

ASID NSW/ACT Individualised Funding & Self-determination Roadshow Event

29th August 2016

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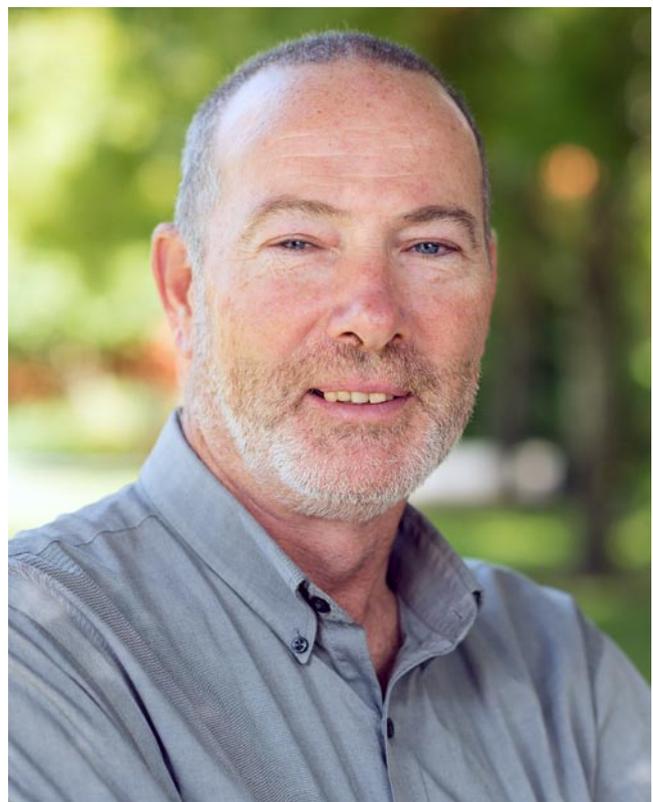


On Monday 29th August 2016, following the IASSID World Congress in Melbourne, ASID NSW/ACT in partnership with the Centre for Disability Studies (CDS), The University of Sydney, hosted a workshop on individualised funding and self-determination. 51 participants from across NSW attended the event, including people with disability, family members, service providers and researchers. This event formed part of the ASID Australasian Road Show schedule.

The key speaker for the event was **Prof. Tim Stainton (Canada)** who spoke on *Individualised Funding and Self Determination: Tools for Citizenship and Inclusion*. Professor Stainton highlighted that inclusive citizenship enables individuals to move from community presence to belonging, and proposed that a Citizenship Policy Framework is required, comprised of the following elements:

- Personal decision making support
 - o Supported decision making and representations
 - o Family and trusted advisors
 - o Advocacy
- Independent planning and facilitation support
- Individualised funding
- Governance

continued page 22



Prof Tim Stainton



... Individualised Funding & Self-determination ...

continued from page 21

To achieve a Citizenship Policy Framework, two key areas of action were highlighted

1. Law reform:

- a. supported or substituted decision making (scope to include health care, financial and personal)
- b. involving regulation and oversight (i.e. authority of supported decision makers, safeguards, and appeals).

2. Support practice:

- a. provision of decision making supports (communication, active support etc.)
- b. identifying and supporting supported decision makers

Supported decision making: During his presentation, Prof. Stainton defined the traditional legal definition of capacity to make decisions as “understanding and appreciating the nature and effects of one’s actions and the consequences of those actions”. However, he noted that a newer relational concept of capacity accepts that “capacity is borne out of trusting relationships, through which our will and preferences can be expressed”. Consequently, at the centre of the supported decision making process is a network of support. A legal and policy framework for supported decision making must therefore provide legal recognition to this group of trusted others to assist in decision making, helping to express the will and intent of a person, and/or helping to weave a coherent life narrative that gives to others a sense of an individual’s personal identity.

A number of individualised funding principles were highlighted and various models and variations were explored and discussed. Sadly, significant issues and challenges have meant that despite initial enthusiasm and plans for change, little progress has been made and individualised funding never became a priority in British Columbia. The final take home message is that there is no ‘perfect system’ and a strong advocacy voice is the only true safeguard!

