

NCAPPS Webinar Questions and Answers

Please see tinyurl.com/introducing-NN for future updates on the questions below.

Q1: How do you help families to think about and focus on strengths rather than just disabilities?

Clayton: I'll give the short answer version with links for more detailed information.

Most introductions to Early Intervention begin by stating your child's name and diagnosis and working from there. Sometimes we even get to add a number identifying ability.

So how do we focus on strengths when we are guided towards deficits right from the start?

The Now and Next co-creators set out to recalibrate a deficit-based system, motivated by their own experiences and the challenges they had faced. They designed a process which embeds the vision that families have for their child, in order for them to have a rich and rewarding life. They then embedded game-like principles to create an empowering experience for participants.

The experience of reflecting on the first strengths that they identify encourages parents to share these with others, and in turn they get more strengths ideas. They break down the first strengths they chose and think about the other qualities that their child displays and share these with other participants. These strengths and attributes become the basis upon which families begin reviewing how these positive qualities can be harnessed to create a good life for their child. Participants borrow from each other's strengths ideas and get inspired to discover even more strengths.

Through this simple approach the child is brought into the room (metaphorically) and introduced through their strengths - rather than through a diagnosis.

Starting from the human being instead of the medical model and then setting goals based on a positive future rather than deficit eradication sets families on a capacity-building trajectory.

Q2: Do you have some specific tools to help families develop a vision?

Clayton: Yes. We have launched and trialed an innovative vision-setting tool that families can truly lead. It is also an essential tool for professionals and organisations wishing to engage in Family Centred Practice.

Pictability^(TM) is a game-like tool for parents to create their positive, strength-based vision for their child, their family and themselves, which marks the start of the Now and Next program. During the vision setting activity participants discuss their child's strengths, design their aspirational vision and long term and short-term goals for their child, family and themselves which they assemble onto an engaging 'Action Board', clearly delineating focus and action points.

Pictability visuals were co-created with families to build capacity whilst growing wellbeing and flourishing (Adler & Seligman, 2016) and designed by an alumnus of the Now and Next program. The process of building the tool was informed by evidence about how parents use Individualised Funding to achieve their goals (Mahmic & Janson, 2018).

The tool includes multiple cards and boards designed to support parents expanding on ideas to create deeper and more meaningful (i.e., developmental, social, learning) children goals as well as family and personal goals for themselves. The visioning experience lasts about 1.5 hours.

Click on www.pictability.org for a short video clip describing how the Pictability tool works and on <https://plumtree.org.au/pictability-reaches-a-milestone> to read about how an organization has embedded Pictability as they redesigned their service pathways.

Q3: How can an organization/agency host a Now and Next program? Are there prerequisites to provide and host the program for families?

Clayton: On a technical level any organisation working with families with a child with a disability or delay may host a program. It requires a willingness to embrace the program and encourage families to be a part of it. As a guideline the cost of the first program for a group of up to 20 parents with two of our facilitators is around \$12,000.

The key prerequisite is an understanding that this is a peer led program. Hosting a program for families is the initial step. It allows families completing the program to be selected for training to become Facilitators themselves. You are then positioned to run future programs with your own team of peer workers. So, the answer to the question of pre-requisites comes back to more than wishing to provide the program to a set group of parents but a desire to create an integral element in providing agency to all families whose journey you have been invited to be a part of.

It is important to note that the programs can be conducted either onsite or via Zoom conferencing. A certain advantage where some countries are already prohibited from group gatherings due to the Covid 19 outbreak. It also allows for participation by families isolated by distance or circumstance.

Hence, we aim to help you develop local capacity. We do this by developing local 'Hubs', starting with the identification of potential with the families that attend the first program and continue developing their emerging leadership through a Facilitator training program. This training program is suitable for organizations that wish to develop a Peer Workforce - beyond facilitating the program. It is a flexible distance program that builds family capacity! The advantage for organization is that you will be able to do "reverse recruitment" through a process that we developed to identify which of these participants have the potential to become Peer Facilitators and contribute back to the organization which provides services to their son or daughter.

Q4: Do you sell your Curriculum?

Clayton: *The curriculum is not sold on its own. To maintain the fidelity of the programs and therefore the experience of family and professional participants only Plumtree Learning accredited facilitators are able to present Pictability and Now and Next programs. The programs themselves can be purchased for facilitation by Plumtree Learning or an organisation may create its own Hub of Peer Facilitators. We cover this further below.*

Q5: How much time to become a peer trainer? Is it by conference call or online training? What type of content do the Peer Workers receive?

Clayton: *I take your question to be about becoming a "peer facilitator" as at present training of Trainers is conducted only by Plumtree learning. To become a peer facilitator requires the prerequisite of having*

completed the Now and Next program as a parent or carer of a child with a disability or delay. The candidate parent or carer must then be invited by the Organisation in consultation with Plumtree Learning, to undertake the Facilitator Training program.

