



Council for
Intellectual Disability



A pathway through complexity

Report from the NSW Roundtable on Meeting Complex Behaviour Support Needs in the NDIS 2017



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This report is primarily based on the inputs to CID’s Roundtable on Meeting Complex Behaviour Support Needs in the National Disability Insurance Scheme (NDIS). However, views expressed in this report are ultimately those of CID and do not necessarily reflect the views of any particular Roundtable participant.

We need to talk about people with complex needs and the NDIS. People with complex needs are a minority within a minority. But they have the same rights as everyone else in NSW. They have the same wants, the same feelings. The same right to a good ordinary life.

Michael Sullivan, opening address at Roundtable

This is a huge change, a huge transition. If we can get it right, it will be an iconic reform. But we have to get it right. I consider it a sacred trust.

Helen Nugent AO, Chair, NDIA

Summary of the report

The Roundtable was held in December 2017. It brought together senior officers in Australian and NSW Government agencies to talk with people from the advocacy and professional sectors in NSW about how NDIS implementation was working including interface issues with service systems like health, education and justice. The aim was to promote better mutual understanding and improved individual and systemic responses to people's needs.

THE CONTEXT

Good practice in behaviour support

The aim of behaviour support is to enable people to experience life outcomes that they value and find meaningful. The well-established positive behaviour support (PBS) has a primary goal of increasing a person's quality of life and a secondary role of decreasing the frequency and severity of an individual's behaviours. The behaviour support process involves

1. Risk assessment and safety planning.
2. Behaviour assessment.
3. Development of a behaviour support plan.
4. Training and implementation support for informal and formal support providers.
5. Monitoring implementation.
6. Review and refinement of behaviour support following the same process again.

Practice has evolved significantly over time. A particular focus in recent years has been trauma informed practice. Many people with complex behaviour support needs have experienced trauma and their behaviour may be related to how these experiences are impacting on them in the present.

The old system

Prior to the introduction of the NDIS, Ageing, Disability and Homecare (ADHC) in the Department of Family and Community Services (FACS) NSW was the predominant disability service provider for people with complex behaviour support needs.

ADHC services and roles included:

- Community Support Teams including behaviour support practitioners, speech pathologists and other professionals.
- The Statewide Behaviour Intervention Service which provided tertiary consultancy for people with particularly complex needs and wide-ranging policy and practice development and training for disability workers and professionals.
- Supported accommodation, predominantly in group homes and large institutions.
- Sector leadership on professional governance and workforce development.
- Establishing collaborative arrangements with other agencies.
- The Community Justice Program (CJP) for people with intellectual disability and very serious histories of offending.

There was also a comparatively small number of behaviour support practitioners and other professionals employed by non-government service providers and private businesses.

There was always a considerable shortfall compared with need in supported accommodation and behaviour support and other professional services. This meant that many people with complex behaviour support needs received very inadequate support.

However, ADHC was the crisis and last resort support provider for people with complex behaviour support needs.

THE NEW SYSTEM

The NDIS

A person with intellectual disability and complex behaviour support needs goes through an NDIS planning process to consider their goals and needs and arrive at a statement of participant supports. This statement spells out any general supports that will be provided to the person and “reasonable and necessary supports” that will be funded by the NDIS. General supports include supporting a person’s access to mainstream services and community resources.

As well as specific support plans for participants, the NDIS has an Information, Linkage and Capacity Building arm (ILC). This will consist of a national network of local area coordinators and funded projects of up to two years.

Transition of existing recipients of disability support from ADHC is governed by a bilateral agreement between the NSW and Australian governments. The agreement required that 37,000 people transition into the scheme in 2016-17 and a further 36,000 in 2017-18. There has been limited scope for new people to come into the scheme in that period but it is expected that a further 67,000 people will come in over time.

In deciding what supports it will fund for a participant, the National Disability Insurance Agency (NDIA) has to consider whether a support is most appropriately funded through the NDIS and not through other mainstream services as part of their universal service obligation or in accordance with reasonable adjustments required under discrimination law (section 34(f) NDIS Act).

The Council of Australian Governments (COAG) has agreed on a set of Principles to Determine the Responsibilities of the NDIS and other Service Systems (the “interface principles”) which seek to make reasonably clear which service system is responsible for what support.

In response to widespread dissatisfaction with the participant pathway, the NDIA has carried out a comprehensive review of the pathway and is currently developing a specific pathway for participants with complex needs.