Professor Stainton was followed by **Dr Samuel Arnold (Australia)** who spoke about the Instrument for Classification and Assessment of Support Needs (I-CAN v5.0) and its relationship with Individualised Funding. Sam was able to show preliminary evidence that the I-CAN V5.0 can help people to ensure their needs are met when they are applying to the National Disability Insurance Agency (NDIA) for individualised support packages.

The **Centre for Disability Studies (CDS) Inclusive Research Network (Australia)** then shared their results of research into the understanding and information people with intellectual disability had of the changes and implications of the National Disability Insurance Scheme (NDIS).

Workshop participants broke into **small groups to explore the implications of the NDIS**. Each group looked at the implications from one of three perspectives:

- 1) people with intellectual disability,
- 2) families, and
- 3) service providers.

Table 1 (next page) shows the issues raised by workshop participants, with the following themes coming through:

- NDIS is an opportunity for increased involvement and control by the person with disability;
- There is a need for accurate and accessible information, education and guidance;
- This is a time of change, in roles and expectations, and with this comes challenges;
- Advocacy is very important and needs to be well supported.

The information gathered will be used as a source of reference to inform future events and activities of NSW/ACT ASID. We are very appreciative of the active participation and contribution of all who were present at this very successful event. ●

continued page 23



Table 1: Implications of the NDIS – Different Perspectives

	Positives	Challenges	What is needed
Perspective of people with disability	<ul style="list-style-type: none"> - Focus is on the individual - Having a voice, choice and control - Reduced waiting lists - Opportunity for new things - New culture of support - Chance for better advocacy - Staff matching - Freedom (home, skills etc) - Dignity and empowerment 	<ul style="list-style-type: none"> - High expectations that may not be met - No guarantee for requested supports - Limited resources (e.g., in rural & regional areas) - Barriers to couples living together - Age care barriers 	<ul style="list-style-type: none"> - Family education re choices - A role for advocacy
Perspective of the family	<ul style="list-style-type: none"> - Service users, together with family, are now customers 	<ul style="list-style-type: none"> - Change in role for families: <ul style="list-style-type: none"> - some will take this on - requires education - siblings may need an 'invitation' and education to become involved - some families may opt out - Hope that NDIA does not over-govern the process - Concern for impact on families where English is a second language (need to get feedback from these families) - Process is still confusing: <ul style="list-style-type: none"> - causing distress - lack of trust in process - concern current service hours will not be maintained - people are not adequately prepared and many still do not know what the NDIS is about 	<ul style="list-style-type: none"> - Advocacy (the need was strongly supported by the group): <ul style="list-style-type: none"> - reduced advocacy funding leads to increased pressure on families - very important for people without family support
Perspective of service providers	<ul style="list-style-type: none"> - More control for pwd (choice) - Providers need to provide a quality service - More diverse and challenging roles - High demand? - More tools to help people achieve goals - Involvement of people with disability in recruitment - Re-aligning the support - Customer focused - Mission statements will now be implemented - Forced to look at systems - Current staff- opportunity to step up - More meaning in staff support - Scrapping the current NSW disability services' audit system 	<ul style="list-style-type: none"> - Loss of control for providers - Not being able to forecast the future - Job insecurities - People with disability can leave - Monitoring funding and spending - Involvement of people with disability in recruitment - Meeting the expectations of people - Current staff (change of perspective) - Precarious employment (casualisation) - Constant changes - Competition - My Place (NDIS participant portal) - Skills 	<ul style="list-style-type: none"> - Being open to change - Pre-planning - Detailed and accurate information - Easy English resources - Self-management resources - Changing business model: <ul style="list-style-type: none"> - staff matching - casuals - flexibility - Changing policies and procedures - Effective systems, less administration - Increased consultation - Clear role descriptions - Guidance on: <ul style="list-style-type: none"> - supporting people who have no informal supports - transition between pre/post NDIS - how service providers can work together when providing support