



**Independent
Advisory
Council**

to the **ndis**

The First Four Years 2013-2017

JUNE 2017



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FOREWORD



The Independent Advisory Council (Advisory Council) was established by Federal Parliament under the *National Disability Insurance Scheme Act 2013* (NDIS Act) which commenced on 1 July 2013. Advisory Council members are appointed by the Commonwealth Minister, in consultation with all states and territories, on the basis of their skills, experience and knowledge of disability and includes a diversity of people with experience of disability.

The Advisory Council was established to bring the views of participants, carers and experts in the disability sector to the heart of the National Disability Insurance Scheme (NDIS) by the provision of independent advice based on the experience of its members and their networks. The independent advice provided to the Board of the National Disability Insurance Agency (NDIA) under s 145 of the NDIS Act, is then in turn, made available to the Minister for Social Services and Council of Australian Governments Disability Reform Council which consists of Commonwealth, State and Territory Ministers within disability and treasury portfolios, as well as a representative from the Australian Local Government Association.

As we now come to the end of the first term of the Independent Advisory Council,

I am pleased to present this Report, which summarises and highlights the important body of work the Advisory Council has developed, as well as identifying some of the issues and priorities. This Report outlines the range of advice, papers and submissions generated by the Advisory Council to date and represents a significant contribution to contemporary disability practice in Australia.

There are many opportunities and many challenges in delivering the aspirations for the NDIS that all Australians share, and the work of this first Advisory Council has contributed to the development of the Scheme contributing to the fulfilment of the vision and values enshrined in the objects of the NDIS Act. The Advisory Council has been honoured to be an important part of the start-up of the most ambitious and transformative social policy of our generation.

I thank each of the inaugural members of the Advisory Council for their incredibly hard work and detailed contributions to the Advisory Council's advice and to assisting the Advisory Council to work effectively and productively as a group.

I thank the NDIA Board, chaired by Bruce Bonyhady until the end of 2016, and chaired by Helen Nugent since January 2017, for their consideration of the advice, thus enabling the Advisory Council to contribute significantly to the ongoing design and continual work to

improve the effectiveness, responsiveness and sustainability of the NDIS.

I thank David Bowen, NDIA Chief Executive Officer and NDIA staff for their high quality engagement with the Advisory Council. This engagement has ensured that the Advisory Council has been able to develop more targeted and nuanced positions, ensuring that the advice is practical, so making it more able to be implemented.

Finally I would like to thank Ms Belinda Epstein-Frisch who has been our adviser from inception and to acknowledge her enormous contribution to the high quality of our papers and advice.

Professor Rhonda Galbally A.O.
June 2017

OVERVIEW

This report describes the work of the first Independent Advisory Council (Advisory Council) of the National Disability Insurance Agency (NDIA or Agency) during its term from 2013 to 2017.

Established under the *National Disability Insurance Scheme Act 2013* (Cth) (the NDIS Act), the purpose of the Advisory Council is to advise the Board of the NDIA on the delivery of the National Disability Insurance Scheme (NDIS or Scheme) for the diversity of Australians with disability, their families and carers. The composition of the Advisory Council is set out in the legislation to ensure that the voice of people with disability is recognised and valued. In addition, the Advisory Council draws its perspectives from a deep understanding of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and through feedback and insights gleaned from roving visits across Australia to hear from participants, families, carers and providers. The Advisory Council's independence is determined by the NDIS Act, in which s 144 provides that the Advisory Council can provide advice on its own initiative as well as at the written request of the Board.

Since 2013, the Advisory Council has worked actively to:

- give advice which provides a detailed and nuanced understanding of the operationalising of principles and intent of the NDIS Act;

- build and share a clearer understanding of the life insurance approach to disability and its ability to deliver improved life outcomes for people with disabilities and financial sustainability for the Scheme;
- encourage policy and practice that support the independence, social and economic participation and inclusion of people with disability and is based on human rights principles;
- analyse self-management - value, risks and mitigation; and
- analyse and promote a sustainable, flexible and responsive service system.

The work of the Advisory Council has involved a diverse range of activities. The Advisory Council has met 19 times over the past four years, participated in numerous working groups preparing papers, considered and debated each of the draft advisory papers, provided feedback on proposals and service delivery approaches proposed by NDIA staff, met with a wide range of disability and community organisations from across the country, informed ourselves of what was happening in the trial sites and then in the commencement of full scheme implementation.

Each meeting of the Advisory Council commences with 'Reports from the ground' in which members report on observations and feedback from their geographical and disability related experience. In addition, the Advisory Council undertook a series of roving visits in all states and territories. The Advisory Council listened to participants, families, carers and

service providers' experiences and sought to draw the learnings from these groups in its advice about policy and practice issues for full scheme roll out. The Advisory Council wishes to thank the many thousands of Australians who helped inform and deepen its advice.

In addition, the NDIA actively sought input and feedback from the Advisory Council in relation to major operational matters including the development and refinement of the Participant Pathway, Information Linkages and Capacity Building (ILC), the Outcomes Framework, the Staff Competency Framework, Early Childhood Early Intervention, Specialist Disability Accommodation (SDA), technology, communication and engagement.

All the work of the Advisory Council aims to contribute to a responsive Scheme that fulfils the vision and values enshrined in the objects of the NDIS Act.

This report summarises the range of advice, papers and submissions generated by the Advisory Council over the past four years. It is a substantial body of work and represents a significant contribution to contemporary disability practice in Australia. The NDIS is a leading international social and economic policy initiative. Australia is at the cutting edge of disability practice and policy. There are many unknowns and many challenges in delivering the aspirations for the NDIS that all Australians share.

The key themes of the advice are:

- an ordinary life;
- self-determination;

- capacity building;
- independence;
- social and economic participation and community inclusion;
- reducing vulnerability and enabling positive risk; and
- equity.

The themes and areas of focus of the inaugural Advisory Council are summarised in Figure 1, which outlines completed advice, identifying the purpose of the paper, the key points made by the Advisory Council and the influence the paper may have had. The Council was conscious of the formal and interactive nature of its advice. NDIA Board members and staff participated in the discussions and deliberations and there was a vigorous interchange of views and thinking about the specific issues and the strengths and weaknesses of different approaches. These interactions and exchanges were an important part of the formulation of ideas and firming up of concepts for the Advisory Council.

Figure 1: Work of the IAC 2013–2017

1 An ordinary life in sustainable NDIS

- R&N support for an ordinary life (2.1)
- R&N support for families (2.2)
- The planning process (2.3)

2 A responsive NDIS fit for purpose

- Members’ reports on the ground
- Roving visits
- Feedback on Service Delivery Operating Model
- Input and feedback to discussions on
 - Participant pathway
 - Information Linkages and Capacity Building (ILC)
 - Outcomes framework

3 Self-determination

- Choice and control (3.1)
- Self-direction & self-management (3.2)
- Productivity Commission Submission into the NDIS costs (3.3)
- Self-management; value, risks & strategies for growth (3.4)
- Evidence of improper payments (3.5)
- What should the NDIA understand about Intellectual Disability? (3.6)
- Support for decision-making (3.7)

4 Capacity building

- Capacity building for participants (4.1)
- Capacity building for staff (4.2)
- Activating capacity building (4.3)

5 Independence

- Promoting independence (5.1)
- NDIS supports for independence (5.2)

6 Social & economic participation & inclusion

- Genuine community engagement (6.1)
- Innovation in housing and support (6.2)
- Barriers to housing and support (6.3)
- Submission to Senate Community Affairs Committee into delivery of outcomes under the NDIS (6.4)

7 Reducing vulnerability & enabling positive risk

- Enhancing personal safeguards (7.1)
- Building capacity and reducing vulnerability (7.2)
- Q&S for people in closed systems (7.3)

8 Equity

- Mental Health and the NDIS: A Literature Review (8.1)
- Implementing the NDIS for people with disabilities related to mental health (8.2)
- Improving access for people in Psychiatric Hostels, Supported Residential Services and Boarding Houses (8.3)
- Guidance on the application and promotion of peer work in the NDIS (8.4)
- Peer workers in the NDIS (8.5)
- Submission to the Joint Standing Committee (8.6)
- Equitable access for people on the margins (8.8)
- Equitable access for people in touch with criminal justice (8.9)
- People who are deaf and hard of hearing (8.10)

