

Now and Next

AN INNOVATIVE LEADERSHIP PIPELINE FOR FAMILIES WITH YOUNG CHILDREN WITH DISABILITY OR DELAY

by **Sylvana Mahmic** and **Annick Janson**



Citizen Network
FOR A WORLD WHERE EVERYONE MATTERS

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FOR FAMILIES WITH YOUNG CHILDREN
WITH DISABILITY OR DELAY

by **Sylvana Mahmic and Annick Janson**

with an overview by **Dr Melanie Heyworth**



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Front cover photo: Parents at the peer worker and family leadership training weekend held at Plumtree in 2018.

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FOREWORD



It is exciting to publish this report because it describes a new high-point in the development of family-centred work. The idea of being family-centred has been with us for many years, and it does describe the approach of the best professionals: respecting the family's expertise and supporting the network around the child. But too often professional power still dominates the family's experience and negative stereotypes and expectations can build up which stop the family moving forward with hope.

Part of the answer to this is to make peer support - family to family support - an essential component of the way forward. But *Now and Next* goes beyond the normal patterns of peer support to develop an approach that has both rigour and depth. *Now and Next* has developed methods of planning, reflection and mutual support that really lift families to a new place of strength.

Now and Next takes the best of professional expertise and puts at the service of families, without abandonment and without dependence. I am sure the growing ranks of the *Now and Next* Alumni will provide us with the foundations for a new wave of innovation, inclusion and active citizenship.

Simon Duffy
Director, Centre for Welfare Reform

OVERVIEW

By Dr Melanie Heyworth

Challenging the Status Quo

Now and Next is a unique, peer-led group program for families of young children who have developmental delays or disabilities. Over recent years, this program has evolved to become a cornerstone of the early childhood intervention (ECI) service delivery for one ECI provider, Plumtree, located in Inner West Sydney, Australia. *Now and Next* is grounded in Positive Psychology and Post Traumatic Growth (PTG) theories, but it also utilises the demonstrated benefits of gamification and mindfulness, and builds on best practice research into family-centred practice. *Now and Next* is the first totally ‘by families, for families’ program of its kind to be offered in Australia and worldwide. By challenging the traditional ‘grief’ mindset often associated with disability, and replacing grief with the concept of overwhelm and the promise of growth, *Now and Next* supports families to engage in authentic, creative visioning for their disabled child and for themselves.

Since its inception, some 250 families have participated in *Now and Next*, which was initially led by both peer family facilitators and professionals, and is now led solely by peer facilitators. Families from culturally and linguistically diverse backgrounds total 48% of the participants. Fathers’ engagement range between a quarter to half participants, depending on the activities organised. Groups have, or will be, run in Vietnamese, Korean, Arabic and Chinese. The program begins with a visioning session, followed by an 8 week, 2.5 hour per week, protocol. Program elements are aimed at progressing children’s goals by engaging their families. Through interactive group work, the program supports families to vision, plan, set goals, and develop goals into action, in the context of a peer led environment.

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Changing Core Beliefs

Families of young children with developmental delays and disabilities are faced with challenges that are especially prevalent and magnified in the initial years after diagnosis. Importantly, these families find it difficult to understand, appreciate and take advantage of their unique role as the leading expert in their child (Kendrick, 1995), instead deferring to professional expertise and experience. Research shows that families struggle to effect meaningful input in their child's goals and developmental journey because professionals are often esteemed – by both families and allied health workers alike – as the preeminent expert (Allread, 2015). This power differential can undermine families' feelings of confidence and self-efficacy, and it weakens their drive to build their capacity and leadership. Families hesitate to 'lean into' genuine professional partnerships, relying on and referring to the dominate influence of the professional.

The ramifications of this unequal power difference are wide-ranging and significant. For instance, families often seek to address their child's challenges with external therapies, and miss the significant impact that they themselves have on their children (Mahoney & Perales, 2011). Moreover, families can find it difficult to assert themselves to achieve genuinely family- and child-centred ECI, which is key to best practice service delivery (ECIA, 2016). Equally importantly, programs explicitly purposed to build family leadership and capacity are limited or non-existent in the ECI sector: families themselves, and the professionals who support them, often fail to see the need to build family capacity since they erroneously perceive that it is a professional's capacity that is most relevant to the child. Most crucially, parents are often adversely effected by the 'grief' model so often adopted by professionals. Within this grief paradigm, professionals often dismiss families' feelings of overwhelm as denial, and families struggle to reframe from a grief-based, deficiency approach to see their child's strengths and gifts, and to envisage the possibilities for their child's future (Janson, 2015; Kearney & Griffin, 2001). They lose their capacity to dream and vision for their child.

Now and Next: A Strategy

Now and Next acknowledges the significant challenges facing families in such circumstances, but it reframes these challenges within the lens of the Positive Psychology and PTG theoretical paradigms (Roepke & Seligman, 2015) to encourage family growth, capacity building, and leadership. PTG describes the process by which families can transform their initial grief and overwhelm, into positive mediators for growth, hope, and strength.

Engaging families in authentic partnerships requires a reconsideration of the preliminary planning sessions between families and professionals. *Now and Next* thus creates a unique space for families to go through an initial creative visioning phase, and offers a new context for families to engage in dreaming for their disabled child from the earliest days of their ECI journey. By employing an image-driven prospection process (called *Pictability*©), a customised and customizable eBook application, and a range of 23 different processes to scaffold learning, including program resources, participants are offered the opportunity to explore and develop their child's – and their own – strengths and capacity. The program incorporates effective and achievable goal-setting, as well as explicit planning for the transformation of goals into results, and addresses the generalization and transference of these skills beyond the program. *Now and Next* participants can thus communicate their goals clearly, and can envisage the strategies that might be used to progress them; they are also better equipped to exercise their natural authority (Kendrick, 1995).

Using the principles of gamification and mindfulness, *Now and Next* disrupts the power imbalance between families and professionals by empowering families with agency and building family capacity. Importantly, *Now and Next* is a conduit by which parents share, support and encourage each other within a cohesive peer network that facilitates the transfer of parental knowledge and expertise, and fosters agency and self-efficacy. The *Now and Next* journey is effective in large part because it occurs within the context of a resilient peer network, which extends genuine and empathetic assistance and encouragement to participants. Families who have experienced this kind of shared authentic and deep visioning process gain the confidence and ability to face professionals with increased leadership.