For children aged up to 6, the NDIA has developed the Early Childhood Early Intervention (ECEI) approach.

The NDIS has a Quality and Safeguarding Framework which will be implemented in NSW from July 2018. The Framework is centred on an NDIS Quality and Safeguards Commission whose functions will include:

- Complaint investigation.
- Oversight of reportable incidents including abuse, neglect or serious injury to a person with disability.
- Monitoring NDIS provider compliance with conditions of registration.
- Behaviour support – a range of roles focused on ensuring good practice and monitoring restrictive practises.

NSW withdrawal from disability service provision

In a parallel process to NDIS implementation, the NSW government is ceasing to be a disability support provider and has been tendering out its services to the non-government sector.

NSW is handing over its whole disability budget to the NDIA for participant plans. Since NSW contracted to do this in 2012, it has gradually become apparent that the NDIS sees its responsibilities more narrowly than did ADHC including:

- The extent of the role of disability support for people with intellectual disability who are in contact with the justice system. This arises particularly in the context of ADHC's specialist Community Justice Program.
- In relation to children who are in "voluntary out of home care" not because of neglect or abuse but because parents are not able to meet their complex behaviour support needs.
- Continuation of some health services that ADHC funded.

Also, the money that NSW is transferring to the NDIS for participant plans includes the funding NSW has been providing to disability advocacy.

What the Productivity Commission says

In its recent report on NDIS costs, the Productivity Commission made findings and recommendations:

- The scale and pace of NDIS rollout is highly ambitious and risks the NDIA not being able to implement the NDIS as intended.
- Groups at risk of having a less positive NDIS experience include those with complex needs.
- Interface responsibilities between the NDIS and mainstream agencies – Implementation of the NDIS should include ensuring continuity of necessary supports. Service gaps should be identified and resolved.
- Supply of providers – Thin markets will persist for some groups including participants with complex needs or who have an acute and immediate need for crisis care and accommodation. The NDIA should address thin markets by a range of approaches, including block funding and releasing its provider of last resort policy and market intervention framework. The COAG Disability Reform Council should immediately clarify and make public the roles and responsibilities of different levels of government with respect to market stewardship.
- The Australian, State and Territory governments should continue to fund disability advocacy organisations.

KEY AREAS FOR ACTION

The NDIS has many potential benefits for people with disability including people with intellectual disability and complex behaviour support needs. If the NDIS works well, it will become much less likely that an individual will develop challenging behaviour and quality support should be able to address challenging behaviour before it becomes complex and entrenched.

However, the implementation of the NDIS and the parallel process of the NSW Government exit from service provision are raising many risks and challenges.

In **Appendix 1**, we set out the issues highlighted by table groups at the Roundtable and their recommendations to address those issues.

Here, we highlight key issues for CID emerging from the Roundtable and its surrounding context.

The participant pathway

CID strongly welcomes the new general participant pathway and the NDIA's current work on a tailored pathway for participants with complex needs. Some key issues to be addressed in the complex needs

pathway are as follows. Then, we move to the supply of workforce and providers and other key issues.

Equity of access

There are many people with intellectual disability and complex behaviour support needs who live isolated lives on society's fringe and who are unlikely to be aware of or seek access to the NDIS. If this group is to have equitable access, there needs to be a well-coordinated system of outreach, engagement and support for people to enter the scheme and/or access other mainstream services and community supports. This system should be a partnership between the ILC and mainstream agencies and advocacy services.

The pathway being responsive to the person's current circumstances

This issue arises for example for people who are in contact with the criminal justice system. If a person is currently facing charges and potentially detention in custody, the pathway needs to be responsive by ensuring that a plan is in place by the time the court will be making a decision about remand or a custodial sentence. The person will then have a fair opportunity to be diverted from custody.

The challenge of choice and control

People with intellectual disability and complex behaviour support needs face major challenges in exercising choice and control due to factors including the impact of the disability on the person's understanding of the NDIS pathway and their life options, the impact of histories of trauma and a lack of adequate decision supports and advocacy whether from families or other supporters.

Through the ILC and participant plans, the NDIA should provide for capacity building and independent support in decision-making. Where advocacy is available, it can also assist the person and/or family supporters.

Families of children have a formal role in choice and control and families of adults commonly have important roles as well. Families, especially disadvantaged families, commonly need capacity building and support to carry out these roles and this needs to be provided through the ILC and participant pathway.