KEY



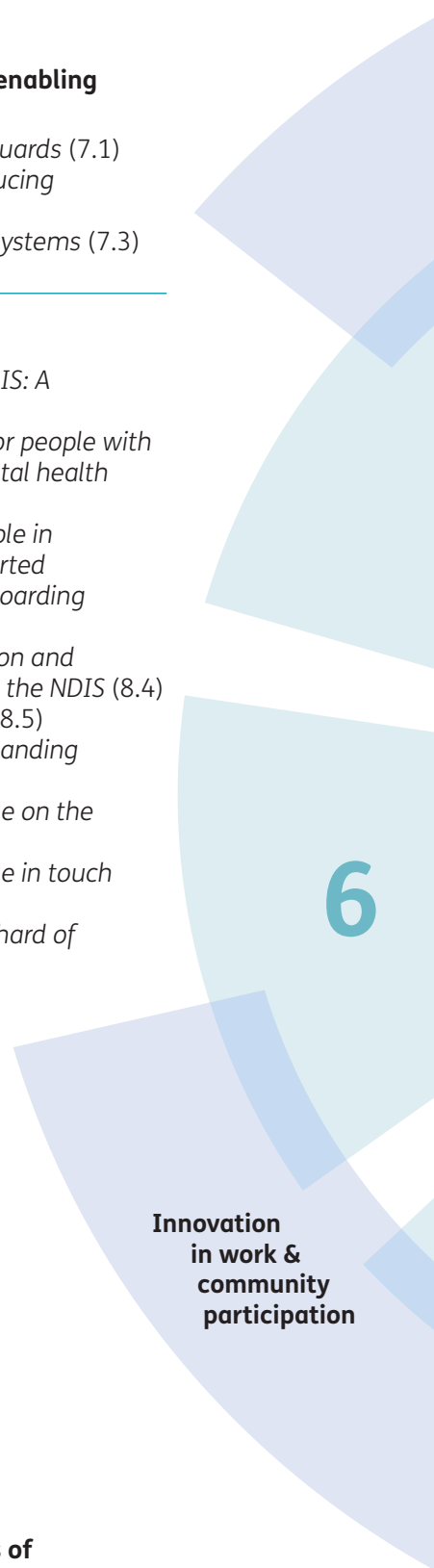
Themes of work



IAC work



Suggested areas of future work



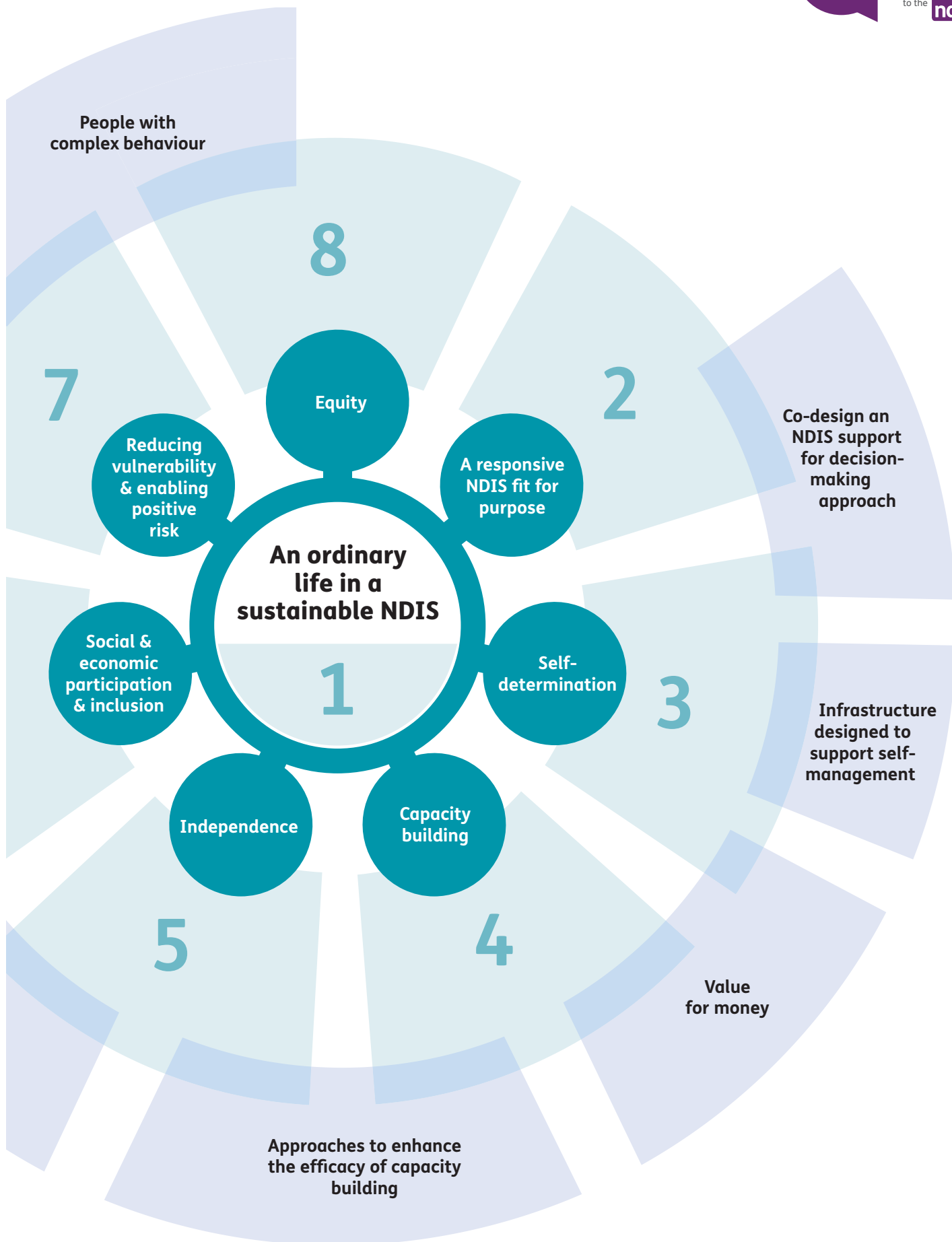
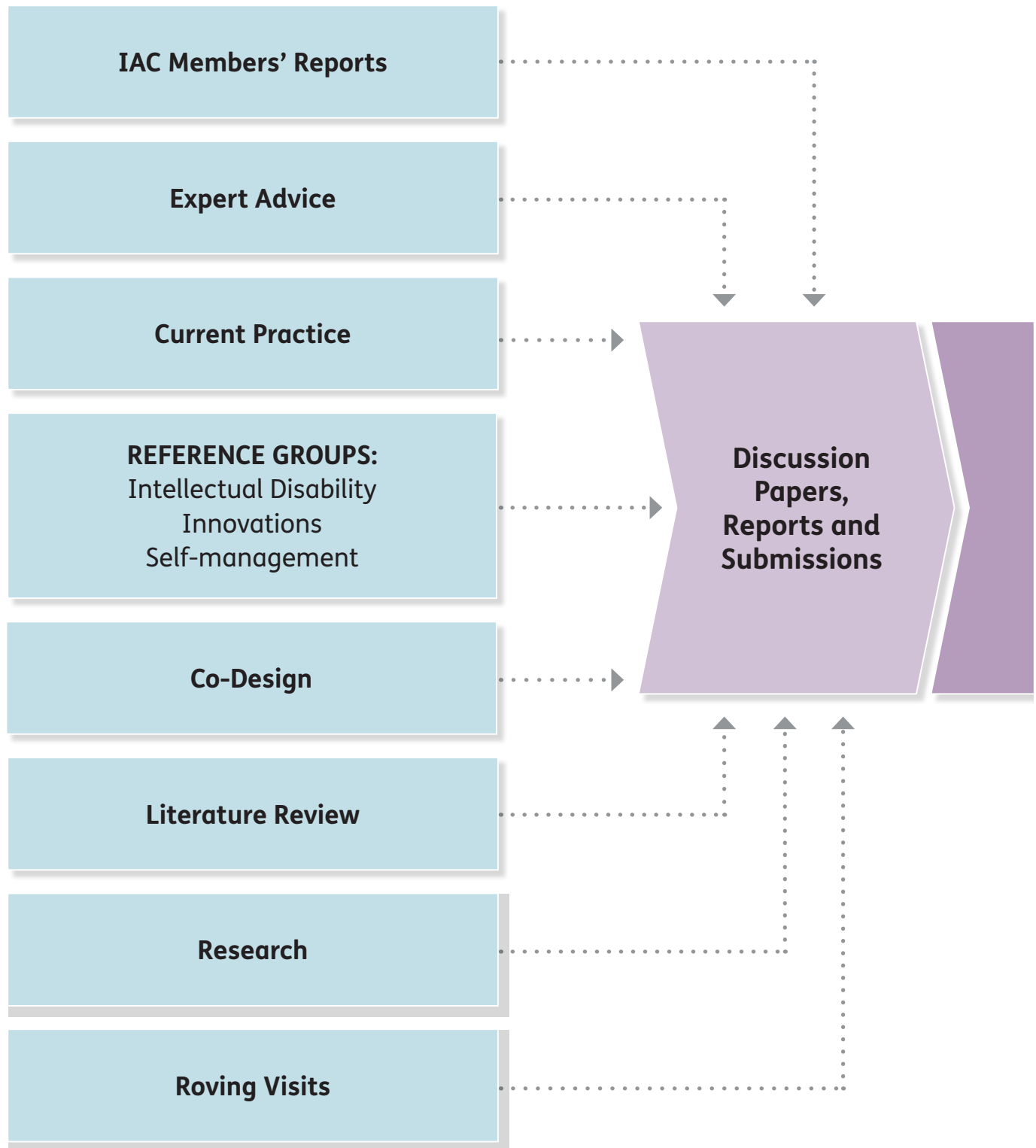
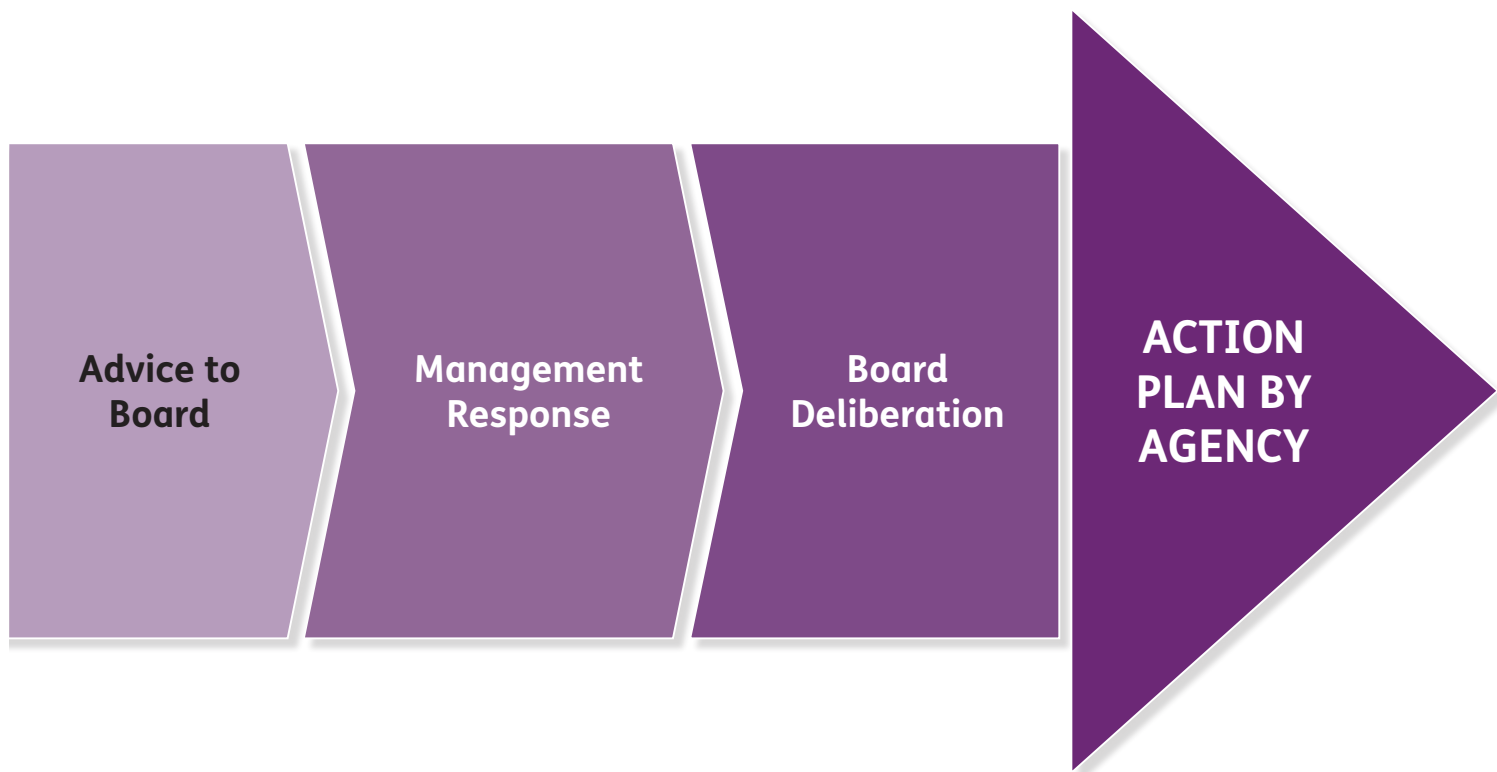


Figure 2: IAC Methodology





OVERVIEW

The 2013–2017 Advisory Council has produced a significant body of work as outlined in Table 1 & Table 2.

Table 1: Independent Advisory Council work by theme

Theme	Number	Titles
An ordinary life in a sustainable NDIS	3	<p><i>Reasonable and necessary support across the lifespan: an ordinary life for people with disability (2.1)</i></p> <p><i>Reasonable and necessary support for families (2.2)</i></p> <p><i>The planning process (2.3)</i></p>
Self-determination	7	<p><i>Choice and control (3.1)</i></p> <p><i>Self-direction & self-management (3.2)</i></p> <p><i>Submission to the Productivity Commission into the NDIS costs (3.3)</i></p> <p><i>Self-management: value, risks and strategies for growth (3.4)</i></p> <p><i>Evidence on improper use of payments in self-management and balancing the fraud response (3.5)</i></p> <p><i>What should the NDIA understand about Intellectual Disability? (3.6)</i></p> <p><i>Support for decision-making: key issues (3.7)</i></p>
Capacity building	3	<p><i>Capacity building for participants, their families and carers (4.1)</i></p> <p><i>Capacity building for staff (4.2)</i></p> <p><i>Activating capacity building (4.3)</i></p>
Independence	2	<p><i>Promoting independence for people with disability (5.1)</i></p> <p><i>NDIS supports for independence (5.2)</i></p>
Social and economic participation and inclusion	4	<p><i>Genuine community engagement (6.1)</i></p> <p><i>Innovation in housing and support (6.2)</i></p> <p><i>Barriers to housing and support that will have cost implications for the NDIS (6.3)</i></p> <p><i>Submission to Senate Community Affairs Committee into the delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities (6.4)</i></p>