- *How much Time: 48 Hours*

The Facilitator Training program is unique in its practical approach. Participants will be trained while conducting a Now and Next program to a second family intake from your Organisation. This is supported by 10 hours coaching prior to the commencement of the program and 9 x 2 hr Just in Time sessions prior to and after each Now and Next Session that they are conducting.

- *Is it by conference call or online training?*

The coaching elements (28 hrs) are conducted via Zoom conferencing but may also be combined with on site training if that is preferred by the organisation. The practical facilitation of the Now and Next program (20 hrs) is recorded, viewed and analysed by the Plumtree learning peer trainer.

- *What type of content?*

Summary of the Training Program includes a total of 48 hrs of learning:

- *Stage 1: An initial 10 hours formal training*
- *Stage 2: 20 hours hands-on experience [facilitating the Now and Next program]*
- *Stage 3: 18 hours coaching and discussing their facilitation experience before and after sessions*

Stage 1

Session 1: Rationale and theoretical background

Session 2: Formulating inspiring goals that are achievable

Session 3: Learning how to achieve goals through our bespoke Goal to Action tool

Session 4: Person-centered facilitation

Session 5: Data collection, administrative responsibilities and data entry in our bespoke data collection platform

Stage 2 & 3

1. Setting a long-term vision and prioritising Child Goal, Family Goal and Personal Goal, with Pictability
2. Using our bespoke "Goal 2 Action" coaching tool to achieve Family Goals and reflect on the impact of our actions
3. Using the Goal 2 Action tool to achieve Child Goals reflect on the impact of our actions
4. Using the Goal 2 Action tool to achieve Personal Goals reflect on the impact of our actions
5. Focusing on Signature Strengths and harnessing them to use to work on goals
6. Understanding flourishing and what practices can enhance wellbeing for different people
7. Partnering with professionals to increase agency over our goals
8. Toolkit review and practice situations in which tools can be most effective

Q6: How is Now and Next funded?

Clayton: In its inception various grants (New South Wales Department of Premier and Cabinet, Workforce Innovation Fund, ADHC) were received in order to allow the program to be piloted to families.

- The funding landscape in Australia has changed considerably since then with the advent of the NDIS (National Disability Insurance Scheme). Our programs were launched at Plumtree, an Australian not-for-profit organisation that provides support for young children aged birth to 8 years old with a developmental delay or disability and their families. Currently, the Now and Next programs are paid for by organizations that wish to undertake the program for their families or directly by families who self-manage their funding package. In Australia, organisations either access funding through government or private grants or parents are able to pay for the program using funds from their individual funding package, under the NDIS.
- In New Zealand, the programs were launched through Social Innovation Funding from CCS Disability Action in collaboration with the McKenzie Centre (www.mckenziecentre.org.nz) an Early Intervention Centre. The McKenzie Centre then applied for and received philanthropic funding (JR McKenzie Trust) to support the Now and Next programs for the next 3 years together with the development of a peer workforce and an alumni group. Another program initiative was also piloted through the government System Transformation Capacity-Building funding. A Good Start in Life, a collaborative cross-government action research project to understand the barriers and enablers to partnership working in Aotearoa/NZ adopted the Parent-Professional Relationship Statement launched by the Now and Next alumni launched at their first conference in 2017. This statement details how parents wish to take responsibility for their partnerships with the professionals in the lives of their children [<https://plumtree.org.au/the-parent-professional-relationship-statement>].
- In Canada, Kinsight a large British Columbia service provider (www.kinsight.org), started with Professional Development about building family capacity through Pictability, hosted a Now and Next program, and launched their first Facilitator Training. These trainees facilitated their first Now and Next program as part of their practical training (see question 5 above). Kinsight is committed to develop future Now and Next initiatives and trainings to support family capacity building. Kinsight to date has been able to use one time only an unearned revenue to run both programs of Now and Next. Kinsight is in negotiation with their funder to either use any surplus or unearned revenue on an ongoing basis and/or redirect funding from their traditional family support program to the delivery of Now and Next. In addition, they are in the process of seeking the support of a major foundation to help us sustain and embed Now and Next and hope to hear very soon.

Q7: What measurements are being used to measure wellbeing, empowerment, and hope and how is the data collected?

Annick: Our program facilitators are trained as participant-observers and collate data in an ongoing manner during our programs. Our bespoke real-time data collection and review ensures that our facilitators and coaches review participants' progress as it unfolds. All our programs contribute to a global database used to benchmark each program. This level of scrutiny enables us to keep a tight quality control at a distance to ensure that participants' experiences are comparable, wherever they are facilitated.