Where, despite maximum efforts, a person cannot currently be supported to make their own planning decisions, the NDIA should consider appointing a nominee within the safeguards of the nominee system. If no appropriate nominee is available, the NDIA or other existing supports should consider an application for a guardianship order.

Skilled planners

It is essential that planners for a person with complex behaviour support needs have specific skills in communicating with the person, in understanding the person's needs and what can and cannot be expected of mainstream services, and in making good judgements. NDIS planning may be informed by reference packages and a range of other general rules. However, each participant is a unique individual with unique life circumstances and lives in locations with a range of variables in factors like available community and mainstream supports.

There need to be subspecialties including planners with specific skills in disability support for children and young people and people involved with the criminal justice system.

Informed and collaborative planning

To decide what are reasonable and necessary supports for a person with complex behaviour support needs, the planner will commonly need a range of information from a range of people, including the person and their

informal supports, disability professionals and other services working with the person, for example schools, health and justice services. With consent, planning should be a collaborative process with the person at the centre plus inputs from other relevant players. Otherwise planning may proceed on false assumptions in relation to disability support needs and in relation to the supports that can be appropriately expected from other agencies.

At the same time, the process needs to be alert to the conflict of interest that existing support providers will have.

Time in the planning process

The planning process will often need to be very time intensive for a person with complex behaviour support needs. However, this will be time well spent if it leads to the person's needs being well met so that crises, escalations of support needs and urgent plan reviews are less likely.

Behaviour support cannot be quick and dirty

The allocations in a plan for behaviour assessment and support and other related inputs such as speech pathology need to be realistic to take account of the time commonly needed to provide quality behaviour support. This includes the behaviour support practitioner developing the plan in close liaison with the person and their family, training and supporting informal and formal support workers to implement the plan, regular reviews and ensuring collaborative action by the range of relevant disability and mainstream services.

Problems could be alleviated if the NDIA moved to greater flexibility in use of overall plan budgets rather than, for example, specifying a particular maximum number of hours for behaviour support.

Allowing for fluctuations in needs

The support needs of people with complex behaviour support needs can escalate quickly, suddenly and unpredictably. Plans could include a buffer amount to allow for immediate responses to escalations and there needs to be a process for extremely urgent plan reviews.

Continuity of support when a person is imprisoned or hospitalised

NDIS funding should continue at least to the extent of allowing for maintenance of trusted relationships between support workers and participants.

Last resort and crisis providers

The NDIA needs a robust structure for ensuring that there is always a suitable provider and accommodation available for a person in crisis and/or where a suitable provider cannot readily be found. This includes situations where an existing provider withdraws on the basis that it feels unable to meet the person's needs.

Expert consultancy

For people with particularly complex needs, there should be funded access to tertiary behaviour support practitioner skills and a panel including representatives from relevant agencies, independent professional experts and an advocate supporting the individual.

A greater focus on outcomes

There is much to be said for the NDIA developing an outcomes framework for planning so that anticipated outcomes for the participant are identified in their plan and reviews include a stocktake on outcomes achieved and why they have or have not been achieved.

Supply and quality of workforce and providers

Ultimately, this may be the biggest challenge facing the NDIA in meeting complex behaviour support needs. A skilled workforce is needed across the board - local area coordinators, planners, coordinators of support, behaviour support practitioners and other disability professionals, and direct support workers. There is a current shortage at all these levels in workers skilled to meet complex behaviour support needs. The demand for these workers will increase with the implementation of the NDIS but at present the supply of them in NSW is arguably declining.

Similarly, there is already a thin market of disability provider organisations to work with people with complex behaviour support needs and this situation may be exacerbated by the withdrawal of ADHC from being a service provider.

Mainstream agencies also need to address their workforce skills including in schools and the health and justice systems.

People with intellectual disability and a psychiatric condition

Many people with intellectual disability and complex behaviour support needs will have disabling psychiatric conditions. A common example is where a person has a history of trauma giving rise to an ongoing psychiatric condition.

In the past, intellectual disability and health professionals have not had to focus on the impact of a psychiatric condition when considering a person's eligibility for ADHC services. Now, they should focus on both the intellectual disability and the psychiatric condition in eligibility assessments.