Theme	Number	Titles
Reducing vulnerability and enabling positive risk	3	<i>How can the NDIS help participants enhance their personal safeguards in order to experience greater independence, economic participation and community inclusion? (7.1)</i>
		<i>Building capacity and reducing vulnerability for people in closed systems (7.2)</i>
		<i>Quality and Safeguards for people in closed systems (7.3)</i>
Equity	9	<i>Mental Health and the NDIS: A Literature Review (8.1)</i>
		<i>Implementing the NDIS for people with disabilities related to mental health issues (8.2)</i>
		<i>Improving access for people in Psychiatric Hostels, Supported Residential Services and Boarding Houses (8.3)</i>
		<i>Guidance on the application and promotion of peer work in the NDIS (8.4)</i>
		<i>Peer workers in the NDIS (8.5)</i>
		<i>Submission to the Joint Standing Committee on the NDIS in its reference into the NDIS and mental health (8.6)</i>
		<i>Equitable access for people on the margins (8.8)</i>
<i>Equitable access for people in touch with criminal justice (8.9)</i>		
		<i>People who are deaf and hard of hearing (8.10)</i>

To access the work of the IAC, please go to www.ndis-iac.com.au

Table 2: Independent Advisory Council work by year

Year	Number	Titles
2013	1	<i>Choice and control (3.1)</i>
2014	8	<i>Reasonable and necessary support across the lifespan: an ordinary life for people with disability (2.1)</i>
		<i>Reasonable and necessary support for families (2.2)</i>
		<i>The planning process (2.3)</i>
		<i>Self-direction & self-management (3.2)</i>
		<i>Promoting independence for people with disability (5.1)</i>
		<i>Genuine community engagement (6.1)</i>
		<i>Mental Health and the NDIS: A Literature Review (8.1)</i>
		<i>Implementing the NDIS for people with disabilities related to mental health issues (8.2)</i>
2015	2	<i>Capacity building for participants, their families and carers (4.1)</i>
		<i>Capacity building for staff (4.2)</i>
2016	9	<i>Enhancing Self-direction & self-management (3.2)</i>
		<i>Support for decision-making: key issues (3.7)</i>
		<i>Activating capacity building (4.3)</i>
		<i>NDIS supports for independence (5.2)</i>
		<i>How can the NDIS help participants enhance their personal safeguards in order to experience greater independence, economic participation and community inclusion? (7.1)</i>
		<i>Building capacity and reducing vulnerability for people in closed systems (7.2)</i>
		<i>Guidance on the application and promotion of peer work in the NDIS (8.4)</i>
		<i>Equitable access for people on the margins (8.8)</i>
		<i>Equitable access for people in touch with criminal justice (8.9)</i>

Year	Number	Titles
2017	12	<i>Submission to the Productivity Commission into the NDIS costs (3.3)</i>
		<i>Self-management: value, risks and strategies for growth (3.4)</i>
		<i>Evidence on improper use of payments in self-management and balancing the fraud response (3.5)</i>
		<i>What should the NDIA understand about Intellectual Disability? (3.6)</i>
		<i>Innovation in housing and support (6.2)</i>
		<i>Barriers to housing and support that will have cost implications for the NDIS (6.3)</i>
		<i>Submission to Senate Community Affairs Committee into the delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities (6.4)</i>
		<i>Quality and Safeguards for people in closed systems (7.3)</i>
		<i>Improving access for people in Psychiatric Hostels, Supported Residential Services and Boarding Houses (8.3)</i>
		<i>Peer workers in the NDIS (8.5)</i>
		<i>Submission to the Joint Standing Committee on the NDIS in its reference into the NDIS and mental health (8.6)</i>
		<i>People who are deaf and hard of hearing (8.10)</i>

To access the work of the IAC, please go to www.ndis-iac.com.au

THEME: AN ORDINARY LIFE IN A SUSTAINABLE NDIS

An ordinary life for people with disability in the context of a sustainable NDIS is at the heart of the work of the Advisory Council. Through its advice on Reasonable and necessary support for participants, Reasonable and necessary support for families and The planning process, the Advisory Council recommended that reasonable and necessary support should be used to bridge the gap between a 'disabled life' and the life of an 'ordinary' Australian citizen.

2.1

Advice: Reasonable and necessary support across the lifespan: an ordinary life for people with disability (2014)

The purpose of this advice was to provide the Board, Agency and ultimately planners, with practical guidance on how to conceptualise and apply the term 'reasonable and necessary' to planning decisions within the values and practical applications of the NDIS in order to maximise independence, social and economic participation and inclusion.

The advice was framed in the context of papers on the participant lifespan (divided into age appropriate domains), families, planning, independence, community engagement and self-management. It drew evidence from a range of disciplines to identify the 'enablers' of an ordinary life, i.e. factors that promote health and wellbeing. These factors include:

- positive relationships;
- a sense of belonging;
- autonomy;
- active involvement in decision-making;
- social and economic participation; and
- opportunities for challenge and contribution.

The advice then considered the gap between an 'ordinary life' and a 'disabled life' across the lifespan.

2.2

Advice: Reasonable and necessary support for families (2014)

The purpose of this advice was to provide guidance to the NDIA about the most effective way to support families in their facilitation of the best possible lives for people with disability.

In deciding the nature and level of support for people with disability, the NDIS is required to take into account what is reasonable to expect families to provide. In addition, the NDIS supports families through the provision of a range of assistance to reduce the impact of the disability on family functioning.

The advice suggested that people with disability need two important things from family if they are to have a good life. They need a family that has capacity to care – that has time and emotional energy to do what it takes. And for the long-term benefit of the person with disability, that support needs to happen in a way that does not overly disadvantage other family members so that they too develop as strong capable adults with a willingness and capacity to remain connected.

Secondly, the advice suggested that people with disability need family guides, people who have a vision of an ordinary life and the knowledge and skills to remove barriers and facilitate opportunities on their behalf. Translated into support for families, this requires two forms of support:

- practical assistance that shares the tasks of caring and other responsibilities. The advice included a reframing of respite to be more

productive for both the person with disability and the family; and

- vision and skill-building support to enhance the capacity of families as advocates.

2.3

Discussion Paper: The planning process (2014)

The purpose of this paper was to enhance the effectiveness of the NDIS planning process.

The Advisory Council highlighted the tension between the need to assist participants to think about goals and aspirations and operationalise them in a plan, and the need to transition participants into the Scheme at a pace consistent with full Scheme roll-out.

In this context, the Advisory Council considered whether the planning process should differentiate between a funding plan and a life plan, proposing that:

- reference packages could be used as the basis of a funding plan;
- participants could be supported over a longer period of time to develop a life plan in which their goals and aspirations guide the process of building informal support, linking them to mainstream services and providing packaged support in ways that complement, rather than drive out, informal and mainstream supports; and
- participants could then return to the NDIS for the sign-off of a funding plan based on their life plan.

Influence

Feedback indicated that these papers influenced planning for full Scheme roll-out including an understanding of reasonable and necessary supports, the need for greater flexibility in funding items, including the bundling of supports, and the alignment of the Support Catalogue with the ordinary life theme. In addition, this work has influenced communications strategies for participants and the development of the Outcomes Framework for the Scheme where it is hoped that the alignment of outcomes with the domains of an ordinary life will contribute to shifting the mindsets of participants and the sector to focus on agreed goals over the lifespan thereby supporting the insurance principles.

The process of developing the ordinary life advice highlighted the importance of co-design as a fundamental approach in the Scheme. To give life to this principle, the Advisory Council established the Intellectual Disability Reference Group to guide policy and practice in relation to people with intellectual disability in the Scheme. Finally, the work highlighted the need for service transformation and the Advisory Council established the Innovations Reference Group to focus on the development of contemporary supports for an ordinary life.

Suggested priorities for future work

- An exploration of innovative supports and service transformation through the Innovations Reference Group.
- Ongoing feedback on Agency policies and processes to ensure they promote an ordinary life.



THEME: SELF-DETERMINATION

Self-determination is a key concept enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that requires the NDIS, in conjunction with the whole of government, give effect to the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The Advisory Council work on the theme of self-determination aimed to assist the Agency to understand and operationalise the meaning of self-determination in the context of Scheme design and implementation. The Advisory Council focused on the nature of choice and control and the way in which self-determination could be implemented by supporting participants to have the level of control they desire over their support and their NDIS funding. In addition, through the Intellectual Disability Reference Group, the Advisory Council sought to ensure that in all its functions, the NDIA operationalised a contemporary understanding of intellectual disability and ensured that people were supported to make or contribute to the decision making process about their support and their lives.

3.1

Discussion Paper: Choice and control (2013)

The purpose of this paper was to demonstrate ways in which the NDIS could maximise support for and opportunities to enable participants to experience choice and control. This was critical because the concept of

choice and control is central to the Scheme's design and represented a paradigm shift in the manner of provision of disability supports. The Advisory Council acknowledged that many people with disability have had little experience of choice and control in their life, and hence the Scheme's effort to support their appetite for, and confidence in, choice and control was important.

The paper explored the nature of choice, differentiating between pervasive (significant) choices, lifestyle choices and everyday choices, and identified enablers and barriers to choice and control. The Advisory Council grappled with the issue of people making choices that are not compliant with the UNCRPD such as people 'choosing' to live in an institution.

The Advisory Council focused on strategies to make the concept of choice and control more tangible and practical with a systemic mechanism that built the capacity of people with disability and families on an ongoing basis. The Advisory Council proposed that user led Disability Support Organisations (DSOs) be strengthened to provide capacity building for people with disability and families to enhance their opportunities for choice and control. The aim was to transform participants from compliant dependent users of services

into active citizens, who exercise choice and control, make decisions and participate in social, economic and political life. DSOs are also one of the strategies identified by the Productivity Commission (in its report on disability care and support) to facilitate participant engagement and the provision of flexible choices.

This led to the development and the implementation of an initial small network of DSOs in late 2014. Eighteen user led community organisations were funded to facilitate and support up to 20 local peer support or mutual support groups to work with people with disability and their families in community development activities that enabled them to exercise choice and control.

The Advisory Council's work in supporting DSOs to develop peer networks has had an impact on building the capacity of people with disability and their families away from the status of dependent clients toward citizenship. Capacity building of this nature is important for the development of the future demand required to stimulate the transformation required through the NDIS.

3.2

Report: Self-direction and self-management (2014-2017)

The purpose of this body of work was to provide advice on the ways in which the NDIS could enhance opportunities and support for increased participant self-direction and self-management.

The issue of enhancing participant self-direction and self-management has been a continuous body of work for the life of

the Advisory Council as these concepts promote positive outcomes for participants, transformation of the sector and sustainability of the NDIS.

The early Advisory Council work identified key elements of self-direction and self-management that remain core: the importance of providing guidance to people as to how to direct their support and manage their funds, the important role that intermediaries can play and the value of flexibility in the use of reasonable and necessary support to both the participant and the Scheme.

This work was developed further in 2016 and 2017 in the context of pressure arising from risks associated with the improper use of payments and participant packages being larger than anticipated. The Advisory Council addressed these concerns using a co-design group made up of self-managing participants, members of the NDIA Board, the Advisory Council and senior Agency staff, a paper on 'Evidence on improper use of payments in self-management and balancing the fraud response', a submission to the Productivity Commission on NDIS costs, discussion with community leaders through the CEO Forum and a report to the Board entitled Self-management: its value, its risks and strategies for growth.

3.3

Submission to the Productivity

Commission into the NDIS costs (2017)

The Productivity Commission submission of the Advisory Council focused on the issue of self-direction and self-management as a market disruptor that has the capacity to enhance Scheme sustainability. Market disruption was seen as desirable because traditional specialist disability provision is expensive and has not led to positive outcomes for people with disability. These challenges are compounded by staff shortages, especially shortages of workers skilled at providing contemporary enabling support.

The submission advanced the view that supporting participants to increase their self-direction and self-management would disrupt current patterns of service provision as the participant would have control over the ‘what, when, where and by whom’ of support they received. Thus making it more likely that paid support would facilitate lifestyle of choice and complement, rather than drive out, freely given support by family and friends (informal support).