The Leadership Pipeline

Throughout *Now and Next*, new family leaders are recognised, and participants who demonstrate leadership capacity and interest are identified, recruited, trained, and employed by Plumtree to fulfill a range of roles, including the delivery of the group program. Importantly, new leaders learn to take responsibility for succeeding in their own journeys, and thereby have maximum impact when they support other families to have increased agency. By utilizing the diverse strengths of its participants, *Now and Next* fosters a cohort of peer leaders to champion and sustain improvements to family participation in the ECI sector, as well as to model to other families how best to avoid long-term over-reliance on the system.

More broadly, the *Now and Next* Alumni (NANA) continue to be part of the peer network after the formal conclusion of the program. The idea of building an enduring peer network is attractive to participants who experience empowerment in *Now and Next*, and want that energizing support to endure. NANA's collective agenda is to inspire a new generation of parents to lead their family's progress, drawing on a sustainable peer-networked foundation of knowledge, capacity and creativity. This purpose stems from the fact that families are acutely aware that peer support is beneficial, reliable and committed, and has the potential to create the impetus for a social movement, led by – and for – families (Kendrick, 2010).

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1. Defining the challenge

For many years, practitioners have been grappling with the challenge of how to build leadership in families with young children with disabilities and developmental delays, even though we know that starting this leadership journey early offers significant promise of fundamental and long-lasting change for families. This report describes a potential solution to this problem by examining the evidence-informed group program called *Now and Next*, its role in developing a leadership pipeline, and the emergence of the first Australian peer network for families of young children who have developmental delay or disability.

The *Now and Next* program has emerged in the context of the Australia-wide rollout of the National Disability Insurance Scheme (NDIS), a national health-care initiative, which promotes independent, outcomes-based management of funding plans for individuals with disabilities. *Now and Next* has been developed by the staff and academic partners of an early intervention service, Plumtree, in Sydney's Inner West.

Capacity building and family-centered practice

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There is a demonstrated need to place a greater focus on the role of families in participating as partners in early childhood intervention by engaging them as early as possible. During the initial period after diagnosis, families often become intensely focused on gathering information, and finding and then engaging services, in an effort to maximise the benefit of early interventions for their child. Many families look to increase therapy services at this time, and fail to appreciate that the single most significant impact on the child, is the family (Mahoney, 2011). Years may pass before families recognise the importance of investing in their own capacity, and even then, learning how to do this is an ad hoc process with scarce resources to assist them.

While some capacity building initiatives are provided by advocacy organisations, these do not specifically target families of very young children (Escalon, 2016). By integrating family capacity building activities within early childhood intervention services, targeted, intentional programs can reach and impact this population, as we will show. It is in the long-term interest of families that they have multiple opportunities for capacity building from the earliest possible point, which will lead to better outcomes for the child and family as a whole.

The paradox is that the bureaucracy originally set up to protect and ensure family participation in the planning process, has in fact limited their meaningful input. Lee (2015), for instance, described how the very legislation that was meant to protect families by ensuring that their perspectives would be taken into account, actually resulted in the bureaucratisation of the planning process by professionals so that the latter often took

an overly directive lead in their interactions with families as a result. However, short of recommending even more training for professionals, there are no real solutions to get better outcomes from an Individual Family Service Plan (IFSP) type of question-and-answer process led by professionals. Indeed many professionals describe their philosophy as 'putting families in the driver's seat', yet the process itself is prone to misuse and tokenism – too often taken over by professionals (Mahmic, 2016).

Some theorists have also outlined the potential for an unequal power differential between professionals and families raising disabled children, in which the former are held as the preeminent 'experts' who have all or most of the answers. For professionals to shift their power from expert to embrace a family's expertise and perspective, they must adopt Dunst and Trivette's theory (2009) that family capacity building can be undertaken through the Family Centered Approach. This radical change has not yet spread in the sector. The challenge is to make it happen now and to change the parent-professional power relationship, requiring professionals to forgo some of the power they have wielded until now (Allread, 2015).

Family-centred practice is central to the best practice approach in early childhood intervention (National Guidelines on Best Practice in Early Childhood Intervention, 2016). Research on family-centred practice has led to an update of the model to highlight the element of intentional capacity building as a mediator of the benefits for intervention with families (Dunst & Trivette, 2009). The capacity-building paradigm uses a strengths-based approach to focus on building the supports, resources, experiences and opportunities for parents, children and families. However, despite over 20 years of evidence reinforcing this approach, it is still common for families to experience traditional deficit-based models where professionals are situated as experts to the detriment of parental expertise.

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Challenging professionals' perspectives about partnerships

A diagnosis of disability for a family's young child starts in motion a series of encounters with professionals that are very influential for years to come. Allread (2015) describes how these interactions are mostly done from the perspective of professionals as experts applying their expertise to families experiencing grief. Janson's (2015a) research showed that families later report encountering difficulties steering away from 'deficiency approaches', with professionals either emphasizing their child's weaknesses or undermining families' abilities to make the right decisions. Families also describe professionals interpreting their feeling of overwhelm as grief – and when they protested – as denial (Kearney and Griffin, 2001).

Authentic partnerships can only happen when both service providers break away from the tyranny of the grief models and when families build agency: these conditions must be fulfilled simultaneously. These conditions allow for more “balanced relationships between those in authority and general citizens, and between service providers (such as doctors and allied health professionals) and consumers” (Moore, 2012, p. 32).

In order for professionals to build authentic partnerships with families, then, the former will have to step outside of the grief model with its built-in 'help' relationship and instead meet families half-way on more equal terms. However, simply training staff to enter such new partnerships is insufficient: on its own, training reinforces a structural problem, which is that it is the professionals' role to teach the family how to be a partner. Training Early Childhood professionals cannot replace family capacity-building, which supports families to learn how to partner on equal footing with professionals. Without this capacity building for families, authentic partnerships between professionals and families will never truly be balanced. We believe that peers are in a privileged position to coach each other to take responsibility for building stronger partnerships with professionals.