Early Childhood Early Intervention

Here is the best opportunity to address developing complex needs before they have established. Anecdotal reports suggest that this opportunity is being missed with the roll out of the ECEI and the blurring of responsibilities and defensiveness of parallel service sectors.

Interface issues

The National Disability Strategy, Disability Inclusion Act NSW and discrimination law all call on mainstream agencies to enhance their responses to people with disability. However, in some spheres, the delineation of responsibilities is not clear. Also, major problems arise where the NDIA takes a narrower view of its role than ADHC did, for example in relation to children in voluntary out of home care.

There are also difficult questions in relation to the Community Justice Program which has been funded by ADHC. The NDIA appears to be taking a narrower view of its responsibility than did the CJP based on a false dichotomy between challenging behaviour which is the responsibility of the NDIS and offending behaviour which is seen as the responsibility of the justice system. The NDIA also appears to be making incorrect assumptions about the role that justice services play for offenders generally in relation to therapeutic programs and support to avoid reoffending.

In this field, CID argues that the interface principles are not consistent with the test in the NDIS Act on which they rest, namely whether supports are most appropriately funded through the NDIA and not through other mainstream services as part of their universal service obligation or in accordance with reasonable adjustment required under discrimination law (section 34(f) NDIS Act).

CID argues that section 34 calls for an individual consideration of a participant's circumstances rather than a rigid application of the interface principles.

Beyond the group home

One of the opportunities that the NDIS should provide is for much more individualised choices of accommodation and support options than the traditional group home model. However, the way the NSW government has gone about moving out of service provision and closure of institutions has instead had a predominant focus on group homes.

Group homes have particular problems for people with complex behaviour support needs due to issues of compatibility between residents and major difficulty for staff in meeting complex individual needs within a group environment.

Alternative and more individualised accommodation should be considered and pursued with a priority for people whose group home accommodation is clearly not meeting their needs.

Residency agreements

NDIA Terms of Business for supported disability accommodation allow an accommodation provider to evict a resident on 90 days notice or shorter notice where "required to address the risk of harm to the participant or others". This is potentially very unfair to residents, including if they have been receiving inadequate behaviour support. The central focus should be on changes of accommodation being consensual focused on moving to a better option rather than eviction by a support provider.

Governance, quality and safeguards

The NDIS Quality and Safeguarding Framework has potential to provide considerable safeguards to people with complex behaviour support needs.

The implementation of the framework needs to have a central focus on the reduction and elimination of the use of restrictive practices. A key issue for the Quality and Safeguards Commission will be the development of a competency framework for providers of behaviour support.

In implementing the framework in NSW, specific consideration is needed to ensuring that valuable functions performed by the NSW Ombudsman and ADHC are not lost in the new safeguarding arrangements.

Advocacy

Related to its handing over of its whole disability budget for NDIS participant plans, the NSW Government currently plans to cease funding of disability advocacy and information services on 30 June 2018.

The Australian Government, the Senate and the Productivity Commission have all called on the NSW Government to continue to fund advocacy.

Ongoing development of programs, policies and practices

CID argues that the best outcomes are achieved if programs, policies and practices are developed in close consultation with representatives of people with intellectual disability. In the sphere of complex behaviour support needs, we also argue that the NDIA and other agencies need to work in active consultation with independent thinking professionals and researchers.