It was asserted that increased self-management has the capacity to transform the market to a place where more participants: seek choice and control; choose their staff for the ability to assist them to have a lifestyle of choice; use mainstream and community services; and seek and work toward greater independence, autonomy and citizenship. The Advisory Council proposed that changed participant behaviour has the capacity to impact on the market and lead to: mainstream and community services becoming more inclusive as they respond to requests one

person at a time; and the emergence of new services or sections of existing services that are responsive to changed demand and pressure on specialist disability services to provide something different.

The submission concluded on the premise that increased self-management aligns positive outcomes for participants with the sustainability of the Scheme as increased self-management: leads to value for money and reduced costs; provides incentives to develop informal support; encourages participants into mainstream and community services; reduces reliance on specialist disability services; and leads to increased independence, self reliance and community inclusion.

3.4

Discussion Paper: Self-management: value, risks and strategies for growth (Work in progress 2017)

The final paper in this theme draws together the body of work and will be submitted to the Board of the NDIA in the second half of 2017. The paper advances the beneficial impact of self-management in terms of improved participant outcomes, the ‘value for money’ it engenders, its capacity to support participant initiative and disrupt the market and the fact that it is fiscally sound. The paper reviews research related to the risks associated with self-management and strategies other jurisdictions have used to mitigate those risks concluding with strategies to support the growth of self-management in a manner that promotes participant choice and control in a safeguarded way.

3.5

Discussion Paper: Evidence on improper use of payments in self-management and balancing the fraud response (Work in progress, 2017)

The purpose of this paper is to provide evidence of the level of improper payments in self-managed programs in the US and UK and the strategies used to mitigate risk.

The Advisory Council has investigated the improper use of payments in large-scale participant-directed programs in the UK, US and Australian states and territories to demonstrate the inaccuracy of perceptions of self-management as a high-risk area for improper payments. Overseas experience also gave confidence that risk-based analysis will facilitate the appropriate balance between the perception and reality of fraud and the appropriate response at the individual and Scheme levels.

3.6

Advice: What should the NDIS understand about Intellectual Disability? (2017)

The purpose of this advice was to guide the Agency to a contemporary understanding of intellectual disability.

The advice from the Intellectual Disability Reference Group, 'What the Agency needs to understand about intellectual disability', recognised that the Agency's understanding about intellectual disability would have a significant influence on the way in which the Scheme facilitated active citizenship. The advice contended that the lived experience of

this significant group continues to be based on low expectations and institutionalised ways of thinking and hence it was imperative that the paradigm changing NDIS embodied a contemporary and empowering understanding of intellectual disability.

The traditional societal and service response to people with intellectual disability was explained by the devalued status of people with disability when measured against dominant societal values of youth, wealth, power, good health, physical prowess and intelligence, casting people with intellectual disability as subhuman, a menace, objects of pity, burden of charity, innocent and childlike. The dominant response was to protect people with disability from society, and society from people with disability, and this led to services that congregate people and separate them from family, friends and community.

The advice outlined what was required to ensure that the Agency, in all its functions, rejected the low expectations and institutionalised ways of thinking in order to enhance opportunities for people with intellectual disability to live ordinary lives in their communities. The advice identified underpinnings at the systemic level; principles to guide practice in working with participants; elements of NDIS staff recruitment and training; and outcome measures to determine the impact of the guidance.



3.7

Discussion Paper: Support for decision-making: key issues (2016)

The purpose of this paper was to explore changes to policy and practice that would enhance support for decision making for people with intellectual disability.

The role of the NDIS in supporting decision-making of participants with intellectual disability was situated in the context of the UNCRPD and the National Decision Making Principles contained in Part 3 of the Australian Law Reform Commission's report on Equality, Capacity and Disability in Commonwealth Laws (2014). Key issues were identified that required resolution including understanding and applying the emerging evidence, assisting all stakeholders to understand the issue and build their capacity to undertake their responsibilities, approaches to the allocation support for decision making, the role of nominees and approaches to respond to market failure. The paper was situated in the context of the requirements of surge and the absence of the Information Linkages and Capacity Building (ILC) which is a newer component of the NDIS focused on community inclusion activities.

Influence

The Advisory Council's work in the self-determination theme assisted the Agency to operationalise choice and control for participants through the national DSO initiative in which peer networks actively assist people with disability to move from dependent clients to active citizens.

This body of work also strengthened the Agency's commitment to self-management as a strategy that will enhance outcomes for participants and improve Scheme sustainability. It highlighted the requirement to support people with intellectual disability to make decisions and, into the future, will contribute to its operationalization.

Suggested priorities for future work

An exploration of the infrastructure and support required to support participants to self-manage.

An exploration of ways to encourage participants to pursue 'value for money' with their reasonable and necessary support in ways that safeguard both participants and the Scheme. This work will be undertaken together with Agency staff.

Support for decision-making: Members of the Intellectual Disability Reference Group to work together with Agency staff to co-design an NDIS support for decision-making approach.

THEME: CAPACITY BUILDING

Capacity building has been a strong and consistent theme over the life of the Advisory Council as building participant capacity is central to better outcomes for participants and for the financial sustainability of the Scheme. The purpose of the Advisory Council's work has been to highlight the potential of, and approaches to, capacity building to support the Agency to understand and operationalise capacity building for participants, their families and carers. Table 3 summarises the key elements of capacity building identified in the advices.

Table 3: The impact of capacity building on people with disability and their families

State & Territory systems	NDIS without capacity building	NDIS with capacity building
People maximise their deficits in an effort to maximise resources allocated to them.	People continue to maximise their deficits in order to maximise their resources.	People know that positive lives are built on high expectations. An overstatement of deficit and need is incompatible with high expectations.
People are frightened to use their initiative lest it reduces their eligibility or priority for government funded services and supports.	People lack examples of the type of initiative that can lead to positive outcomes. People do not know how to help people with disability to develop informal support (relationships with people who are not paid).	People have ideas and develop confidence. They understand that paid support contributes to positive lives but that an excess of paid support can drive out freely given relationships that are central to a meaningful life.
People with disability defer to others as the experts on their lives.	People create plans that continue to defer to service providers as the centre of expertise.	People have confidence to negotiate what they want and how they want it. They exercise choice and take the level of control they feel comfortable with.

State & Territory systems	NDIS without capacity building	NDIS with capacity building
<p>People have service plans.</p>	<p>Case managers from services assist people to go through the motion of planning, but limit their thinking and planning to the current disability system.</p> <p>A key focus of planning is to get as much as you can from the NDIS.</p>	<p>People develop goals for the life they want to live and develop plans to enable the use of NDIS resources to complement the support provided by family and friends.</p>
<p>Funding is allocated to services that provide assistance to the most needy.</p>	<p>Funding is used to purchase services from traditional disability service providers.</p>	<p>People are actively choosing from a range of services and supports including mainstream and informal supports. The NDIS package assists people to build informal support.</p>
<p>People are dependent users of service.</p>	<p>People are consumers of service and have some choice but limited opportunity to avail themselves of the choice and control anticipated by the NDIS.</p>	<p>People are active citizens, exercising choice and control, engaging in social, economic and political life.</p>

4.1

Advice: Capacity building for participants, their families and carers (2015)

The purpose of this advice was to identify effective ways to deliver capacity building supports to both participants and non-participants, with the latter group served through the NDIS Information, Linkage and Capacity Building system (ILC).

The advice drew on research evidence to identify effective ways to support people with disability to move from dependent clients to active citizens, building capacity through relationships, increased connection and skill. The advice focused on the role of the Scheme in facilitating this change.

The advice provided evidence in relation to mentoring, role modelling, learning by doing, one off information sessions and peer network. The advice recommended a capacity building approach that:

- assists potential participants to strengthen their belief in their own capacity to influence their lives and their environment;
- targets potential participants at times when they will be open to, and ready for, capacity building and uses strategies that respond to and support their increasing knowledge and skills; and
- uses a problem based approach that acknowledges potential participants as adult learners, recognising the different learning styles and timing of participants, and delivering flexible learning opportunities.

The advice included a framework to determine whether a proposal used evidence-based practice and stressed the importance of multi-

pronged capacity building strategies delivered for sufficient periods of time to support behavioural change.

In reviewing possible capacity building options in the NDIS ILC, the advice drew on the UK Government support of Disabled Persons User Led Organisations (DPULO) to recommend support for capacity building by user-led organisations. These organisations have made a major contribution to sustainable capacity building in the public health field but to date there has been limited evaluation of their potential impact in the disability sector in Australia. The Advisory Council suggested funding for user led organisations because of their potency as role models, their capacity to extend the horizons and self-efficacy of participants and their ability to support informed risk by participants. The paper drew on UK experience to suggest that support for user led organisations would lead to a stronger and more diverse market of capacity-building organisations and would be more likely to facilitate the systemic change required to realise the intent of the UNCRPD and the Australian National Disability Strategy.

In relation to capacity building through reasonable and necessary supports, the advice highlighted its importance not only at periods of life stage transition, but in increasing independence and self-management in everyday lives.

The lack of registered capacity building providers was identified as a weakness in market development strategies to build changing participant expectations and forms an important part of the Advisory Council's position encouraging user led organisations to register as providers.

The advice included eight (8) appendices that provide a detailed assessment of the different

approaches to capacity building and provides practical recommendations as to their use.

4.2

Discussion Paper: Capacity building for staff (2015)

The purpose of this paper was to identify the knowledge, skills and experience required of staff regarding the participant pathway.

The paper was delivered when the Agency was in the process of developing a comprehensive competency framework and outlined in detail the essential skills, knowledge and behaviours required of each role.

In preparing the paper, the Advisory Council considered the outcomes the NDIS should anticipate from the participant pathway experience, examined research in relation to promoting a positive experience and outcome for participants, consulted with NDIA staff, reviewed NDIA commissioned consultant reports and identified knowledge and skills required for all staff. This included additional understandings for staff working with particular cohorts of participants.

The paper provided that by the end of the participant pathway, the Scheme should expect that participants have a plan that meets the legislative principles underpinning reasonable and necessary support, that participants feel more empowered and able to do more things for themselves in the future and that the effectiveness of their utilisation of informal support and mainstream services is enhanced.

The paper drew on UK research by Think Local Act Personal (TLAP) to identify core elements that determine a good experience of, and outcome from, planning. These were: being

clear about who owns the process and the plan, and therefore who is involved in doing and leading it; a focus on planning not plans; and how to achieve outcomes.

Discussion with NDIA staff, review of consultant reports and observations from Induction Workbooks identified enhancements in relation to NDIA requirements to enable staff to better assist participants to build enhanced self-efficacy and self-management.

The paper concluded with a compendium of topics considered essential learning for staff if they were to better assist participants to achieve authentic growth and development with increased use of mainstream services and effective informal support. The paper recommended that new material be developed by, or at least in collaboration with, community organisations with long standing leadership in the area of capacity building for people with disability and families.

4.3

Discussion Paper: Activating capacity building (Work in progress 2016)

The purpose of this paper was to evaluate strategies that facilitate capacity building for people with disability.

Acknowledging the significant constraints faced by the NDIS in its transition environment, this paper reviewed the NDIS strategies to activate capacity building in order to give consistent messages that positive outcomes for participants (built on increased independence and inclusion) were consistent with the sustainability of the Scheme. To this end, the paper reviewed the role, strengths and challenges of Local Area Coordination, Support Co-ordination and peer networks.

The paper suggested that with the pressures of transition, Local Area Co-ordinators (LACs) do not have the time or relationship to do more than include capacity building items in the plans of motivated participants. They are unlikely to be able to change the appetite of participants and their families for increased independence and inclusion. Support Co-ordination on the other hand can be beneficial, but its generalist nature and the fact that it is not allocated to some very motivated participants who need guidance suggests that it may not be applied in the most effective way. Finally, peer networks provide low cost capacity building over an extended period of time but are not available to most participants because there are limited local peer networks across Australia.