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2. A potential solution

Shifting practice from a grief lens to post-traumatic growth approaches

Martin Seligman, one of the architects of the Positive Psychology movement, developed the Post Traumatic Growth (PTG) concept (Roepke & Seligman, 2015), which offers an appropriate and beneficial way to see beyond the 'grief' model, whilst still acknowledging the challenges of the family (Lopez and Kerr, 2005). PTG interventions target growth using strategies that gently elicit progress without dismissing suffering or attributing it to personal failure (Roepke, 2015). Carrying out a meta-analysis on PTG research, Roepke noted that the mediators of change are challenging assumptions, reflecting practice and new learning. Instilling hope is another mediator of change (Snyder, 2002). Roepke (2015) concluded that there are good indications that these mediators may foster PTG but called for further research to develop more measurements and theoretical developments to explain these growth mechanisms. Jarden (2009) also reviewed research illustrating how some people can become stronger after negative experiences, and noted that the list of conditions researched by PTG researchers is growing to include medical conditions such as cancer, heart disease, HIV, paralysis and infertility, or extreme experiences such as house fires, combat, plane crashes, rape, assault, bereavement and earthquakes. Jarden's review shows people benefitting in three ways from trauma, beyond the traditional notions of self-efficacy and internal locus of control: firstly, revealing abilities, thereby enhancing a person's self-concept and inoculating against future pressure; secondly, intensifying important relationships, and thirdly inducing priorities and changes in philosophies towards the present and others.

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Families starting new conversations with professionals

The authors of this paper acknowledge all of the challenges facing families of children with disability. However, approaching a professional relationship with families from the grief model perspective leads families to focus on what is not working for them. Our experience has shown that powerful change interventions can take place when reframing families' experiences as overwhelm rather than as grief. Given recent neuroscience developments that have emphasised the connection between presence, focus and outcomes (Hanson, 2013), the concept of overwhelm leaves more room for parents to focus on the action needed to start seeing progress for their child.

3. *Now and Next* as a strategy

Based on evidence collected over six years, the *Now and Next* program was developed to build family capacity and decision-making supports. Through our research, the authors, alongside families, co-developed the *Now and Next* mechanism and resources to engage families at the point of early intervention, based on the PERMA (Positivity, Engagement, Relationships, Meaning, Achievement) wellbeing and flourishing framework (Seligman, 2013).

Between August 2016 and April 2018, some 250 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. Families from CALD (Culturally And Linguistically Diverse) backgrounds totalled 48% of the participants. 23% of participants were males, with this ratio growing to 50% at the Alumni conference. Groups were run in Vietnamese, Korean and Arabic, and plans to run groups in Chinese are underway.

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The program begins with a visioning session, followed by an 8 week, 2.5 hour per week, protocol. It utilises curriculum based on positive psychology and family-centred practice in order to build family agency, leadership, and collective capacity as a group. *Now and Next* replaces the 'grief paradigm' with theoretical constructs drawn from positive psychology research (Damon, 2008; Seligman, 1990, 2011; Seligman & Csikszentmihalyi, 2000), which provides a robust foundation to understand the transformation from 'grief' to 'growth'.

Program elements are aimed at progressing children's goals by engaging their families. Through interactive group work, the program supports families to vision, plan, set goals, and develop goals into action in the context of a peer led environment. Together families explore how to use the individual funding provided in the program to help meet goals so that they learn some of the skills needed to manage Individual Funding provided on a national scale through the NDIS. Families learn to develop their inspirational long-term vision for their child; peers assist each other to build skills to achieve positive outcomes for their child and family, whether these families will be eligible for funding or not.



A radically new way of visioning and planning actions

When developing *Now and Next*, we recognised that engaging in authentic partnerships requires a fundamental rethink of the initial planning sessions between families and professionals. We therefore concluded that a new process could be devised where families take a lead role in planning. Guided by parents themselves, this process takes families through a very creative dreaming and visioning phase where they are supported to imagine possibilities for their child and family. This process, which we have called *Pictability*®, begins the *Now and Next* program. Families who have experienced an authentic deep visioning process gain confidence and the ability to face professionals on a different footing (Janson, forthcoming). Families going through the *Now and Next* programs can thus communicate their goals clearly and can envisage the strategies that might be used to progress them; they are also better equipped to exercise their natural authority (Kendrick, 1995).

When the *Now and Next* journey starts with the *Pictability*® game, families are offered a radically new way to prospect and vision the future they want to build for themselves and their child. Building on the work of Christian et al (2013) on action goals and temporal distance, we harnessed the central role that images play in people's ability to preview the future through prospection.



Participants’ comments supported this finding, showing that visuals “enhanced the prospection of alternatives” (Seligman et al, 2013) in the brainstorming stages of the visioning process:

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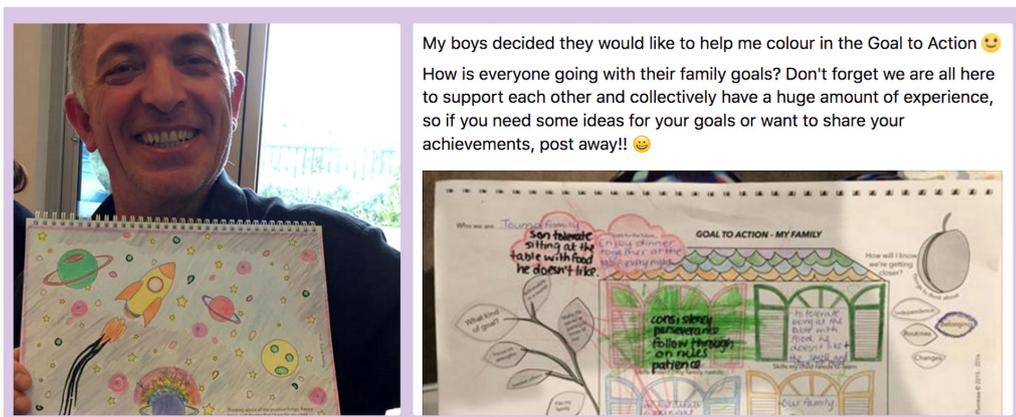
The visuals in Pictability© were extremely helpful in thinking about my child’s future progress. The images inspired me in designing new goals in ways that Individual Family Service Plans could never. On the contrary, during the IFSP I almost froze when asked about goals for my child and felt disempowered at having one or a few professionals question me this way and to add insult to injury, when I received the typed up report 3 weeks later I never recognised the goals we talked about. Pictability© on the other hand was fun and empowering, it was obvious that my husband and I were leading the process and thinking up so many meaningful goals for my child... and we received the visual summary of our session with all the goals we had written in our hand writing as the session ended!

