fact that important contributions are made on both sides.*
- *Use of real time data to provide feedback to facilitators on how participants are tracking so that they can provide support to participants if needed.*
- *Parents learn skills that are transferrable into other areas of their life which helps to increase their capabilities in many aspects of their life through the coaching tools that are used during the program.*

Determining which of these key features are the key ingredients for the effectiveness of the program will require further experimentation and research.

Recommendations for further areas of research

Now and Next has a number of unique features that warrant further investigation. Possible research studies include:

- *Further trials of the outcomes of the Now and Next program.* The numbers in the present evaluation are still relatively small, limiting the strength of the conclusions. More studies of the program with greater standardisation of evaluation measures are needed.
- *Identifying the active ingredients.* What are the features of the program that are most central to its success? Are all of the candidate active ingredients essential? Are any more vital than others? Further experimentation and trialling is needed to explore these questions.
- *Trialling the program in different sites.* The participants in the present evaluation are unusual in that they included a majority of CALD families, and a high proportion of fathers. Was there any differential efficacy – is the *Now and Next* program particularly more suited to some groups than others?
- *Comparison with other programs and pathways.* How does *Now and Next* compare with other programs? It would be valuable to compare outcomes for those who enter the NDIS after a *Now and Next* experience with those who go through the standard pathway.
- *Timing of program.* One issue that needs to be explored further is at what point do parents engage with professionals? Best practice in ECI involves a partnership between parents and professionals in which information and expertise are shared. While parents can help each other think about practical solutions to the challenges they face, professionals possess a wealth of knowledge of a different kind that needs to be factored in at some stage. The best timing for this needs further exploration.
- *Long term outcomes.* It will be important to track one or more cohorts of parents over time to see what the long-term effects are, and whether the short-term gains found in the present evaluation are sustained.

Policy implications

As this evaluation has shown, the *Now and Next* program demonstrates the power of parent-to-parent support when properly structured and facilitated. For parents of young children with developmental disabilities, such support can be beneficial in a variety of ways: in helping them clarify their goals for their children, families and themselves; in promoting their personal capabilities to meet these needs; in fostering a positive and constructive approach to the challenges they face; and in contributing to their general well-being. These are goals that early childhood intervention services around the world aspire to, so the *Now and Next* program offers a program for achieving those goals with families who have young children with developmental disabilities or delays.⁶ The current evaluation has shown that the program is also effective with non-English speaking groups, suggesting that the program could have widespread potential.

The program could also serve as a template for other forms of parent-to-parent support services. Parenting a child with a developmental disability is a long journey, and there are many other points on that journey when parents could benefit from the support provided by a program such as *Now and Next*. From the evidence of the present evaluation, the key features to include when designing such programs include that they are co-designed with and facilitated by parents, use a structured format addressing the particular challenges the parents are facing at that stage, and are based on positive psychology and strength-based frameworks.

Implications for policy in the NDIS environment

In the Australian context, the value of *Now and Next* lies in its potential role in improving *Now and Next* is designed for parents of young children with developmental disabilities, some of whom will end up needing the support of the NDIS. A comparison of the NDIS and *Now and Next*'s pathways into the ECI service system is instructive.

Access to the NDIS is via the National Disability Insurance Agency (NDIA) which is responsible for the NDIS. The NDIS's national early childhood early intervention (ECEI) approach is delivered through a national network of Early Childhood Partners. These partners, who are meant to be experienced in providing early childhood intervention, arrange to meet parents of newly referred children to talk about the child's and family's needs. Together, the parents and the NDIS early childhood partner decide what supports the child and family need. This support might include giving the parents information or emotional support, linking them with mainstream supports like a community health service, and providing short-term early intervention support and strategies. If the child has longer-term support needs, the NDIS early childhood partner can recommend that the child moves quickly to an individualised NDIS plan and help the parents request NDIS access. If the child becomes an NDIS participant, the NDIS early childhood partner then helps the parent develop an individualised NDIS plan for the child and submit it to the NDIA for approval. This plan should outline the support that best meets the child's needs and goals. Once the NDIS plan is finalised, the parents can choose a service provider to start putting the child's plan into action.

⁶ Whilst outside the scope of this evaluation, the *Now and Next* program was trialled in British Columbia, Finland and New Zealand in 2018.