The paper proposed approaches best suited to activate capacity building at surge and at full scheme roll out.

This paper will underpin future work on capacity building.

Influence

Feedback from these papers influenced the Agency to identify 'delivery by people with disability for people with disability' as a priority investment area for the ILC.

In addition, the work on capacity building for staff led directly to additional topics being added to the competency framework.

Suggested priorities for future work

An exploration of the use of capacity building in reasonable and necessary support to advise the NDIA as to strategies to enhance their effectiveness.



THEME: INDEPENDENCE

The NDIS Act requires the Scheme to support the independence and social and economic participation of people with disability as it leads to more positive outcomes and promotes the sustainability of the Scheme.

Many participants enter the Scheme from systems that have rewarded crises and dependence and are fearful that their increased independence and capacity will leave them without adequate support. The NDIS must secure the trust of participants that increased independence will be reflected in enhanced health and wellbeing and that if their needs change over time, reasonable and necessary supports will be adjusted to reflect these changed circumstances accordingly.

The Advisory Council's body of work with respect to this theme aims to assist the Agency to maximise the independence of people with disability.

5.1

Advice: Promoting independence for people with disability (2014)

The purpose of this advice was to explore a person with disability's barriers to independence and provide guidance as to what independence might 'look like' across the lifespan and in different domains and stages of an ordinary life.

The advice described key themes in the literature on independence, explored systemic barriers to independence and provided guidance as to what independence might look like in eight life domains. The advice concluded

with a discussion of the implications for reasonable and necessary support as well as for Information Linkages and Capacity building (ILC) resources to support independence.

5.2

Discussion Paper: NDIS supports for independence (Work in progress 2016)

The purpose of this paper was to provide guidance as to what the Agency can do to maximise the independence of all participants. The paper arose from observations by members of the Intellectual Disability Reference Group that some participants with intellectual disability were losing skills as a result of the way in which their NDIS support was provided.

The first section outlined factors that have led to dependence and passivity of people with disability and their families, including factors related to surges that work against increased independence. Whilst most factors identified predate the NDIS, they provide insights to sharpen the focus and effectiveness of the NDIS approach.

The second section proposed strategies to enhance the NDIS approach to independence making recommendations in relation to the ILC, planning, reasonable and necessary support, plan implementation, learning and

culture and operations.

The paper suggested that most services and support workers do not encourage independence in participants and recommended a market scan to test provider competence in enhancing participant independence as well as an audit of registration requirements for consistency with expectations of increased independence, self-direction and social and economic participation.

Influence

Although not yet finalised, discussion with Agency staff on this topic has influenced the planning conversation that now includes a question in relation to increased independence. Ongoing work will be engaged in to maximise the NDIS support for independence.

Suggested priorities for future work

Further exploration in promoting independence will be taken up in future Advisory Council work on the theme of capacity building.

THEME: SOCIAL AND ECONOMIC PARTICIPATION AND INCLUSION

Increased social and economic participation and inclusion are core objectives of the Scheme and the purpose of the Advisory Council's work in this area is to guide the Agency in maximising participant outcomes within this theme. Recognising the need for service transformation, the Advisory Council established the Innovations Reference Group to advise as to the nature of contemporary practice and approaches to service transformation.

6.1

Discussion Paper: Genuine community engagement (2014)

The purpose of this paper was to explore factors that contribute to people with disability being genuinely engaged in the community with a true sense of belonging.

The paper reviewed literature to demonstrate a strong relationship between community engagement and wellbeing. The paper proposed a three-pronged approach to promoting genuine community engagement with action focused on: (1) facilitating the willingness of the individual; (2) facilitating the willingness of the community; and (3) strategies to connect the two. The paper contributed to the advice 'Reasonable and necessary support for an ordinary life.'

6.2

Discussion Paper: Innovation in housing and support (Work in progress 2017)

The purpose of this paper was to describe the continuum of housing and support options enabled by the NDIS.

The paper considered that transforming housing and support into a home was critical for positive outcomes of health and wellbeing. It was suggested this could be achieved by linking the Scheme's response to housing and support to the achievement of the enablers of an ordinary life identified by the Advisory Council in its advice 'Reasonable and necessary support for an ordinary life'. This required the home to provide opportunities to foster positive relationships, enable participants to feel 'at home' with a sense of belonging, and to strengthen the participant's identity and ability to make decisions. In addition, a participant's home should provide the launching pad for their active social, economic, community and cultural engagement, enabling the person to experience challenges and make contributions.

Hence, the paper highlighted that the choice about who shares a home is as important to people with disability as anyone else and an active role in choosing fellow residents is vital.

The paper identified ten building blocks of housing and support with the expectation that participants, supporters and the Agency would work together to enable people with disability to live in a 'home of their own'.

6.3

Discussion Paper: Barriers to housing and support that will have cost implications for the NDIS (Work in progress 2017)

The purpose of this paper was to outline barriers to housing and support that may lead to cost pressure on the NDIS.

The paper acknowledged a context that included participants who see themselves as dependent clients with little personal agency, a national crisis in affordable housing experienced even more sharply by people with disability and a COAG whole of government approach to people with disability that has not been implemented with serious intent.

The paper outlined five main challenges related to housing and support that could create cost pressure on the NDIS.

The first cost pressure arises as a result of a lack of effective implementation of the COAG interface principles resulting in mainstream systems and services not fulfilling their responsibilities to people with disability. These high level pressures were reported to be outside the responsibility of the NDIS however the advice outlined evidence and discussion that could be used in representation in relation

to the roll out of obligations under the National Disability Strategy.

The second cost pressure arises from the lack of safe, secure, affordable housing for some participants. The paper acknowledged that housing affordability was the responsibility of state and territory governments, including in relation to people with disability but many NDIS participants would continue to experience challenges. As a result many will seek to become eligible for Specialist Disability Accommodation (SDA). Some will remain in their family home longer than planned and this may lead to increased package size as participants lose skills or fail to develop skills. Some families will experience burn out and some participants will develop behaviours of concern. Some participants will stay in shared supported accommodation when they could do well in less restrictive and less expensive alternatives. Others will live in sub-optimal housing such as boarding houses or in the private rental market, with a lack of permanency and having to move continually. This will have cost impacts on the Scheme including repeated home modifications and supports associated with relocation and building new networks.

A third cost pressure relates to the ineffective operation of systems and markets. The lack of a central repository of information with respect to accessible housing means that accessible housing may be vacant or rented to a person who does not value the access features while a person requiring access remains in inappropriate or inaccessible housing. Similarly, the lack of mechanisms to find housemates will mean long vacancies in shared housing (SDA and non SDA), potentially threatening the viability of an option for other residents. The paper recommends mechanisms for more

effective matching of properties and home sharers.

The complex and inconsistent approach to urban planning and building was reported as another example of an ineffective market. For example, the variable interpretation of fire regulations in the National Construction Code potentially makes a significant number of Victorian participants eligible for SDA as the State Government's requirement for fire sprinklers in housing for unrelated people with disability makes it impossible to find housing in the mainstream housing market.

A fourth cost pressure relates to the lack of awareness of contemporary approaches to housing and support and the lack of contemporary options on the ground. The paper indicated that the failure to address these pressures would lead to a growth in demand for traditional shared supported accommodation. In addition, many participants exploring more contemporary value for money propositions would need Agency confirmation that their innovative use of reasonable and necessary support was considered proper.

The paper proposes that the lack of understanding of contemporary approaches also related to some providers who were exerting pressure to remove the requirement for separation of housing and support that is recognised as fundamental to the contemporary best practice approach of using the NDIS capital for participants who need specialist built form (SDA payments). The paper recommended upgrading current information strategies already in place as well as the use of the Agency's market steward role to foster the growth of contemporary approaches.

Finally, the paper explored cost pressures associated with people with disability not

maximising their independence and urged that participants be assisted to build informal support, enhance skills for independence and have personal safeguards in place as these capacity building ingredients are fundamental to reducing the long-term need for care and support. The paper recommended enhanced effort at capacity building for participants.

6.4

Submission to Senate Community Affairs Committee into the delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities (2017)

The Advisory Council's submission addressed the issues of universal design, housing and transport. It identified the potential barriers to progress and how these might be addressed and focused on the impact of restricted access for people with disability on their inclusion and participation in economic, cultural, social, civil and political life. In particular, the submission focused on the extent to which lack of progress: created dependence in people with disability; reduced their opportunities to be more independent, more engaged socially and economically and more included in their communities; and forced people with disability into congregate services, created increased demand for Specialist Disability Accommodation (SDA) and created increased financial pressures on the NDIS.

The submission identified the major barriers to progress as the lack of leadership from Government and the lack of genuine co-design with people with disability who directly experience the impacts of lack of action. The submission recommended accountability requirements on the heads of government departments and the use of reference groups

consisting of people with disability reporting to senior management.

Suggested priorities for future work

The exploration of innovation in work and community participation through the Innovations Reference Group.

THEME: REDUCING VULNERABILITY AND ENABLING POSITIVE RISK

An understanding of vulnerability is a critical step to reducing it. While vulnerability is part of being human, people with disability generally experience heightened vulnerability because they are more likely to experience disadvantages in life, have fewer opportunities and are more likely to be severely affected by the vulnerability they experience.

The key message of the Advisory Council's advice was that individual capacity building is the most effective way of balancing freedom from harm with choice and control. This message built on UK research and practice that demonstrated that in the context of personalisation, assisting people with disability to plan for risk contains the seeds for a transformation of care systems, not just the prevention of abuse and neglect.

7.1

Advice: How can the NDIS help participants enhance their personal safeguards in order to experience greater independence, economic participation and community inclusion? (2015)

The purpose of this advice was to demonstrate the importance of the Scheme in assisting participants to enhance their personal safeguards in order to experience greater independence, economic participation and

community inclusion safely.

Dignity of risk was identified as critical for identity formation and part of the transition from client to citizen. This advice suggested that a changed approach to risk was required to enable people with disability to experience the dignity of risk associated with the increased opportunity for choice and control. In this context, personal safeguards were integral to ensuring people with disability were safe whilst also enjoying the freedom to maximise their independence.

The advice suggested that the context of the development of the National Quality and Safeguards Framework (the Framework) provided a forum to establish a new equilibrium between independence, choice and control and the dignity of risk on the one hand and calls for safety on the other. The Advisory Council recommend that the new Framework resolve the tension between the current risk-averse framework built on conservative state and territory legislation with the growing emergence of choice and control as a basic right of people with disability. Experience

from the UK was instructive in assisting all stakeholders, including the Agency, to work toward reframing risk through a significant program of well-coordinated transformation to reach a new equilibrium between choice and control and the management of risk.

The Advisory Council considered that the development of personal safeguards was central to enabling people to experience positive risk and build their capacity. This would involve personalised planning, the development of self-advocacy skills and support for decision-making, all contributing to people's personal safety and their confidence to experience increased independence, economic participation and community inclusion.

Two clear strategies were proposed by the Advisory Council to assist people to identify services that are below standard as well as report abuse and neglect. The first involved supporting people with disability to have relationships with people who are not paid. The second strategy related to empowering people with disability to speak for themselves. The role and limitations of self-advocacy were discussed and the importance of structures to support people to speak for themselves was emphasised.

The advice outlined requirements for planning, for the Information Linkages and Capacity building (ILC) and for reasonable and necessary support to enable all people with disability to have access to support to develop personal safeguards. At the systemic level, the advice proposed the development of processes to manage risk in ways that did not curtail choice and control, and in a manner that has been successful in the UK. Finally, the Advisory Council encouraged the NDIA to respond to market failure in the area of intermediary

services including Support Coordinators skilled at designing supports that enable the participant to experience positive risk safely.