Jane

The visioning process used in *Now and Next* builds on gamification principles, using game design and mechanics to ‘hook’ players’ interest to address a challenge and achieve their goals. To explain how game-induced behaviour changes can improve health and wellbeing, Paredes et al (2013) showed that gamified progress can act as a proxy for self-efficacy. Eliciting progress is a key element of game design, which effects behaviour change, and is a conduit to players’ insight that change is possible (Rodger, O’Keefe, Cook & Jones, 2012). Gamification principles also explain how visioning with *Pictability©* can provide participants with an ‘energy boost’: participants experience potential future outcomes that are hopeful and positive, and begin to envisage and plan how to rally

natural and community supports to help them to fulfill their goals. Lopez and Kerr (2006) name such bursts of mental energy, 'agency thinking'. In addition, as far back as 2004, the potential for positive psychology to influence early childhood intervention practice was identified (Johnston, 2004), and the *Now and Next* program extends this PTG concept to parenting young disabled children so that *Now and Next* families reported experiencing an initial energy boost from the very first weeks of the program. This energy boost, stemming from their first experiences with *Pictability*®, indicated to them that they were 'on the right track' so that old undermining beliefs started to be replaced by new empowering thoughts, laying the groundwork for further positive changes (Lopez and Kerr 2006; Winter, 2013).

The *Now and Next* program also employs gamification to disrupt participants' past negative experiences and to engage deeply with families in mindfulness experiences; it equally uses fun and collaborative activities based on adult learning principles. Between sessions, families interact with each other and the peer facilitators in the social media space that they create for this purpose. Families report that the program stimulates them to start fresh conversations with professionals, since they feel newly empowered by both the technology and the process inherent in the activities, thus enhancing the impact and sustainability of the program's outcomes. Our methodology also rested on the gamification principles enunciated by Reeves and Read (2009) who demonstrated how these principles tapped into the basic desires and needs of users, using their intrinsic motivation to overcome challenges and achieve goals through engagement. This principle was evidenced in our case in the way families engaged with the group process and with facilitators (Mahmic et al, 2015).



Damon (2008) understood a sense of meaning and purpose as a model of strong future direction. Much theorizing about change emerged from work on hope (Little, 1996) and optimism (Seligman, 1990, 2011). *Now and Next* participants have confirmed 'building meaning and purpose' (Seligman et al, 2013) as they experience (re)discovering, uncovering or voicing their dreams for their children and families, and then pursuing them. This experience happens in part when participants learn to uncover inner strengths and reformulate them into 'affirmations', 'mottos' or 'signature strengths'. These reformulations are evidence of construction of authentic meaning and purpose because they are borne out of people's real learning experiences.

The above processes are reinforced by a mindfulness colouring book that accompanies family learning. Though research into the field of mindfulness drawing is in its very early stages (Hanson, 2013), initial results indicate the positive role of mindfulness on enhancing well-being in clinical settings, although there remains work to be done to build

measurements tools to show its impact (Brown & Ryan, 2004). We prototyped our *Now and Next* mindfulness colouring book as a potential measuring tool in the data collection process.

Impact on child, self and family: Putting our oxygen mask on first

Families join the *Now and Next* program with the primary aim of helping their child; however, it is often the caregivers themselves who initially feel the most profound benefits from the program. Paradoxically, these same caregivers reflected that they would not have enrolled if they had been told to join the program to benefit their own learning. They nevertheless reported that creative visioning, coupled with experimentation and strategies to transform goals into results, created a welcome change.

The program added personal goals - it is not about being selfish, it's a necessity to survive! "When you fly, instructions are to put the oxygen mask on yourself first" [and then help your child second]!!

Mark

Following the first progress towards achievement of their child's goals, participants described experiencing a boost of energy, which in turn reinforced their engagement with the program more broadly. Participants also discussed early signs of burnout and identified the self-care needed to address it, such as addressing family-life balance. These experiences taught families how to set and implement achievable goals, which in turn helped them to identify a range of formal and informal supports, and thereby to identify the 'right' amount of therapy required by their child. Importantly, participants began to acknowledge how far they actually could help their child before needing the specific intervention of therapies.

This series of learning experiences delivered families with additional learning 'boosts', which participants often qualified as significant life experiences:

I feel extremely fortunate to be a part of the Now and Next program. I am not exaggerating when I say it has been a life changing experience. Each session has been informative and covered a wide range of topics – not just on goal planning. The facilitators are amazing; they are positive and supportive and their knowledge is invaluable. I don't want the program to end because it has been such an enjoyable experience.

Sydney

In addition, many families described the impact that the program had on them as providing a unique opportunity and a safe space to think about their child’s future with renewed dreams and aspirations:

We joined the Now and Next group program with Pictability©. I cannot speak highly enough about how it strengthened us as a family not only to help our son but it put me and my husband on the same page in terms of supporting our son and how we move forward as a family with a special needs child. We are looking forward to the new year now.

Monique (unsolicited feedback)

Past participants greatly valued the group setting that brought together families raising children with a disability because in building their own agency, their family leadership was enhanced (Janson & Davies, 2014).

I cannot begin to explain to you how wonderful it feels being around other families and having discussions. At first I was concerned that I would feel out of place because my child’s disability is rare and seemed more severe than others. This feeling receded as I discovered we are on a shared journey and each person will go through their own. Throughout sessions, we readily connected on many issues.

Karima

Seeing results brings about a second turning point at which participants begin to make pivotal personal decisions, for example, to cease worrying about those things over which they have no control.



4. Measuring future outcomes

The question of how to measure and report on outcomes that occur after the program finishes, is central to demonstrating its effectiveness: 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?

Although anecdotally we knew that participants learnt new strategies and ideas from each other and empowered and inspired one another, we demonstrated these results by collating field notes (about 30,000 words) and analysing them thematically. The following three themes emerged in our analysis that were relevant to how families used the knowledge and skills which they learnt in sessions.