List of recommendations

1. In the development of the complex needs pathway, the NDIA should:
 - a. Ensure a robust system of outreach and engagement with people with complex needs who are unlikely, of their own initiative, to seek out NDIS access. This system should include:
 - i. designated time of local area coordinators who have skills in outreach and engagement,
 - ii. funding of grounded community groups through the ILC,
 - iii. close liaison with advocacy services,
 - iv. close liaison with State government agencies and mainstream community organisations which are likely to have contact with marginalised individuals with disability, and
 - v. assistance to obtain assessments needed for NDIS eligibility.
 - b. Ensure that the pathway is responsive to individual circumstances, for example the need to have a plan in place before a court makes a decision about diversion from a custodial sentence.
 - c. Ensure that the pathway is well linked with other specialist pathways the agency is developing, including that for Aboriginal and Torres Strait Islander participants.
 - d. Ensure that participants and, where relevant, their family supports have access to capacity building and independent support in decision-making. This should occur through funded ILC services, advocacy where available, and funding in participant plans.
 - e. Where, despite maximum effort, a person cannot be supported to make their own planning decisions, the NDIA should appoint a plan nominee and, if necessary, instigate an application for a guardianship order.
 - f. Ensure that planners for people with complex needs have the requisite skills, including having subspecialist planners for children and young people, people with complex mental health needs and people involved with the justice system. Planners need skills to make good judgements about individual plans rather than starting from rules of thumb about hours of behaviour support and being overly reliant on reference packages.
 - g. For people with very complex needs, draft participant plans should be reviewed by an expert panel including independent expert professionals and advocates.
 - h. Planning should be based on a broad information base and collaboration, with the participant at the centre. Whilst being alert to conflict of interest, the process should include input from disability professionals and mainstream services working with the person.
 - i. Planning should move to a greater focus on outcomes to be achieved by disability and, if possible, mainstream supports, with the NDIA developing an enhanced outcomes framework in collaboration with advocacy, disability service provider and mainstream agencies.
 - j. Plans should provide increased flexibility in use of overall plan budgets rather than, for example, specifying a particular maximum number of hours for behaviour support.
 - k. As a matter of the greatest urgency, the NDIA should establish crisis provider and provider of last resort arrangements including a range of suitable physical accommodation.
 - l. Planning should allow a quick and flexible response to unfolding individual circumstances through:
 - i. greater flexibility in relation to use of total funding, for example less specificity in relation to a set amount for behaviour support,
 - ii. consideration of a buffer amount in a plan which is available where circumstances change, and
 - iii. allowing for continuity of support and maintenance of trusted relationships with support workers where a person is imprisoned or hospitalised.
 - m. Through individual plans and/or block funding, ensure capacity for access to tertiary behaviour support practitioner skills and an expert advisory panel.
2. The Department of Social Services, in collaboration with the NDIA, NDIS Quality and Safeguards Commission and State and Territory Governments, should take urgent action to ensure an adequate and skilled workforce to work with people with complex behaviour support needs. This workforce development is required across the spectrum from local area coordinators, planners, coordinators of support, managers and staff of providers, behaviour support practitioners and other relevant professionals. Workforce development must include tertiary education and ongoing mentoring and skills development in the workplace.

3. The NDIA should take action to ensure an adequate supply of provider organisations for people with complex behaviour support needs including through consideration of incentives, adequate pricing for direct supports and block funding.
4. The NDIA should provide clear public information in relation to the evidence required for eligibility where a person has both an intellectual disability and a possible disability related to their psychiatric condition.
5. The NDIA, in collaboration with State and Territory government agencies, should develop and implement a framework to ensure realisation of the potential of the ECEI approach to provide early intervention to children who have or can be foreseen to develop complex behaviour support needs.
6. The NSW Government should ensure ongoing enhancement of the accessibility and appropriateness of mainstream services for people with intellectual disability and complex behaviour support needs including through:
 - a. the disability inclusion plan scheme required by the Disability Inclusion Act NSW, and
 - b. ensuring that NSW Health maintains the functions of health services previously funded by ADHC.
7. The NSW Government should ensure the continuation of the ADHC Community Justice Program as a community based and disability support focused program including meeting any funding shortfall arising from NDIS implementation.
8. The NSW Government and the NDIA should promptly resolve their respective responsibilities for holistic support of children and young people in voluntary out of home care.
9. The NDIA and State government agencies should continue to build collaborative relationships at individual and systemic levels including through:
 - a. mainstream agency input to individual planning,
 - b. ensuring that a person is not deprived of necessary supports while State agencies and the NDIA resolve demarcation issues,
 - c. applying the Principles to Determine the Responsibilities of the NDIS and Other Service Systems taking account of individual and local circumstances rather than treating the principles as establishing sharp lines of demarcation, and
 - d. establishing a shared outcomes framework.
10. The Australian and State and Territory Governments should review the Justice section of the Principles to Determine the Responsibilities of the NDIS and Other Service Systems.
11. The NDIA planning pathway should include specific consideration of whether a person's current accommodation is able to meet their goals and needs with a view to seeking out more appropriate accommodation where appropriate.
12. As a top priority, where there is clear evidence that a person's accommodation is not able to meet the person's goals and needs, the NDIA should ensure systems to provide the person with appropriate accommodation.
13. The NDIA should review its terms of business in relation to service agreements with a view to ensuring that agreements are fair to participants with complex behaviour support needs, in particular in relation to circumstances in which a person may be evicted from their home.
14. The NSW government should ensure that its proposed legislation for residency agreements in supported accommodation is fair to participants with complex behaviour support needs, in particular in relation to choice of new residents and circumstances in which a person may be evicted from their home.
15. The NSW Government should ensure that the establishment of the NDIS Quality and Safeguards Commission does not leave gaps in roles previously performed by the NSW Ombudsman including in relation to scrutiny of the NSW health system and ongoing auspicing of the community visitor scheme.
16. The NDIA and the Quality and Safeguards Commission should ensure ongoing performance of roles previously played by ADHC in relation to people with complex behaviour support needs including practice leadership, professional and resource development and research.
17. The NSW government should continue to fund individual and systemic disability advocacy at least to the level currently funded.
18. In ongoing development of programs, policies and practices for people with complex behaviour support needs, the NDIA, the Quality and Safeguards Commission and the Department of Social Services should act in close consultation with representatives of people with intellectual disability and skilled disability and health professionals.