This process is very different from the pathway provided by the *Now and Next* program. The NDIS pathway does not involve any contact with other parents, and the first formulation of goals is done with a professional rather than with other parents. These professionals are not current providers of early childhood intervention services, although they are meant to have had experience.

The effectiveness of this whole process in achieving positive outcomes for children and families is unproven at this stage. This does not mean that it could not be made to work. Theoretically at least, it is possible for those who have worked in ECIS and are skilled in family-centred practice and ECI best practice to achieve similar outcomes to the *Now and Next* program – helping parents identify and achieve realistic short-term goals, helping parents realise what they can do with their own resources, and building parental capabilities and confidence. However, the evidence suggests that it is harder for practitioners to consistently achieve these outcomes, and that use of family-centred and other best practices is very uneven across existing services.

This appears to have become even more so in the early stages of the NDIS rollout. This is partly because of the influx of new service providers into the field, many of whom have little or no experience of ECI provision or awareness of ECI best practices. It is also proving difficult to find enough Early Childhood Partners with appropriate experience and skills. These issues may represent teething problems and can be resolved in time as the provider market matures and if the right training, support and regulatory oversight are provided.

In the meantime, the *Now and Next* program offers a highly promising model that could serve as an adjunct to the existing NDIS pathway or be incorporated into it. At the time they first encounter the NDIS system, parents of young children with developmental disabilities are likely to be at their most vulnerable – unsure of what they need, naturally deferring to professionals, etc. It would be immensely helpful for parents to have had experience of the *Now and Next* program before they meet with NDIA or early childhood partners. They would be much clearer about their short- and long-term goals, and much more confident about their ability to achieve at least some of these by themselves. This would equip them to negotiate service plans that have clear focus on the outcomes they want to achieve, rather than the services that professionals offer. The NDIS is intended to be outcome-focused, so the *Now and Next* experience will help achieve this by ensuring that parents are already clear about the outcomes they want when they come to the planning meeting with the Early Childhood Partners.

The *Now and Next* program will also help professionals deliver best practice services. It has long been accepted that best practice in the ECI sector involves family-centred practice and collaborative partnerships between professionals and parents. However, professionals have struggled to deliver these practices consistently. Parents who have been through the *Now and Next* program will be much better prepared to be fully contributing members of the professional/parent partnership, thereby helping professionals achieve a more consistent standard of family-centred practice.

Evaluation limitations

Limitations of the evaluation include the question of how to measure and report on outcomes that occur after the program finishes. In particular, how does one know when knowledge learnt in session is (or will be) applied in external circumstances, and what constitutes evidence that this has indeed happened. The overall program logic included short, medium and long-term impact however, for the purposes of this evaluation, only short-term outcomes were included due to time frames.

The evaluation data that has been collected measures changes or impacts for the parent which can be inferred to have a positive impact on the child, however, it does not provide any direct evidence on how the program impacts on the child.

It should also be noted that the parents who are involved in the *Now and Next* program are self-selected – they have chosen to attend rather than being automatically enrolled as part of a more comprehensive program. It is unclear whether the program would be as effective if all parents of young children with developmental disabilities were enrolled.

Conclusions

Now and Next has a number of unique features that make it worthy of further testing and dissemination. There is no other Australian program that has been co-designed with parents, that places parents in such a leadership role, and that can show such results. These qualities make it an especially good option for parental empowerment as the early childhood intervention field transitions to the NDIS.

Appendices

Appendix 1: Pictability visioning session

Participant feedback on the Pictability visioning session was collected in the following ways.

NN3 participant groups rated the following 2 questions:

1. The Pictability experience helped me understand how to set a vision for my family (1=Lowest, 6=Highest)
2. I understand the difference between long term (inspirational) and short term (the ones we can start working on soon) goals (1=Lowest, 6=Highest)

NN7 participants answered the following questions after the Pictability session:

1. Have you ever had a goal planning session?
2. If yes, what sort of planning (NDIS or IFSP...?). How did it go?
3. (if yes) What goals did you choose and how did you go about achieving them?
4. How has this experience planning with Pictability been?
5. What was most useful?
6. What was least useful?
7. Any other comments?