1. Engaging with new possibilities and using signature strengths

The researchers that coined the term “homo prospectus” (Seligman et al, 2016) expressed their belief that there is tremendous potential in the joint construction of the future. By focusing on their future, the program provides a transformative opportunity for families to inform, support and motivate each other to aim high and see new opportunities for their child. During the program families developed ways to envision their future through the Goal to Action process which assist families to unpack long term goals into shorter range achievable objectives. Families also disproved and disrupted earlier (erroneous) representations of helplessness by experimenting with new ways of doing things and by modifying elements of the situation to test the extent to which strategies are achievable. Now and Next processes lead to participants experiencing a turning point where they leave ‘negative baggage’ behind and let go of the elements of their life and their future over which they have no control. ‘Developing more effective prospection’ and ‘disconfirming unrealistic prospections’ have been described by Seligman et al (2014) as relevant to prospection.

Participants explore new pathways to help their child achieve their goals as well as to foster the family’s own self-development goals. In doing so, participants identify their strengths, and the Now and Next processes assist them to repack their signature strengths and use these when facing future challenges. Examples of self-affirmations were: “we are on the right track”, “I can achieve anything I decide to”, “I am a good planner and can use this skill to help my son progress”.

In their pivotal research, *Doors opening: A mechanism for growth after adversity*, Seligman and Roepke (2015) describe in depth how people who engage with new possibilities after traumatic experiences experienced positive outcomes by pursuing those possibilities:

... existing work on core belief disruption suggests that people obtain benefits by reflecting on shattered beliefs after a crisis. Here we suggest that growth can happen without this existential earthquake, through attention and imagination, people who see and pursue new opportunities may derive great benefit as they move forward after adversity.

Seligman and Roepke (2015 pp. 113-114)

Our research responds to Seligman and Roepke's call for prospective observational studies to test the relationship between engagement as an adaptive strategy on the one hand, and growth on the other.

In earlier research, Seligman showed how using one's strengths (2005) has proven a very powerful intervention. Our participants use their strengths by actively identifying and embedding them in the many everyday actions connected to working on goals, thus using strengths to create defined growth outcomes.



2. Applying learning across settings and beyond the program

Participants report applying their learning beyond sessions as they learn how to build new social skills (Seligman et al, 2013), such as formulating active-constructive responses to good events, or reaching out to other professionals to define more precisely the help needed from them. The former was addressed using mindfulness exercises and the mindfulness colouring book, as well as through the sharing of multimedia evidence (for instance small video clips) to celebrate successes (“with *Now and Next* we learnt to celebrate ‘inchstones’ when milestones were too far out”, Josey). The latter emerged in ongoing conversations with families after they graduated from the program.

The paragraph below was extracted from an (unsolicited) email sent by a participant to her son's headmaster asking for different types of interventions to take place at school to address the goals she had crafted for her child during *Now and Next*. The family did not feel that they had enough control over the school IEP, which had focused on academic goals; they wanted educators to put more emphasis on their child's social well-being, for instance, having active input in helping him develop friendships:

I have recently done a pilot program [...] on planning/goal setting. I just wanted to give some feedback on my experience as a client of their service and as part of the pilot program. Firstly, this planning process for an IEP has been family driven. Secondly, the pilot program I have been a part of has had a much more holistic view of the individual, and it was through this process that I realised our major focus was around [our child's] social wellbeing. So I just wanted to feed that information back to you.

Lynette

Human relationships have the power to instill hope to pursue new goals and shared tasks, and to create new meaning out of personal strengths. New hope has the potential to fuel goal thoughts, pathways thinking (how to reach new goals), and agency (the initiative and sustained energy needed to create a better life) (Snyder, 2000). Lopez and Kerr (2006) explain that “practicing hopeful thinking” (p. 149) is helpful for people to be able to identify how to use it in the future. This cycle explains how new hope has the potential to facilitate the identification and use of personal strengths, which in turn can create more hope.

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3. Using technology to embed long term change

Snyder (2002) and Reichard, Avey, Lopez and Dollweit (2013) have showed how goals, pathways and agency intertwine when people work to create positive change, demonstrating that hope can be boosted with even brief interventions.

Click [here](#) to hear the account of a *Now and Next* family's engagement with technology told by Smita Bharti.

We addressed the prospection factor, ‘incentivizing the future’, proposed by Seligman et al (2014), by specifically inducing future thinking via our purpose-built app, an interactive and personalised eBook. The eBook documents families' plans, and holds photos, videos and audio celebrating their child and family's achievements.

Emerging from initial overwhelm, families in *Now and Next* learn to plan, to unpack long-term aspirational goals into short-term achievable objectives, and also to experience a turning point where they re-evaluate options and ‘let go’ of issues outside of their control. Within and between sessions, families use our customised iPad app to embed their learnings and changes into their personalised eBook. This multimedia solution is offered as a long-term solution to collate relevant information in preparation for future IEPs and NDIS planning meetings, allowing families to offer evidence of strengths to build on, and to open possibilities for future progress. This fun, living document can be also shared with friends or professionals, and replaces reports that are usually filed away and rarely used.

I also learnt that to make use of the Book Creator App will be quite helpful for communication with educators and record inspiration for myself.

Joan

Participants also create their own virtual, online peer network for the duration of the course, so they can interact outside of face-to-face sessions. Through this network, families build their agency, family leadership, and collective capacity as a group. Participants and peer facilitators exchange materials, including the online family *StorySharing* that we have collated, backing up the main concepts covered in the program.

5. Taking others on the journey

Why is it so challenging to engage young families? While some capacity building initiatives are provided by advocacy organisations, these do not specifically target or report difficulties in engaging families of very young children (Escallon, 2016).

There is a dearth of literature about leadership building with families raising young children. Pivotal writing about parents' leadership development (Murray, 2011; Udistky & Hughson, 2016) mostly talk about families with children older than six years, or about adult children. Mahmic (2016) raised the issue that families raising young children follow different trajectories, but that 'getting it' early will reduce service needs and teach families to be more resource efficient. If this is so for individual families, the corollary question is what will enhance peer capacity?



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The call for leadership: Why is family engagement core to changing the system?

A growing body of literature (Gatmaitan & Brown 2015; Lee, 2015; Pang, 2011; Ridgley, Snyder & McWilliam, 2014) has concluded that in spite of express guidelines to ensure the contrary, when partnerships with families are left to professionals to form, the result is not necessarily quality engagement from or with families.