We measure 4 variables before and after our programs. We consistently find that the increase in each of these is significant, both at individual group levels and over our benchmarking global sample.

The tools that we use are robust and have been extensively peer-reviewed and documented. Our impact research focuses on the following variables (references below).

- Participants' engagement, measured through PCOMs (Partners in Change Management Outcome - Duncan and Reese (2015)).
- Psychological Empowerment Scales (PES) developed by the Beach Center, Kansas University specifically for parents raising children with special needs (Akey, Marquis and Ross, 2000). PES measure (a) Attitudes of control and competence, (b) cognitive appraisals of critical skills and knowledge, (c) formal participation in organizations, (d) informal participation in social systems and relationships.
- Adult Hope Scales (AHS) supporting the cognitive model of hope, developed by Snyder and colleagues. It 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).
- Wellbeing and flourishing, as measured by the PERMA profiler (Positive emotions, Engagement, Relationships, Meaning and Achievement - Butler and Kern, 2015). The PERMA-Profiler is a brief multidimensional measure of flourishing, endorsed by the University of Pennsylvania Positive Psychology Department.
- We also coach parents/families to formulate long term goals and achieve associated short-term goals during our programs: child goal, family goal and personal goals of parents. Short term goal achievement ranges between 90.7% to 96.9% as per our 2019 global results of 447 participants across 4 countries (Australia, New Zealand, Finland and Canada).

More info and references at: tinyurl.com/Research-principles

Link to the 2018 external evaluation of the Now and Next program carried out by Dr. Tim Moore's team at the Melbourne Children's Research Institute:

<https://plumtree.org.au/now-and-next-an-external-evaluation>

Q8: How strong is the self-advocacy movement in your nations? Do self-advocacy organizations get funding?

Sylvana: Thank you for the question, this answer is my personal reflection of the situation. The self-advocacy movement in Australia has been poorly funded in the past however, they have always been active, passionate and influential in my opinion. Advocacy and self-advocacy have more recently been under threat under the new individualised approach of the National Disability Insurance Approach. For the past few years, there has been a lot of lobbying to argue to the government that advocacy and self-advocacy are even more important under an individual funding approach. It is reassuring that this message is finally getting through.

- There are more talks with our government about this and recently the NDIA invested into Disabled Person Organisations and Family Led Organisations. For more information on this <https://www.ndis.gov.au/community/grants/funded-projects#disabled-people-and-families-organisations-dpfo-grant-round> where you will find a list of recently funded organisations.
- You can learn more about one organisation Valid here <https://www.valid.org.au/> and hear from their CEO here: <https://www.disabilityservicesconsulting.com.au/podcast-ep13>

- For a practical presentation delivered by one of our peer workers at a family conference read or watch <https://plumtree.org.au/fostering-your-childs-self-advocacy-skills-l-dr-melanie-heyworth-l-now-and-next-conference-2018/>

Q9: To what extent or what "portion" of the process are the families prepared for dealing with politics in advocating?

Sylvana: This is my personal interpretation of the question and I speak on behalf of myself as someone who works primarily with families of young children Birth-to-8-years old. Families who have children this age are primarily focused on learning about their child, understanding the impact of this on their lives and how they as parents can support them. Most families are fully occupied with these priorities. However, they have so much to offer in terms of supporting the broader community to understand the particular issues that they face. These can be different from those that adults advocate for. Both are important. One organisation seeking to bring together families and adults with disability is Reframing Disability, a very new organisation which has only been going for 6 months <https://www.reframingdisability.com.au/>. I encourage you to read/watch this speech delivered by the Executive Officer Stacey Touma which she delivered at the recent International Society of Early Intervention Conference held here in Sydney 2019 which has been influential in shining a light on the specific issues facing families of very young children. <https://plumtree.org.au/our-journey-to-a-family-centred-early-intervention-experience/>

Q10: Does this program also work for children with mental illness as well? How many families do you have participating that are dual diagnosed? Is this a program for children with severe mental health as well?

Sylvana: We developed the program for families of a child with a disability. We have had some families who are foster parents attend and they have felt it was applicable to them. We cannot make any claims about the impact of the program on parents of children with mental health as we have not specifically collected data about that.

Q11: Clayton, do you think that approaching fathers initially by asking for their participation to support the other parent, rather than as a goal-setting program for their child, might be beneficial? I think that for my husband that could be the "hook".

Clayton: The challenge is that it takes participation in the program to understand how much we really need it. I recall that I believed I had goal-setting sorted. But goal setting was a small element of what I gained. So yes, if that is the hook that works for you, cast away. And if that fails, I urge hiding the TV remote and refusing to divulge its whereabouts or withholding conjugal rights. I guarantee he will thank you in the end. **I think.** Who can ever be sure?