Appendix 2: Partners in Change Measures measuring program impact and participants' outcomes

Monitoring participants' outcomes, when combined with feedback to facilitators can significantly increase program effectiveness. For each session of the program, participants completed the Partner in Change Outcome Measures (PCOMs) *Duncan and Reese (2015)*.

PCOMs uses two brief scales:

1. The "Outcome Rating Scale" (ORS) measures participants' perception of the programme effectiveness and is administered **before** each session. Participants rate how they feel on 4 levels:
 - Individual level (personal wellbeing),
 - Interpersonal level (family, close relationships),
 - Social level (work, school, friendships) and
 - Overall (general sense of wellbeing).

Note: "Overall Sense of wellbeing" measured so represents a quick "snapshot" rather than the in-depth measure taken through the wellbeing/PERMA test.

2. The "Group Session Rating Scale" (GSRS) measures session feedback and is administered after each session. Participants rated how they feel about 4 types of data:
 - Their Relationship (with the facilitator and the group)
 - The Goals and Topics that were part of each session's program,
 - The Approach or Method used in each session and an
 - Overall feedback score.

As per the specifications of the test, each PCOM sheet contains 4 scales which participants rate by ticking a place on the ruler. One of the peer facilitators or a trainee then measures the scores (from 0 to 10) and enters them in the "Mission Control" real time data collection tool. The "Mission Control" tool creates automatic graphs as soon as data is entered to offer "information at a glimpse" for facilitators. PCOM scores are graphed for each participant.

Participants' ratings allow the program to obtain a reliable and valid method of gathering their progress so that the program can tailor support to suit their needs in order to progress each one successfully to the end of the program.

PCOMs has been shown in 3 randomized clinical trials to significantly improve effectiveness in real clinical settings, thus this measure is in wide use in a range of settings.

Appendix 3: Qualitative data- Participants' goals, concerns and 'moving forward' comments

Goals are tracked in real time throughout the program via 'Mission Control'.

For each participant, the program collects the following data for each of the three goals they chose to address during the program:

- Whether they have achieved their family goal, their goal for their child and their personal goal.
- If achieved, at what session they have achieved each goal.

Participants concerns are addressed at mid-point during the *Now and Next* program.

During this activity, participants write their main concern about their child's future on a small note. The notes are grouped and participants pick up and read one note aloud (to avoid participants reading their own concern out loud). These concerns are discussed by the group. It is reported that participants enjoy this activity as they get many good ideas on how to address their concern or understand the part of it that is outside of their control and can concentrate on the part of it that they have influence over. For instance, worrying about a child's level of independence in the future can be addressed by understanding what part of their independence parents can invest in as they grow up.

The data here is a simple phrase: worry about my child being bullied, worry about my child not having friends...

Moving forward

Participants' thoughts/ideas about how they will use their learning moving forward were collected from the NN3 to NN7 groups. Eight different questions across the groups that participants discussed and summarised on posters:

1. Life can get tough. But what we know from evidence that our mindset can change the way we feel and then our outcomes. What tools and strategies will you use when you meet an obstacle?
2. Now that you understand agency as a parent, how will you use it in the next month?
3. Now that you have done *Now and Next* program, how will you bring your family and community on-board with your learning from the program?
4. Where will I use my learning from *Now and Next* in the future?
5. What will I use my e-book for?
6. How will I institute the Goal to Action as a habit?
7. How can the Alumni help me?
8. What skills will I contribute to the Alumni network?

Appendix 4: Wellbeing and PERMA

Wellbeing levels are measured at the start and the end of the *Now and Next* program. Participants answer a compilation of 65 questions about wellbeing via a Survey Monkey link.

Following on from the strength-based approach of the *Now and Next* Program, the program research is situated within the psychology of wellbeing. Wellbeing items are empirically validated measures, compiled from comprehensive published research over the past decade with input from wellbeing assessment scientists and experts headed by Dr. Aaron Jarden, Head of Research, Wellbeing and Resilience Centre at SAHMRI Adelaide (see Hone, Jarden, Schofield & Duncan, 2014; Iasiello, Bartholomaeus, Jarden & Kelly, 2017). The contents of this assessment are further described below. This survey used 1 item used in the Gallup’s World Poll, the items from the PERMA profiler put together by Butler and Kern with input from Martin Seligman, and one additional item from the Flourishing Scale by Diener et al (2010).