Given that professionals have found it challenging to form, and have generally not acted on recommendations to foster, the types of partnerships with families that are evaluated by families as 'authentic', it is time for the families to take responsibility to understand

why forming these partnerships matters, and how to do so. It is necessary for families to raise the bar and play their role ('lean in') in creating new paths for collaborations. Equipped with the knowledge discussed above about starting new conversations with professionals, families can build – and have built – the self-confidence and impetus needed to approach organisations to form these partnerships.

Whilst some commendable partnership examples happen in isolated pockets, we need to research the parameters that would help such innovative approaches to be upscaled (Carpinter, 2016), an area in which translational knowledge research can inform the process. Translational research targets implementation of what is already known but not yet applied (Ward, House & Hamer, 2009). Through interviews of families of young children, translational research showed how families uncovered the learning pathways that assisted them (Janson & Davies, 2014) in ways that could add value beyond the impact of traditional support groups. It is imperative to educate families about the value of creating partnerships with professionals across the board, in order to create new expectations and better outcomes for these stakeholders. These families, then, can be enrolled to reach other families in their communities who have not yet been identified by professionals or who have shied away from them.



Janson (2015b) reported that many families felt reticent about participating in 'support groups' and wanted to move on from traditional advocacy because they did not perceive themselves as needing an advocate. Many had attended some support groups but did not engage, describing that attending unstructured groups made them, at times, feel worse because there were too many cases where negative participants monopolised the group's time and attention. These families instead wished to develop their positive leadership with clear group, family and individual outcomes. Whilst there are cases when people in the disability sector need advocacy, this approach goes beyond advocacy to people speaking in their own voice, explaining what they need from the system (Janson, 2015a).

Families were able to explain how structured learning did make a difference to help them to organise opportunities for their young children, and at the same time uncover within themselves the will to make a difference to other families (Mahmic & Janson, 2014). Families said that information and knowledge from peer stories contributed in ways that complemented established information services in unique ways. That

information could be shared via technology and professional coaches, and could also be used to contribute to the building of a peer leadership movement.

One of the highlights of the program has been going on this journey with other families because everyone has been so honest and open in sharing within the group and we have all learnt so much from each other. I definitely leave the program feeling confident and empowered.

Sydney

The *Now and Next* program enables the identification of new family leaders, and the group also serves as a leadership pipeline: participants who demonstrate leadership capacity and interest during the program are identified, recruited, trained and employed to fulfill a range of roles including the delivery of the group program. Ongoing training and support is provided to the peer facilitators through a number of strategies. We provide additional training to these peer leaders in *Pictability*© planning and facilitation of the workshop through a ‘train the trainer’ model. Building family leadership takes a different approach than training for ‘advocacy’: leaders take responsibility over their own actions, and maximise the impact they can have in supporting peer families to have increased agency to help their children. These leaders can support peer parents with the aim of decreasing long-term over-reliance on the system.



We recognise that families have varying initial degrees of agency, and that the early years are particularly trying both physically and mentally, but our research has shown that there are many families that are ready to take the lead and bring their peers along with them. These families are akin to the ‘early adopters’ reported in the innovation literature: the group that first takes up new ideas and then champions them into their reference groups. Hence, it is imperative to strengthen these natural leaders so that their impact can reach further. This idea supports Uditsky and Hughson’s report (2000) about families recognizing that there are numerous forms of leadership, and that collective knowledge engenders strength in action and influence.

Peer families leading change: Building a social movement

Through our research we have developed a way to cultivate family leadership and peer networks, which have the potential to create the impetus for social movement led by families (Kendrick, 2010).

We feel that we are a part of a community of like-minded people and this took care a lot of the stress we were under, like thinking I wasn't doing enough. We now have a network of people who 'get it'. I want to help other families like the help we got, from people 'who get it'. I have always been interested in Psychology - my interest is motivating people, gain empathy for the world they live in, for the things they see on stage. I feel so blessed with the information and positivity I got from the Inner West Mums' FaceBook page - this gave me the strength to carry on. So I wanted to be like this positive facilitator and give this dose of positivity to other parents whilst raising awareness about autism as an invisible disability; enhance empathy and inclusion for this group of people. I am excited that I can give insight to others about it.

Nandu

In Duffy's words: "Citizenship is something we build - together - for each other" (Innovation: Keys to Citizenship, 2010). The idea of building an enduring peer network was appealing to these families – they had had an empowering experience and wanted to share it with more families. In a knowledge-poor situation, the role of peers becomes more salient. One way to accelerate change is to design a mechanism for families to share their learning directly with each other via technology in a way that adds value to services imparting information. The mechanism that enables such collective capacity building could be aided by mass communication, such as social media; it will reinforce families' social change movement (Kendrick & Sullivan, 2009) with evidence of leadership building.

In our busy lives, the idea of sharing our stories and experiences online is liberating. We can tap into other parents' knowledge at the time we need it the most 24/7.

Marcel

Challenge: Sustaining the impact

The network's collective agenda (to inspire a new generation of parents of young children with disabilities to lead their family's progress, drawing from a sustainable new peer-networked foundation of knowledge, capacity and creativity) stems from the fact that families are acutely aware that "professionals come and go – families are here to stay" (Antoinette). We take it as our responsibility, then, to build a leadership pipeline through which families rise as leaders and carry on their work together. Identifying family leaders throughout the service delivery process, and then providing them with training so that they are able to conduct planning and workshop facilitation as paid peer workers, is actively building capacity into the disability sector. 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.

Secondly, sustainability the peer network is supported by the concept of an Alumni mechanism. Alumni engagement will ensure that all participating families can periodically meet and continue growing their network face-to-face as well as online through social media. This Alumni engagement has already been evidenced with the Alumni organizing the first family conference of its kind.

Another sustainability factor is the high father engagement rate, which is in contrast to evidence that fathers find it challenging to participate actively and meaningfully in family capacity building. In contrast with Dunst, Bruder & Espe-Sherwindt (2014), who mention a 97% participation rate from mothers, our groups have 23% participation from fathers with this ratio climbing to 50% for fathers' participation at the conference that the Alumni organised for themselves. Participant fathers were well aware of the central role they play in their children's education and the importance of preserving family units at risk in families raising children with disability:

It is important for me to stand up and be counted in my daughter's life – but I am aware that many dads find it hard to be involved. I noticed that most posts on the Internet are from Mums of disabled children... I want to play my part in bringing other dads along and supporting them.