7.2

Advice: Building capacity and reducing vulnerability for people in closed systems (2016)

The purpose of this advice was to focus attention on strategies to maximise outcomes and promote Scheme sustainability in relation to the most vulnerable participants. The advice proposed this is best achieved through simultaneous work to build the capacity of individuals as well as strengthen the capacity building elements of the Scheme.

The advice drew on previous Advisory Council and Intellectual Disability Reference Group work to identify the most vulnerable participants and recommended that attention to capacity building, support for decision-making and building personal safeguards would reduce risk and enhance opportunities for positive life outcomes.

The advice recommended the need for adjustments to capacity building elements of the NDIS to better enhance their effectiveness. It highlighted the limitations in the current scope of functions of Support Coordination and the need to understand a role for support co-ordination in contributing to capacity building as well as co-ordination of services.

The advice expressed concern that the current market of registered capacity building organisations was thin, in part because user led organisations had failed to register as providers of capacity building support. In addition, shortcomings in the current registration process were identified raising doubt as to

whether the registration requirements in fact addressed questions of competence to provide the identified support.

7.3

Discussion Paper: Quality and Safeguards for people in closed systems (2017)

The purpose of this paper was to identify what was required to enable participants in closed systems to be assured of quality support and to have opportunities to experience positive risk safely.

This brief paper focused on issues critical for quality support and safeguards for people who experience a most profound vulnerability – that of living and spending the day in residential and day services that are closed systems where they had very little contact with people who were not paid to be there. The paper considered that people in closed systems have little or no access to information that might let them know that their lives were very different to the lives of other Australians, including other Australians with similar disability; they had little or no insight to other possibilities that they might rightfully claim; they have very little experience to know whether the way in which staff treat them was appropriate; their lives were diminished because they experienced the cumulative impact of vulnerabilities arising from their impairment, from unresponsive services and systems and from the loss of opportunity for a life well lived.

This paper identified what was required of the National Quality and Safeguards Framework to assure each individual who lived in a closed system and had no informal support that:

- they would be assisted to exercise their

rights, make decisions, learn about new possibilities and develop personal safeguards;

- they would have access to a person independent of the service with whom they could meet on a regular basis;
- if their behaviour was perceived as challenging, they would be appropriately supported;
- they would receive quality support; and
- if things went wrong, they could expect appropriate support to remedy the situation and take action to prevent it happening again and to others.

The first section outlined the requirements from the perspective of the participant. The second section outlined the requirements from a systemic perspective in the developmental, preventative and corrective domains of the Quality and Safeguards Framework. A concern was the lack of attention to assisting participants in closed systems to develop personal safeguards, assuring them that they would be assisted to exercise their rights, make decisions, learn about new possibilities and develop personal safeguards and have access to a person independent of the service with whom they can meet on a regular basis.

Whilst the Advisory Council recommended Support Coordination be an integral part of the reasonable and necessary support for participants in closed systems, observations on the ground led the paper to reflect that the safeguarding elements may be diminished where the provider of core supports is also the provider of Support Coordination.

The Advisory Council recommended a review of the registration requirements for the capacity building clusters to ensure that registrants demonstrate knowledge, skills and experience relevant to capacity building.

Finally, the Advisory Council recommended that in the context of thin markets of capacity building organisations that do not also provide core supports, the Agency undertake a targeted approach to register user led organisations for Support Coordination and other capacity building supports.

Influence

The Board endorsed the Advisory Council advice that the Scheme assist participants to develop personal safeguards.

THEME: EQUITY

The Agency is mindful that within its core design framework, the Scheme needs to be responsive to the impacts of different functional impairments and life circumstances. To strengthen that responsiveness, the Advisory Council recognised the importance of giving voice to leaders of disability communities to contribute to the shaping of Scheme design and implementation. The formation of the Intellectual Disability Reference Group is one active step the Advisory Council has taken to give voice to consumer leaders.

Other steps involve the active engagement and leadership of Advisory Council members in NDIS Reference and Working Groups focused on responsive provision to people with disability arising from mental health issues, from Aboriginal and Torres Strait Islander communities, Culturally and Linguistically Diverse backgrounds, and to young children with disability including an additional focus on young children with autism.

Mental Health

The Advisory Council has made a significant contribution to improving the Scheme's responsiveness to people with psychosocial disability arising from mental health issues, a major participant group who were included late in the planning for the Scheme. In considering strategies, members of the Advisory Council:

- listened to the views of consumers and family and carer advocates and the mental health sector;
- proactively worked with key stakeholder groups to inform and engage with the NDIS and generate both critique and support;

- built an understanding of how the trial sites were responding to applicants and participants with disability arising from mental illness;
- participated in the NDIS Mental Health Reference Group, which was a national reference group set up to address implementation issues for people with psychosocial disabilities. This group contributed to an Operational Access Review for psychosocial disability and members of the Advisory Council chaired various working groups of this reference group.

In 2015, the Board accepted the Advisory Council's recommendation that an annual mental health work plan should be developed and approved by the Board with input from the Advisory Council. On an annual basis, the Advisory Council provides feedback on the mental health work plan and achievements to the Agency's Expert Mental Health Consultant and this feedback is incorporated in the report to the Board.

8.1

Mental Health and the NDIS: A Literature Review (2014)

The Advisory Council commissioned an extensive literature review in partnership with Mind Australia and the Centre for Mental Health within the School of Population and Global Health at the University of Melbourne. The review examined the current state of evidence relating to the impact of psychosocial disability in the context of the implementation of the NDIS Act.

The literature review assisted in the formulation of the Advisory Council's advice to the Board and provided an excellent resource for people interested in the implementation of the Scheme for people with psychosocial disability.

8.2

Advice: Implementing the NDIS for people with disabilities related to mental health issues (2014)

The purpose of this 2014 advice was to assist the Agency in improving sensitivity and responsiveness of the Scheme to people with disability related to mental health issues.

Of critical importance was the advice in relation to interpreting permanency and assessment of the degree of impairment. The advice recommended that the Agency:

- monitor patterns of eligibility and ineligibility in relation to permanency of disabilities related to mental health issues to develop an informed approach to the robustness and consistency of practice across the Agency;
 - develops its own working definition and guidelines of permanency of disabilities related to mental health issues;
 - promote its working definition of permanence of disability related to mental health issues within the Agency and to staff in external agencies who make judgements about diagnosis and functional impairments upon which the Agency relies;
 - monitor patterns of eligibility and ineligibility in relation to functional impairment and a psychiatric condition to build a picture of who is being included and excluded, track compliance with the requirements of the legislation and the consistency of the assessments being undertaken; and
 - invest in the development of a validated instrument for identifying an evidence-based approach to the determination of functional impairments and support needs for people with an impairment related to a psychiatric condition.
- In considering the implementation of the Scheme for people with psychosocial disability the Advisory Council considered:
- how the Scheme could harness opportunities to improve engagement with the mental health sector and mainstream services;
 - the importance of consistency in the assessment of severity and permanency in the determination of reasonable and necessary supports;
 - the development of a forward-looking Mental Health Implementation Plan as a clear statement of the strategy for implementing the Scheme for people with psychosocial disability; and

- the need to amend outcomes measures (and the development of reference packages) to better reflect the needs of people with psychosocial disability and current practice in the mental health sector.

8.3

Discussion Paper: Improving access for people in Psychiatric Hostels, Supported Residential Services and Boarding Houses (Work in progress 2016)

The purpose of this paper is to build on the agency's work in this area and to highlight people living in 'supported' residential facilities, psychiatric hostels and private boarding houses who were thought to represent approximately 2% of the total NDIS target population, and to argue that specific strategies be developed to respond to their particular needs.

The paper identified that this specific group has missed out on reforms in the disability sector because they live in accommodation not registered as specialist supported accommodation. The paper identified the numbers of potential NDIS participants living in these private sector facilities and highlighted the need for pro-active engagement strategies to ensure potential participants were aware of, and had support to develop the confidence and skills to proceed through, the participant pathway. The paper recommended a suite of strategies including the use of assertive engagement by LACs and Agency staff and a good pro-active model of engagement such as that undertaken by the Western Australian Office of the Agency in Perth.

The paper suggested that tender specifications and guidelines for LACs need to identify this population cohort as one that required focused

attention in their area co-ordination function. This function could be undertaken within the scope of the existing LAC arrangements but would require contract monitoring.

Finally, the paper suggested that this large group of future participants needed to be part of the planning considerations for the Specialist Disability Accommodation (SDA) as it evolves over the next five years, because, while their current accommodation is not SDA, many of the participants may well be SDA eligible.

8.4

Discussion Paper: Guidance on the application and promotion of peer work in the NDIS (Work in progress 2017)

The paper provided an overview of what peer work is, the evidence of its benefits, the relevance of peer work in the context of the Scheme, and its broader application and a role for the Agency in supporting its development.

The paper demonstrated that peer support was a concept that has been well developed in the mental health sector over the last decade. It is an item in the NDIS Catalogue of Support described as assistance with and co-ordination or management of life stages, transition and supports from someone with lived experience of disability as well as other appropriate skills. Lived experience can also be built into any service type: this is a strategy that individual providers may pursue if they deem it relevant to their particular target market.

The paper recognised that the current conceptualisation of peer work was largely drawn from its application in mental health systems in Australia and overseas. There is an emerging evidence base for the efficacy of peer work in supporting people who have

experienced mental health challenges to develop the confidence and capabilities they need to lead contributing lives in the community. The evidence pointed to the effectiveness of peer work in promoting people's independence and contribution, and reducing their reliance on professionally provided services over their life time. The focus on the development of confidence and capability was relevant to all disability types, particularly those where cognitive disruption, motivation and/or emotional distress impair an individual's functional capacity or ability to engage in participation activities.

Importantly, the evidence relating to the implementation of peer work in organisations and across systems suggested that merely creating the conditions in which peer work can occur (i.e. by providing a funding mechanism) was insufficient to ensure its development. There was a role for the Agency to promote and support the development of peer work in order to expand the range of services that participants can choose from.

The Advisory Council recommended the development of peer work services across all disability categories as a means of expanding and maintaining choice and control for participants. This involved specific goals, actions and targets relating to the development and growth of a disability peer workforce and advice to participants and potential participants, Local Area Co-ordinators and service providers on the value of peer support.

The paper included specific recommendations in relation to a peer workforce guideline, discussions with the Australian Industry and Skills Committee and Skills IQ Ltd on the inclusion of an accredited peer worker qualification in the Community Services training package and specific registration

standards for providers wishing to offer peer support services.

8.5

Discussion Paper: Peer workers in the NDIS (Work in progress 2017)

The purpose of this detailed technical paper was to clarify the concept of the peer worker role in relation to the disability field and provide the necessary information for the Agency to:

- create and implement a specific strategic goal/policy statement regarding the employment of those with lived experience; and
- create, adapt and implement a peer workforce strategy based on the suggestions, ethics and principles outlined.

The paper proposes that a specific strategic goal/policy statement direction would enable the employment of people living with particular disability (provided they were appropriately skilled) to offer expertise, support and leadership to participants in the Scheme with similar life or participation challenges.

It is envisaged that 'peer workers' (see Definitions, page 4 of the paper), would act as support facilitators or providers and/or mentors. They would, by their professionalism, intent and status as lived-experience experts, model aspects of how to challenge oneself, offer encouragement and raise participants' awareness of their individual potential.

The paper suggested that this would combine the best of what peer support work has to offer and would learn from the health and social sector's knowledge and expertise to support the very best of what we can bring to participants.

The paper outlined a peer workforce strategy

that would lead in time to new disability support workforce directions, further policy developments and the ability of providers to employ adequate support personnel as demands grow with full Scheme roll-out. A by-product of this activity would be the enhancement of employment opportunities for those people who had gained insights and considerable knowledge through their personal lived experience of disability.

The paper proposed that agreement on the philosophy, ethics and principles that underpin the employment of those with lived experience in the support workforce was pivotal as a starting point. Such considerations would provide guiding principles for the development of additional policies and protocols around the employment of people with lived experience in agencies offering services to participants under the Scheme.