We polled our global alumni dads and here were some points that they would share with other dads:

- *"Attending together with your partner will lead to better results because you will make decisions and implement them together"* (14 answers)
- *"Partnering with my wife to grow more together in our child's needs. Started to see more of where I stood with my whanau (extended family/clan in Maori) and where I needed to focus more for my whanau. I'm a better dad because I am working with my wife and kids"*

- *“It’s an activity that we can do together... It also strengthened my marriage. Sometimes my wife felt like she was on her own so yes would recommend this programme for dads (solo or in relationships)”*
- *...“Also strengthens the partnership between spouses communicating with each other same page”*

Q12: The Now and Next program sounds very collaborative and interactive among the participants. I’m both a parent of a child with disabilities, and I work with other parents as a Family Network Coordinator. I know that my husband in particular would be uncomfortable in this type of setting, I’m wondering if you have encountered “reluctant participants” and how you overcome this?

Clayton: Please let me firstly declare that I am in no way an expert in this area, but I do have a little acquired knowledge on the subject.

I think that it is essential that when facilitating we accept a diversity of personality types and avoid any homogenised expectation of participant reaction. Firstly, a person should be encouraged to participate but never pressured or coerced. People will often find their own way of joining in, in their own time and there should never be an assumption that because someone is not vocal, they are not engaged, involved and benefitting from participation.

I believe that doing the program as a couple may provide some relief from individual focus and that the more reluctant participant may find the use of their partner a welcome conduit for exchange rather than the overwhelm that may be experienced by speaking or sharing directly with a dozen strangers. Again, this may also be something that eases over time, as familiarity sets in. Here is a blog post I wrote about our personal experience as a couple: <https://plumtree.org.au/impact-parents-now-next-together-auto-ethnography/>

Perhaps changing the environment might alleviate any reticence in participation. This may be achieved by taking the program over video conferencing which may reduce the feeling of being under the spotlight, trapped and unable to retreat. It may also comfort the participant to be in their own space controlling their own territory.

Thank you so much for this question. In answering it I have recalled just how much I have been taught by my five-year-old son and how much has stayed with me since I walked into Now and Next with my wife 4 years ago.

Q13: Can this program be adapted across the lifespan, not just for families with young children?

Annick: The families we worked with initially were very keen to help develop a program for parents of older children. We packaged the learning from our Now and Next research into CitizenYou, a 20 hrs program for parents to coach their teenagers and young adults, and 2 follow up sessions.

CitizenYou is an evidence-based program, based on adult learning best practices, where parents come together with the professionals and/or teachers in their children’s lives to learn together and build sustainability into their lives. The foundational theory of this program is the ‘Keys to Citizenship’ formulated by Dr. Simon Duffy as core to a good life for people with disability and their families. The

concept of citizenship goes beyond that of inclusion because we are all citizens, and all have rights and responsibilities as citizens.

During the program, participants build an aspirational vision for their family, their child and themselves, whilst strengthening empowerment, hope and wellbeing. They are also guided about coaching their son or daughter to make goals, learn from the process and strengthen their voice in the process.

The evidence shows that when parents are actively involved in such a coaching process, their son or daughter gradually learns to improve with goal setting, goal achieving and the decision-making process, which help strengthen their voice.

Elements of this program were piloted and a research program built to evaluate its impact. Contact us for more information and program details.

Reference

Duffy, S. (2010). The citizenship theory of social justice: exploring the meaning of personalisation for social workers. *J. of Social Work Practice*, 24(3), 253-267.

Q14: I was glad to hear that this program is evidence-based. However, I guess the 'evidence' is established in the Australian context where it is presumably rich in professional resources. How would we use the 'evidence' wisely and adaptively if we want to administer this program in a low-resource setting?

Annick:

Building the capacity of families to create a new peer-workforce can benefit a variety of situations.

Our evidence was gathered from 4 countries: Australia, New Zealand, Canada and Finland. Whilst it is true that these countries are rich in professional resources, they also experience acute workforce shortages.

On the one hand, if we consider the low-resource setting mentioned in the question, we can see how governments would see fast Return on Investment on up-skilling parents and families with programs such as the Now and Next suite of trainings. Here is a link to our research on Peer Work:

<https://plumtree.org.au/research-on-peer-work-in-eci/>

In both cases, a peer workforce could be identified and trained through the mechanisms described above. Families raising children with special needs would greatly benefit from a flexible peer workforce that can mentor and support them, whilst workforce shortages are addressed in either cases.

We are looking for partners interested in training and deploying peer workforces in countries with fewer resources or workforce shortages as such interventions at these 'leverage' points of disability sectors can create great impact. Please contact us if you are interested in such opportunities.