Radu

I notice that men are lacking in the disability sector – I want to be a voice to share my experiences and bring other men along. It's not necessarily that men don't want to talk, but I know many struggle with communication, and I see it also in the trainings that I have done. I want to help here. Men also need to be reminded of the power of a network and the benefits of sharing, in helping us learn about parenting and the added complexity of having children with special needs. I want to help others, men and women benefit from sharing. One role I'd like to play is helping with bringing along dads that may be isolated.

Maurice

Buchanan and Kern (2017) describe how people can develop along the continuum of 'Fixed' to 'Growth' Mindset (Dweck, 2017) onto the 'Benefit Mindset' - "a purpose-driven mindset that is redefining success from being the best in the world, to being the best for the world" (Buchanan & Kern, 2017; p. 2). Complementary to Duffy's citizenship concept

(2010), the 'Benefit Mindset' leads us to examine how our attitudes and actions affect others so that the decisions we take are tactically based on mutual advantage. There are indications that Now and Next participants who actively contribute to their Alumni group may develop a 'Benefit Mindset' because they choose to share their knowledge for mutual benefit towards an exchange can make a difference to the disability sector.

The *Now and Next* Alumni (NANA) Network as a mechanism to sustain family leadership

When families share with each other, they build capacity as a group. New evidence-informed processes can provide the basis for beginning to build family understanding. However, continuity is required to maintain the momentum and to ensure sustainability. Harnessing this collective energy is required to grow a network on which to build a social movement Kendrick (2010), and to create mechanisms to nourish and inspire families throughout the lifespan to continue to create a better future for their child and their family. Our work outlines the benefits of families coming together as early as possible in their journeys to take control of their future.

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 share the common experience and understanding offered by the program. Plumtree is incubating this social movement to harness the collective capacity of families at the earliest possible point in the families' experience. The network's collective agenda and long-term vision is to build a social movement to inspire a new generation of parents of young children with disabilities to lead their family's progress, drawing from a sustainable and deeply embedded peer-networked foundation of knowledge, capacity and creativity. The network's first Family Conference took place in April 2017.

Developing the leadership of families who have young children will create a significant impact on the long-term outcomes for children, families and communities (Moore & McDonald, 2013). Our mechanism offers a structured approach to developing a leadership pipeline where families of young children are identified as potential peer leaders, then provided with training and support to become paid peer mentors to deliver a set curriculum. Moreover, graduates of the program become alumni members who have access to regular online and face-to-face opportunities to connect, which provides them with ongoing information, inspiration and support into the future. This alumni network provides a sustainable peer-led vehicle to keep families connected to one another through intentional capacity-building opportunities. Empowering families creates the environment where families act not only to advance the best interests of their child and family, but also to strengthen their capacity as a community.

6. Conclusion

This study was not set up to compare the progress of experimental as opposed to control groups. Though it could be considered a methodological lacking, we have adopted this approach to be able to add rich qualitative knowledge about families' experiences - from their perspective - as they were building capacity (Russell et al 2016). As Kendrick (2016, personal communication) notes: as new social movements grow, benefits start to emerge out of the 'useful messiness'.



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An evidence-informed strength based approach for families

The field of positive psychology offers families a new paradigm to inform their experience and understanding of raising a child with a disability. In *Now and Next*, families were encouraged to develop a new vision for their child through a creative process which led them to dream and imagine new possibilities for their child. This transformational experience has the potential to assist families to focus on the long-term outcomes of inclusion and independence, which are fundamental to a good life and are also reflected in the outcomes framework of Australia's NDIS. Together, families experience new ways to strengthen their existing capacity through evidence-informed structured, planned and collective processes, which can alter the family and child pathway in new and positive directions. When young parents or carers share stories with peer families, their field of vision about future planning expands considerably. This has been shown in the 20-year span of the Alberta family leadership development experience (Hughson, 2016). Uditsky and Hughson (2000) documented that when families of young children with disabilities meet with families of older children, they come to realise that there are far more possibilities for the future of their child than they originally imagined. Hence, when

families operate from a basis of hope, they are empowered to experiment with different ways of prospecting the future, both in terms of establishing a long-term inspiring vision, and focusing on shorter-term goals.

Actively building family capacity for partnership with professionals

The learning described above is vital for change: as families internalise new possibilities, they commence the process of actively building the skills they need to participate more actively in the family-professional partnership. They then bring these skills to bear at each Individual Family Service Plan meeting, at each school Individual Education Plan session, at each engagement with allied health professionals, and in the many situations in which they will find themselves throughout their child's life in which they will have an active role in supporting the best outcomes for their child.

The result of this increased participation in family-professional partnerships, and of an attention to outcomes, leads families to drive change for their child. Such drive paves the way to a clearer focus on inclusion, curriculum and academic achievement, tertiary studies, employment opportunities, and ultimately to widespread attitude change when mainstream society witnesses children with disabilities achieving successes. *Now and Next* thus creates the very chain of events which creates good lives for children, and which will ultimately fulfill the Australian NDIS vision that a significant proportion of adults with a disability will join the workforce.

Family-Centered Practice research has highlighted the element of intentional capacity building as a mediator of the benefits for early intervention with families (Dunst & Trivette, 2011). By integrating family capacity building activities during the early childhood intervention period, we have shown that targeted, intentional programs can reach and engage this population. It is in the long-term interest of families that they have multiple opportunities for capacity building from the earliest possible time as this will lead to better outcomes for the child and family as a whole.

Training to enrich professionals' skills at building partnerships with families can only carry us half of the way. Families need to build the bridge from the other side and prepare themselves for this partnership, stepping into a new space and positioning themselves as active partners. This paper shows how families learning together can create new discussions with professionals to bring about new outcomes for their child and families.

Imminent work

We have funding to create a participatory action research so that the families will become co-researchers in documenting the development of this initiative. We have undertaken to collect longitudinal data to qualify and quantify the extent to which families build agency, that is, the extent to which they remain motivated to use the new pathways learnt, or remain committed to the belief that they can achieve changes for their children. Our plans are to operationalise what agency might look like when families 'lean into' partnership models with professionals, and how the different components of the well-being and flourishing models come into play during and after the *Now and Next* program. We hypothesise that a change in agency will reduce families' dependency on the system. Conversely, an increase in capacity will enable families to make more efficient use of

professional time because they will have done all the work that they can achieve before coming to the professional, and will be better equipped to formulate for what purpose additional help is sought.