Question 47: Life evaluation:	Scale
On which step of the ladder would you say you personally feel you stand at this time? NOTES: Used in Gallup's World Poll.	0 to 10: 0 = Worst possible life to 10 = Best possible life

Questions 48 to 70: PERMA	See answer scales below
NOTES: Inspired from the wellbeing and flourishing approach (Forgeard, Jayawickreme, Kern and Seligman, 2011), we chose to focus on Positive emotions, Engagement, Relationships, Meaning and Achievement (often described by the PERMA acronym). The theory proposes that these five elements can help people reach a life of fulfilment, happiness, and meaning and designed this model to be applied in developing programs to help people develop new cognitive and emotional tools. The PERMA profiler was developed by Margaret Kern from Melbourne University (see Butler and Kern, 2015). Their PERMA-Profiler: A brief multidimensional measure of flourishing is available from http://www.peggykern.org/questionnaires.html , and is endorsed by the University of Pennsylvania (https://ppc.sas.upenn.edu/resources/questionnaires-researchers/perma-profiler). PERMA profiler items are pasted below.	

The PERMA-Profiler Measure

#	Label	Question	Response Anchors
Block 1	A1 E1 P1 N1 A2	How much of the time do you feel you are making progress towards accomplishing your goals? How often do you become absorbed in what you are doing? In general, how often do you feel joyful? In general, how often do you feel anxious? How often do you achieve the important goals you have set for yourself?	0 = never, 10 = always
Block 2	H1	In general, how would you say your health is?	0 = terrible, 10 = excellent
Block 3	M1 R1 M2 E2 Lon	In general, to what extent do you lead a purposeful and meaningful life? To what extent do you receive help and support from others when you need it? In general, to what extent do you feel that what you do in your life is valuable and worthwhile? In general, to what extent do you feel excited and interested in things? How lonely do you feel in your daily life?	0 = not at all, 10 = completely
Block 4	H2	How satisfied are you with your current physical health?	0 = not at all, 10 = completely
Block 5	P2 N2 A3 N3 E3	In general, how often do you feel positive? In general, how often do you feel angry? How often are you able to handle your responsibilities? In general, how often do you feel sad? How often do you lose track of time while doing something you enjoy?	0 = never, 10 = always
Block 6	H3	Compared to others of your same age and sex, how is your health?	0 = terrible, 10 = excellent
Block 7	R2 M3 R3 P3	To what extent do you feel loved? To what extent do you generally feel you have a sense of direction in your life? How satisfied are you with your personal relationships? In general, to what extent do you feel contented?	0 = not at all, 10 = completely
Block 8	hap	Taking all things together, how happy would you say you are?	0 = not at all, 10 = completely

<p>Question 71: Flourishing I am optimistic about my future</p>	<p>Strongly agree Agree Slightly agree Neither agree nor disagree Slightly disagree Disagree Strongly disagree</p>
<p>NOTES: From the Flourishing Scale (Diener et al, 2010)</p>	

From: http://www.peggykern.org/uploads/5/6/6/7/56678211/the_perma-profiler_092515.pdf

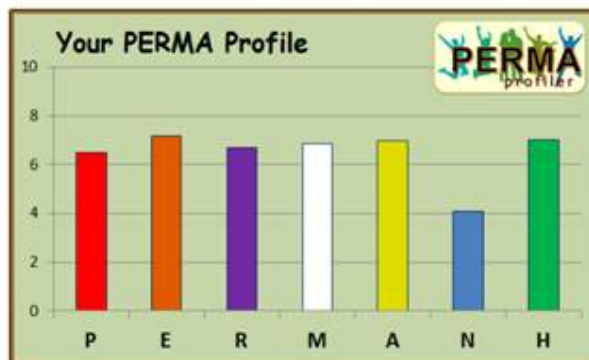
Scoring:

Scores are calculated as the average of the items comprising each factor:

Positive Emotion:	$P = \text{mean}(P1,P2,P3)$
Engagement:	$E = \text{mean}(E1,E2,E3)$
Relationships:	$R = \text{mean}(R1,R2,R3)$
Meaning	$M = \text{mean}(M1,M2,M3)$
Accomplishment	$A = \text{mean}(A1,A2,A3)$
Overall Well-being	$\text{PERMA} = \text{mean}(P1,P2,P3,E1,E2,E3, R1,R2,R3, M1,M2,M3, A1,A2,A3, \text{hap})$
Negative Emotion:	$N = \text{mean}(N1,N2,N3)$
Health =	$H = \text{mean}(H1,H2,H3)$
Loneliness	Lon (single item)

Sample Scoring Presentation

In reporting information back to people, we have used a bar graph, providing a person's PERMA Profile:



Appendix 5: Psychological Empowerment Scales (PES)

Participants answer the empowerment questionnaire from the Beach Center Psychological Empowerment Scales (PES) for parents raising a child with disability (Akey, Marquis and Ross, 2000) via a SurveyMonkey link. Empowerment levels are measured at the start and the end of the *Now and Next* program. The four subscales underlying the PES are:

- attitudes of control and competence,
- cognitive appraisals of critical skills and knowledge,
- formal participation in organizations, and
- informal participation in social systems and relationships.

Parents answer the following questions on a five-point scale of (strongly disagree, disagree, neutral, agree, strongly agree).

1. I think I make good choices about what my family needs
2. If I don't do something well, I am likely to try harder the next time.
3. I try to actively keep up with what my family's legal rights are.
4. I feel isolated from other parents.
5. I deal with the service system effectively.
6. I know my rights as a parent of a child with a disability.
7. I feel a sense of community with other parents who have a child with a disability [for instance through our *Now and Next* group]
8. I believe I have the power to make positive changes for my family.
9. I spend time with other parents talking about my family [for instance through our *Now and Next* group].
10. I try to act as an emotional support for other families.
11. I feel I make good decisions about what my family needs.
12. I know whom to talk to when there is a problem with my family.
13. I share my knowledge and experience with other parents and value theirs.
14. I think my input into services has an important influence on how decisions are made about providing services to my family.
15. I know how to use the resources available to my family.
16. Socialising with other families is something my family does often.
17. I think I make good decisions about my family's well-being.
18. I know where to get information about the resources my family needs.
19. There are other families that understand my family's situation - for instance the Alumni group of *Now and Next*.
20. I help lead or participate in an informal or formal support group for other parents, such as *Now and Next*.
21. I effectively advocate for my child with professionals.
22. I share resources with one or more other parents [example: respite care, housework or perhaps something specific to your family]

23. I intend to participate in a formal or informal support group for parents of children with a disability - *Now and Next* Alumni group or other group.
24. I believe that organisational skills are a strength of mine.
25. There is at least one parent I can go to for emotional support.
26. I am actively involved in a parent organisation - *Now and Next* or other.
27. I see myself as someone who usually achieves the goals I set for myself.
28. I would be likely to speak out about an important policy issue concerning families.
29. I serve on an advisory board or help in a parent organisation or service program.
30. I understand how service systems and parent organisations work.
31. There are other parents I can count on to help my family if I need it.
32. When I have to get something done, I get right to work on it.

Appendix 6: Adult Hope Scales

Hope levels are measured at the start and the end of the *Now and Next* program. Participants describe their hope levels from the Adult Hope Scales from Snyder 12 items questionnaire via a SurveyMonkey link.

Each participant fills the Adult Hope Scale (AHS) which measures Snyder's cognitive model of hope. This model defines hope as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals)" (Snyder, Irving, & Anderson, 1991, p. 287). The Adult Hope Scale contains 12 items. Four items measure pathways thinking, four items measure agency thinking, and four items are fillers. Participants respond to each item using an 8-point scale ranging from definitely false to definitely true and the scale takes only a few minutes to complete. See Snyder (2002) for a review of hope theory and research. [AHS available from:

http://fetzer.org/sites/default/files/images/stories/pdf/selfmeasures/PURPOSE_MEANING-AdultHopeScale.pdf]

Questions 35 to 46: Adult Hope Scales	Scale
The 34 questions and more documentation are at: http://ppc.sas.upenn.edu/resources/questionnaires-researchers/adult-hope-scale	See the Psychological Empowerment article. Items 2, 9, 10 and 12 make up the Agency subscale; Items 1, 4, 6 and 8 make up the Pathway subscale. Agency+Pathway=Hope score

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