8.6

Submission to the Joint Standing Committee on the NDIS in its reference into the NDIS and mental health (2017)

The Advisory Council prepared a submission and presented its case to the Joint Standing Committee on the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

The Advisory Council recognised that significant progress had been made in improving the responsiveness of the NDIS to people with psychosocial disabilities but that additional work was required. On the issue of eligibility, the Advisory Council restated the recommendations outlined in the 2014

advice outlined in its advice 'Implementing the NDIS for people with disabilities related to mental health issues'. On the issue of the planning process for people with psychosocial disability and the role of primary health networks in that process, the Advisory Council's submission acknowledged variations in LAC programs, in the knowledge and skills of staff in psychosocial disability undertaking the planning function and encouraged the Agency to increase expectations of LACs in this area in future service agreements.

On the issue of the role and extent of outreach services to identify potential Scheme participants with a psychosocial disability, the Advisory Council emphasised the role of LACs and marketing strategies in informing all potentially eligible people about the Scheme and having assertive engagement strategies at the Agency and LAC levels.

8.7

Establishment of the Intellectual Disability Reference Group (2015)

The Advisory Council's Intellectual Disability Reference Group (IDRG) was established in 2015 to provide systemic and strategic advice to the Advisory Council on how the Scheme could better promote and enable an ordinary life for people with intellectual disability. It was recognised that more than half of the future users of the Scheme would be people with intellectual disability, providing particular challenges for the Scheme as it is anticipated that many of this cohort would face significant barriers accessing the Scheme and reaching full citizenship.

The Advisory Council invited external people to participate in this reference group. Members

included people with intellectual disability, parents and experts in the field of intellectual disability.

Priority issues identified by the IDRG work plan included:

- What should the NDIA understand about intellectual disability?;
- Promoting equity of access to the NDIS;
- Definition of Intellectual Disability;
- Planning and implementing support where participants lack effective informal support;
- Decision making and participants with cognitive impairment;
- Participants with complex behaviour;
- Creating a positive vision for participants with intellectual disability;
- Information, Linkages and Capacity Building (ILC);
- People with intellectual disability in large residential centres and other closed services; and
- Parents with intellectual disability.

8.8

Advice: Equitable access to the NDIS for people on the margins (2016)

The purpose of this advice, which stemmed from the IDRG, was to identify enhancements to current policy and practice to maximize equitable access for individuals with intellectual disability who were ‘on the margins’ and traditionally under-represented in disability services. The term ‘people on the margins’ was used to refer to people with intellectual disability who experienced

complex disadvantage associated with mental ill-health, insecure housing, the use of drugs and alcohol and/or contact with the child protection and/ or criminal justice systems and parents with a disability (especially parents with an intellectual disability).

The advice documented challenges in the current approach to outreach, the determination of eligibility, pre-planning, planning and plan implementation and in engagement with the health system that would inhibit effective engagement with people on the margins.

In its formal response to the Advisory Council, the Board accepted the vast majority of the recommendations. Those noted but not planned for implementation related to areas outside the remit of the Agency as reflected in the COAG agreed Principles to Determine the Responsibilities of the NDIS and Other Service Systems 2015 (Interface principles), or not possible under the bilateral phasing schedules.

8.9

Advice: Equitable access for people in touch with criminal justice (2016)

This advice was to be read in conjunction with the paper ‘*Equitable access to the NDIS by people with cognitive impairment on the margins*’. The purpose of the advice was to identify enhancements to current policy and practice to maximize equitable access for individuals with intellectual disability who are in touch with or at risk of contact with the criminal justice system.

The advice recognised that there was a significant danger that people with disability who were in contact with justice systems would continue to experience disadvantage as

a result of the Applied Principles between the NDIS and Justice and the inability of justice systems to meet their responsibilities under the National Disability Strategy (NDS) and their obligations under the *Disability Discrimination Act* (1992) (Cth).

Of particular concern was the fact that justice agencies had responsibility for *‘the assessment of cognitive ability, psychiatric conditions and other matters required to assess a person’s ability to plead in court or considerations prior to sentencing or diversion’*. As a result, justice agencies control the gateway to reasonable adjustment, diversion and disability support. Experience across all jurisdictions indicated that justice agencies in fact only provide cognitive and other assessments in very limited circumstances and commonly did not recognise signs that a person has an intellectual disability. Opportunities for diversion and early intervention were thereby lost.

In addition, the Applied Principles did not appear to acknowledge the fundamental difficulties faced by people with intellectual disability in understanding and dealing with police and court processes and the disability support that was required in this context.

In its formal response to the Advisory Council, the Board noted all the recommendations indicating the gaps in provision were within the realm of the Agency under the COAG interface principles governing the responsibilities of the NDIS and Justice Agencies.

8.10

Discussion Paper: People who are deaf and hard of hearing (Work in progress 2017)

The purpose of this paper was to build on work currently being undertaken by the Agency to support a nationally consistent approach to people who are deaf and hard of hearing by identifying additional considerations that would strengthen the final approach.

The paper reviewed work currently being undertaken on key issues of access and eligibility, planning, reasonable and necessary support, choice and control, communication, peer support, research and governance. The Advisory Council supported the direction of the Agency’s practice and recommended enhancements to overcome the identified concerns.

The Advisory Council was pleased to see that people with a moderate to severe hearing loss under 25 years were eligible to be participants but expressed concern that the current inadequate provision of reasonable adjustment by mainstream agencies for people over 25 years with mild to moderate hearing loss would have deleterious impact on the individuals and may have long term implications for the Scheme. Similarly, the lack of reasonable adjustment by mental health services left many people who are deaf and hard of hearing and are in need of mental health services without appropriate support.

The paper stressed the importance of capacity building for participants who are deaf and hard of hearing, especially capacity building that disrupts low expectations about work and

provides employment related skills.

The future funding of the National Auslan Booking Service (NABS) was also of concern since under transition arrangements, the funds for the NABS has been transferred to the NDIS but people over 65 and those under 65 who were not eligible for the Scheme could lose interpreter services.

The lack of choice in relation to hearing services was highlighted. The concern was compounded by unethical practices in the sale of hearing aids documented by the Australian Competition and Consumer Commission¹ where incentive based sales and commissions were commonly used to motivate clinicians to sell hearing aids that are unnecessary or more expensive than a consumer needs.

The paper commented on the inconsistent approaches to the Agency's communication with people who were deaf and hard of hearing and identified the need for the development of new Auslan communication to ensure NDIS concepts and terms were interpreted in a consistent manner.

The importance of peer support was stressed and encouragement was expressed for the development of peer worker approaches emerging from the mental health field.

The paper acknowledged the valuable contribution made by the NDIS Early Intervention Expert Hearing Reference Group, but believed that broader avenues for advice of a nature similar to that provided by the Intellectual Disability Reference Group and the National Mental Health Sector Reference Group were required in relation to people who were deaf and hard of hearing.

8.11

Representation in relation to equitable access for Aboriginal and Torres Strait Islander Peoples

The Advisory Council has been instrumental in raising awareness as to how the Scheme can improve on its response to Aboriginal and Torres Strait Islander people with disability, their families, carers and communities.

In 2015, the Agency developed the Rural, Remote and Aboriginal and Torres Strait Islander Reference and Working Groups that developed the Aboriginal and Torres Strait Islander Engagement Strategy, adopted by the Board and noted by COAG in 2016. Ms Jennifer Cullen, an Advisory Council member, played an active role in these groups, emphasising the need for a participant-centric response that reflected the nuances of the way to engage and work with Aboriginal and Torres Strait Islander peoples if their under-representation was to be addressed. This culminated in 2017 with the launch of the Aboriginal and Torres Strait Islander Engagement Strategy (The Strategy) in Cairns.

The advice from The Strategy provided the Agency with an understanding of the 'proper way' to conduct business with Aboriginal and Torres Strait Islander communities. The Strategy was included in Operational Plans, to ensure that the roll-out of the Scheme across the jurisdictions addressed Aboriginal and Torres Strait Islander peoples.

The Advisory Council will continue to provide advice to the Board on outreach, place based engagement and roll-out across urban, rural and remote Australia.

¹ <https://www.accc.gov.au/system/files/Issues%20around%20the%20sale%20of%20hearing%20aids%20-%20Consumer%20and%20clinical%20perspectives.pdf> Accessed 21 April 2017

8.12

Representation in relation to equitable access for people from culturally and linguistically diverse backgrounds with disability

The Agency recognises that Australia is a nation of diverse peoples with diverse language, ethnic backgrounds, traditions, and religious characteristics who have a right to equitable access to the Scheme. People from culturally and linguistically diverse backgrounds with disability and their families and carers face a combination of barriers in accessing disability supports and engaging with their local communities.

Two members of the Advisory Council were members of the Cultural and Linguistic Diversity (CALD) Stakeholder Advisory Group whose membership included representatives of organisations representing people with disability from CALD backgrounds, key interest and advisory groups. The group provided feedback and guidance to the NDIA on the issues of: definition and measurement of cultural and linguistic diversity, the issue of interpreting and the development of the Cultural and Linguistic Diversity Strategy. In April 2017, the reference group contributed its final comment on the draft document.

8.13

Representation in relation to Early Childhood Early Intervention

Early childhood intervention has been recognised as a critical component of the Scheme as support in these early years has the potential to positively impact long term outcomes for a child and their family. Throughout the first term, an Advisory Council

member provided detailed reports at each meeting on the practical aspects of Scheme implementation for this age group from across the country. This information highlighted issues which were unique to early childhood which included: the importance that planners be knowledgeable about early childhood development; the particular needs of families who have very young children; the value of inclusion; and the need for evidence based practice including the imperative that services be family-centred. The Advisory Council also recognised the need for capacity building for families of children and this theme is documented in several papers.

Throughout trial, the Agency learnt that the Scheme could be improved in order to provide families with a more respectful experience that accounts for the unique circumstances of early childhood. This experience should include the provision of information which will assist families to make decisions regarding the supports they will choose for their child in order to maximise opportunities to participate in their everyday environment. However, the experience of families in the Scheme varied significantly across the country.

The introduction of the Early Childhood Early Intervention (ECEI) approach was therefore, designed to create a nationally consistent approach to the provision of early childhood intervention for children from birth to 6 years old. Through this family-centred approach, the Agency will engage early childhood partners who have particular expertise in this field. These partners can therefore engage with the family to help them understand their child's development, identify goals and discuss evidence based supports. Central to this approach is building the capacity of children and their families to be connected to, and participate in, their communities along with building the capacity of the broader

community for inclusion. Given the work undertaken by the Advisory Council on the equity and capacity building themes, the new ECEI approach was of particular interest as the implications of such an approach for both participant outcomes and Scheme sustainability were consistent with the fundamental principles of the Scheme.

8.14

Representation on the Autism Stakeholder Reference Group

National experts in the field of autism provided the Agency with advice throughout the development of a 14-month project on Autism Spectrum Disorder (ASD) for preschool children. This group included two members of the Advisory Council with expertise in autism and early childhood intervention. The project produced the report *'Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers'*. The report was considered by the Agency as part of the broad knowledge and research evidence used in designing an improved approach to early childhood early intervention.

Influence

The Advisory Council's work has reinforced the efficacy of a co-design approach, supporting the Agency's establishment of a Co-design and Inclusion Branch. Feedback suggests that the use of population specific reference groups has enabled the Advisory Council to draw on leaders in their fields to support the development of an evidenced based approach to Scheme design and implementation.

Suggested priorities for future work

NDIS practice in relation to people with complex behaviour that will be explored through the Intellectual Disability Reference Group.