To our knowledge, this is the first description of a mechanism for families raising a young child with disability that uniquely supports them to operate such a mindshift and work towards achieving outcomes for all families. We are carrying out further research about the factors at work in the *Now and Next* program that support its participants to develop such a 'Benefit Mindset' and how this process may evolve out of the combination of meaning-making and flourishing that characterise this mindshift.

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Sylvana Mahmic's interest in disability began 24 years ago, when her first child Abdul-Karim was diagnosed with a disability. Seeking to understand what lay ahead for her son, she completed post graduate study in special education and is the CEO of Plumtree. She is currently a doctoral candidate researching individualised funding in the early childhood intervention context.

Sylvana is an advocate for people with disabilities and their families and has served on over 15 reference and advisory groups in addition to five Ministerial appointments. She is currently the Vice President of Early Childhood Intervention Australia NSW Chapter and immediate past President. In 2013, she was appointed to the National Disability Insurance Scheme Independent Advisory Council. Since 2009 Sylvana, her son and the extended family have been learning about how to use a self-managed package using individualised funding and she uses these experiences to shine a light on the potential of this approach for people with a disability and their families.

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Annick has authored over 50 peer-reviewed research publications including for the UNESCO and the Human Rights Commission. She has received a NZ Ministry of Health (Te Pou) Knowledge Translation Fellowship for her research about the impact of capturing and disseminating stories to build capacity in the disability sector. Annick has professional and lived experience with the disability sector. Her youngest son is a talented artist who also lives with Asperger Syndrome.

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Melanie Heyworth became interested in disability three years ago, when her eldest son was diagnosed with autism. In the subsequent years, her two other sons, and Melanie herself, have also been given an autism diagnosis.

In order to better understand the implications of her sons' autism diagnoses, Melanie completed her postgraduate study in autism in 2015. She is a passionate champion of autism acceptance and inclusion, equity, neurodiversity, and listening to autistic voices. Although she home-schools her three boys, Melanie is deeply committed to helping families with school-aged children in their journey to experience genuinely inclusive schooling in educational institutions by promoting strengths- and gifts-based differentiated pedagogy.

At Plumtree, Melanie has joined a team of peer facilitators to help parents to reframe their autism journeys to see the opportunity, the optimism, the hope, and the joy of parenting autistic children. Melanie believes in seeing our children as beautiful, not broken, and as different, not less, and wants every parent to see their child through the lens of their child's strengths and gifts, and not defined by their deficits or diagnosis.

Before her children, Melanie was an early career academic in early Medieval Studies, with a passion for research and teaching. Now, Melanie utilises those skills to support the important and innovative work that Plumtree is doing in the early intervention sector.

Email: Mheyworth@plumtree.org.au

Plumtree

Plumtree is a 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. Our vision is a society where children with disabilities and developmental delays, and their families, are supported to have a full life in the community.

Website: www.plumtree.org.au

Email: info@plumtree.org.au

Facebook: [plumtree2204](https://www.facebook.com/plumtree2204)

Centre for Welfare Reform

The Centre for Welfare Reform is an independent research and development network. Its aim is to transform the current welfare state so that it supports citizenship, family and community. It works by developing and sharing social innovations and influencing government and society to achieve necessary reforms.

To find out more go to: www.centreforwelfarereform.org

We produce a monthly email newsletter, if you would like to subscribe to the list please visit: bit.ly/subscribe-cfwr

You might like to follow us on twitter: [@CforWR](https://twitter.com/CforWR)

Or find us on Facebook here: [centreforwelfarereform](https://www.facebook.com/centreforwelfarereform)

Citizen Network

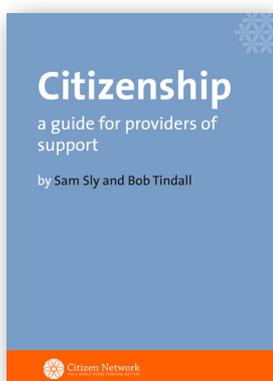
Citizen Network is an international movement to advance citizenship for all by tackling prejudice, poverty and powerlessness.

Individuals and groups who believe in human equality and the value of diversity can join for free at: www.citizen-network.org

You might like to follow us on twitter: [@Citizen_Network](https://twitter.com/Citizen_Network)

Or find us on Facebook here: [citizennetwork](https://www.facebook.com/citizennetwork)

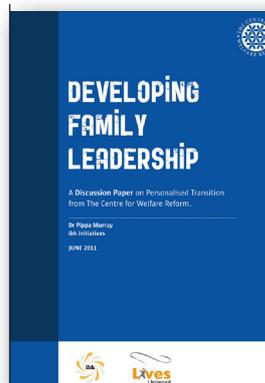
Relevant publications



CITIZENSHIP: A GUIDE FOR PROVIDERS OF SUPPORT

Sam Sly and Bob Tindall explain why support should be focused on helping people to be full citizens and explain how this can be achieved in practice.

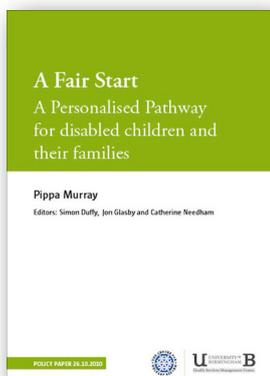
<http://bit.ly/citizenship-guide>



DEVELOPING FAMILY LEADERSHIP

Pippa Murray shows how you can help families take the lead by building new relationships built upon equality and mutual respect.

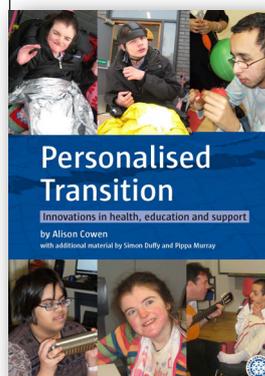
<http://bit.ly/developing-family-leadership>



A FAIR START

How to work with communities and families to develop an integrated pathway for the care, support and education of disabled children.

<http://bit.ly/a-fair-start>



PERSONALISED TRANSITION

Alison Cowen describes the success of a new model of personalised transition to help disabled children leave school and move into adult life.

<http://bit.ly/personalised-transition>



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