MEMBERSHIP OF THE INDEPENDENT ADVISORY COUNCIL



Professor Rhonda Galbally AO (Principal Member)

Professor Rhonda Galbally AO is dedicated to working in health development, disability, social and health policy in Australia. In recognition of her service to community Prof Galbally was made a Member of the Order of Australia in 1991; awarded the Centenary Medal in 2001; and awarded honorary degrees in health and social science from La Trobe University in 1999 and RMIT in 2005.

Prof Galbally began as a teacher in the early 1970s at secondary and tertiary levels. In the late 1970s she was senior policy analyst for the Victorian Council of Social Services. In the early 1980s she was appointed CEO of the Sidney Myer Fund and the Myer Foundation. Since the mid-1980s, Prof Galbally has been the

foundation CEO of five new Australian organisations, including the Australian Commission for the Future.

For 10 years Prof Galbally was CEO of the Victorian Health Promotion Foundation (VicHealth). During this time VicHealth established a number of research centres, including: the Centre for Adolescent Health Melbourne University, the Australian Research Centre in Sex, Health and Society Latrobe University, the Centre for research into Mother and Child Health Latrobe University, Onenda VicHealth Koori Health Centre Melbourne University.

In the late 1990s, Prof Galbally established the Australian International Health Institute. In 2000 she was appointed as the Independent Chair of the Review of Drugs Poisons and Controlled Substances Legislation (the Galbally Review). From 2000 to 2010 she was co-founder and CEO of Our Community Pty. Ltd. From 2004 to 2013 Prof Galbally was Chair of the Royal Women's Hospital. During this time the hospital established the Research Centre for Women's Mental Health funded by the Pratt Foundation.

In 2005 Prof Galbally was a member of the expert panel that developed the Charter of Human Rights and Responsibilities (2006). From 2008 to 2013 she was the Chair of the National People with Disability and Carer's Council. In 2011 Prof Galbally was appointed CEO of the newly created Australian National Preventive Health Agency.

In 2012 Prof Galbally chaired the International Evaluation Committee for the Thai Health Promotion Foundation. She was a member of the independent Advisory Panel for the Productivity Commission Inquiry into a lifetime care and support scheme for people with a disability and chronic illness. Since its establishment in 2013 Prof Galbally has been a Board member of the National Disability Insurance Scheme.

Prof Galbally was a trustee of the Reichstein Foundation 1985-2010; trustee of the National Gallery of Victoria 1985-1995; member of the Malthouse Theatre 1983-1992; Board member of the Alfred Hospital 1990-1995; council member of Monash University 2002-2007; council member of RMIT 1992-1997; member of the Commonwealth Tertiary Education Commission Advanced Education Council 1983-1987; and chair of Philanthropy Australia 1982-1985.

Prof Galbally is patron of The Compassionate Friends Victoria Inc.

Prof Galbally is the author of *Just Passions*, published in 2004 and republished in 2012.



Dr Ken Baker AM

Dr Ken Baker is the Chief Executive of National Disability Services (NDS), the peak association for non-government disability service organisations. In that role, he provides information, representation and policy advice.

Dr Baker has been a member of numerous committees advising government on disability policy matters, particularly employment. He has worked in social policy and public affairs for over 30 years and has personal experience as a carer. He campaigned for the introduction of the NDIS and is keen to see it implemented well across Australia.

Organisational affiliations

- Member, National Disability and Carer Alliance
- Member, Disability Employment Advisory Committee (NSW Public Service Commission)
- Member, Disability Employment Services Reference Group (Department of Social Services)
- Member, Community Services Advisory Group (Department of Social Services)
- Member, CEO Forum (National Disability Insurance Agency)
- Member, Service User Group (ACNC)



Ms Joan McKenna-Kerr

Ms Joan McKenna-Kerr is CEO of the Autism Association of Western Australia, an organisation funded by the State and Commonwealth Government to provide specialist services to children and adults with Autism Spectrum Disorder (ASD). She is formerly a member of the Commonwealth NDIS Advisory Board and Co-Chair of the NDIS Expert Group on Eligibility and Assessment.

Ms McKenna-Kerr is President of National Disability Services (NDS) and has been involved in the disability sector for over 25 years.

Ms McKenna-Kerr has served on numerous working parties tasked with advising on unmet need for disability services. She has also been involved in major initiatives involving disability sector development and reform.

Organisational affiliations

- President, National Disability Services (NDS)
- Vice President WA Division NDS
- Appointed Member of the West Australian Partnership Forum
- Director, Australian Advisory Board on Autism Spectrum Disorder
- State Representative: West Australian South West Native Title Settlement Pre-Qualification Committee



Mr Dean Barton-Smith AM

Mr Dean Barton-Smith AM is the CEO of Deaf Children Australia; the former CEO of the Victorian Mental Illness Awareness Council; CEO LINK Community Transport and CEO of Australian Association of Practice Managers.

Mr Barton-Smith was a former Chair of the Board of the Australian Federation of Disability Organisations. He is a Fellow with the Australian Institute of Management; Associate Fellow with the Australian Marketing Institute and a Certified Practising Marketer.

Mr Barton-Smith has held a number of senior directorships and high level advisory positions in the telecommunication, disability,

youth, sport/recreation and not for profit sectors over 30 years. He graduated as a National Mental Health Leader, led by the National Mental Health Commission, in 2013.

Mr Barton-Smith is also an accomplished sportsman, representing Australia in the Decathlon at the 1990 and 1994 Commonwealth Games and the 1992 Barcelona Olympics – the first deaf Australian to do so. He has competed in four Deaflympic Games holding numerous world and games records. He was also founding chairperson of the Melbourne 2005 Deaflympic Games Limited.

Mr Barton-Smith was awarded Member of the Order of Australia (AM) in 2013, received the Advance Australia Award, Prime Minister Sports Medal and the rare Edwin Flack Medal.

Organisational affiliations

- Non-Executive Director, Australian Communication Consumer Action Network



Dr Gerry Naughtin

Dr Gerry Naughtin is the Chief Executive of Mind Australia and has an extensive background in human service management, research and the delivery of disability, mental health and aged care services. He has held senior management positions in government and CEO positions in the commercial and not for profit sectors.

Dr Naughtin has extensive knowledge of the Australian mental health, aged care and disability sectors.

Earlier career positions include Associate Professor at LaTrobe University, senior policy officer retirement and ageing at the Brotherhood of St Laurence and founding Chief Executive of Silver Circle Home Support Services.

Organisational affiliations

- Chief Executive of Mind Australia



Ms Jennifer Cullen

Ms Jennifer Cullen is CEO of Synapse in Queensland and New South Wales. She has extensive experience providing a comprehensive range of community-based services to support and benefit people with disability. Ms Cullen has a strong understanding of and detailed experience in supporting people with neurocognitive disabilities.

Ms Cullen has extensive experience working with Aboriginal and Torres Strait Islander people with disability and their communities.

Organisational affiliations

- Member, Aboriginal and Torres Strait Islander Advisory Council
- Member, National Disability and Carers Advisory Council
- Core Working Group Member, Queensland Transition to NDIS for Mental Health
- Non-Executive Director, MJD Foundation
- Adjunct Associate Professor, James Cook University



Mr Kurt Fearnely OAM

Mr Kurt Fearnely is an Australian Paralympian and wheelchair athlete. He has represented Australia at four Paralympic Games, winning a total of eleven medals including three gold, is a seven-time World Champion and winner of 35 wheelchair marathons.

In 2009 Mr Fearnely was recognised as the NSW Young Australian of the Year, in 2007 was awarded the Confederation of Australian Sport Athlete of the Year with a Disability and in 2005 was awarded the Medal of the Order of Australia for service to sport as a Gold Medallist at the Athens 2004 Paralympic Games.

Mr Fearnely represents a number of charitable organisations, is a board member of Australian Volunteers International and a member of the NSW Australia Day Council. He is a qualified physical education teacher and works in a number of public school education programs in NSW.

Organisational affiliations

- Sponsorship with Invacare Pty Ltd
- Ambassador, CROWNability

Mr Fearnley resigned from the IAC on 5 May 2016 to focus on his sporting commitments. Mr Fearnley's contribution to the IAC was valued during his term.



Ms Janet Meagher AM

A teacher and librarian by profession, Ms Janet Meagher was a founding member of several mental health Consumer organisations. She has lived with schizophrenia since the early 1970s, and as a result of institutionalization she became an activist and advocate and has worked for rights and equity, participation and respect for people living with mental health issues.

Ms Meagher has had a long association with the mental health and disability sectors. From 2012 to 2013 she was a Mental Health Commissioner for the National Mental Health Commission.

Earlier, Ms Meagher was the foundation co-chairperson of the Mental Health Consumer and Carer Forum, Board Member of World Federation for Mental Health and previously, General Manager, Inclusion, for Richmond PRA (now Flourish Australia).

Ms Meagher was honoured as a Member of the Order of Australia (AM) in 1996 and as a Churchill Fellow in 1994 investigated *Consumer Empowerment and Self Advocacy*, subsequently authoring *Partnership or Pretence*.

She has been appointed to many Ministerial and National Advisory bodies in Health, Mental Health, Suicide Prevention and Disability areas over the past 37 years.

Organisational affiliations

- Member, National People with Disabilities and Carer Advisory Council



Ms Sylvana Mahmic

Ms Sylvana Mahmic is the CEO of Plumtree and an advocate for early childhood intervention and self-management. Ms Mahmic has served on over 15 reference and advisory groups in addition to five Ministerial appointments including membership of the Disability Council NSW.

Ms Mahmic has worked for over 20 years in the early childhood intervention field, with a particular expertise in a whole of family and community approach to early childhood intervention. She has developed several initiatives which target the wider community, in particular, the culturally and linguistically diverse community.

Ms Mahmic is currently undertaking post graduate research with a focus on individualised support and self-directed funding.

Ms Mahmic has a son who has cerebral palsy and an intellectual disability. He has been utilising self-managed funding since 2009.

Organisational affiliations

- Treasurer, Early Childhood Intervention Australia NSW
- Member, Access Advisory Group NSW Department of Premier and Cabinet



Mr Michael Taggart

Mr Michael Taggart is the inclusion Project Officer for Salisbury City Council Northern Adelaide. He received the 2009 National Disability Award (Local Govt).

Mr Taggart initiated the South Australian Local Government Access and Inclusion Network which liaises with the Local Government Professionals Community Managers Network. The Network is open to all LG Professionals SA members working in the field of community development and community services in local government and allied sectors.

Organisational affiliations

- Member, Blind Citizens Australia
- Member, Australian Services Union local government division (SA and NT branch)
- Member, People with Disability Australia



Mr Dale Reardon

Mr Dale Reardon is a qualified barrister and solicitor. Mr Reardon was the founding President of Blind Citizens Australia (Tasmania) and is a former Director of Royal Guide Dogs Association of Tasmania. He is the Founder and Director of My Disability Matters Pty Ltd, which published disability news and opinion, along with a social network for the global disability community.

Mr Reardon has been blind since age 17 and currently has his fourth seeing-eye dog, Charlie.

Organisational affiliations

- Member, Vision Australia
- Member, People with Disabilities Australia
- Member, National Disability Services
- Member, Blind Citizens Australia



IAC consultant Ms Belinda Epstein-Frisch AM

Ms Belinda Epstein-Frisch has more than 35 years of experience in advocacy, community development, social policy and consultancy with and on behalf of people with disability, including having been a member of ministerial advisory councils on education and disability reform at the State and Commonwealth level.

Ms Epstein-Frisch is consultant to the Independent Advisory Council (IAC) of the NDIS. In this role she works with members of the IAC, the Intellectual Disability Reference Group and the Innovations (in Housing and Support Provision) Working Group to prepare advice for the Board of the National Disability Insurance Agency.

Ms Epstein-Frisch works with JFA Purple Orange as the lead agency supporting disability support organisations to develop peer networks for people with disability and is a member of the Guardianship Division of the NSW Civil and Administrative Decisions Tribunal.

Ms Epstein-Frisch has 3 daughters, one of whom will become an NDIS participant in 2017.



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