The roundtable

This was the third annual Roundtable led by CID on key issues facing people with intellectual disability in Australia.

The Roundtable was held in December 2017. It brought together senior officers in Australian and NSW Government agencies to talk with people from the advocacy and professional sectors in NSW about how NDIS implementation was working including interface issues with agencies like health and justice.

The aim was to promote better mutual understanding and improved individual and systemic responses to people's needs.

Prior to the Roundtable, CID consulted with most Roundtable participants to obtain views on key issues.

The Roundtable itself included:

- An opening address from Michael Sullivan, vice-chair CID including feedback from a consultation with people with intellectual disability.
- Scene setting addresses from Michelle Herwood of The Benevolent Society on the old system and Stephanie Gunn of the NDIA on the new system.
- Discussion of how the new system is currently working.
- Small group discussions on a range of key issues with feedback to the plenary group.
- Closing reflections from Stephanie Gunn NDIA, Carolyn Reed Department of Premier and Cabinet NSW, Helen Nugent NDIA chair and Judy Harper board member CID.

Good practice in behaviour support

Dowse and others (2017) have prepared a discussion paper, Responding to Behaviour Support Needs in the Disability Services Future. www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/discussion-paper/

This paper is based on reviews of literature and policy and interviews with family members and behaviour support practitioners. The authors say that the aim of behaviour support is to enable people to experience life outcomes that they value and find meaningful. The well-established “positive behaviour support” (PBS) has a primary goal of increasing a person's quality of life and a secondary role of decreasing the frequency and severity of an individual's behaviours.

In a recent Western Australian report, Edward and others (2017) say

Positive Behaviour Support (PBS) is a scientific, evidence-based and best practice approach to systemic change for supporting people with disability through improving their quality of life. It builds on and integrates many previous initiatives in the disability field. PBS is particularly effective in dealing with complex “challenging” or “concerning” behaviours. PBS adopts a person-centred lens in meeting people's needs through systemic change, mindset shifts and the collaboration of stakeholders. In addressing complex behaviours, PBS challenges the assumption that the person with disability needs to change and opens up new opportunities for services to respond in innovative ways. PBS proposes that designing flexible and supportive environments and quality services will result in:

- i) improved opportunities and outcomes,
- ii) reduced incidents of behaviour that challenge and, consequently,
- iii) reduced reliance on restrictive practices.

There is much evidence in the disability literature that supports PBS as an effective approach to addressing complex needs and improving the quality of life of people when effectively implemented.

(Edwards and others (2017), Positive Stories: An Exploratory Analysis of the Implementation of Positive Behaviour Support in the Western Australian Disability Sector) www.cadr.org.au/safety-and-security/positive-stories-an-exploratory-analysis-of-the-implementation-of-positive-behaviour-support-in-the-western-australian-disability-sector

Dowse and others identified three key elements of good behaviour support:

1. A governance framework encompassing oversight and accountability through legislation and policies.
2. Relationships and partnerships between individuals and their families and support providers, including providers from the range of relevant disciplines and sectors.
3. Processes and responses - Positive behaviour support includes a cycle of assessment, support planning, intervention, evaluation and monitoring. Assessment should be flexible and continuous. For complex behaviours, assessment should be multidisciplinary. A behaviour support plan should include proactive strategies to reduce the likelihood of behaviours, a focus on quality of life, strategies to alter the contexts that lead to behaviours, skill building in areas that serve the function of and replace behaviours and reactive strategies to minimise escalation and reduce the risk of harm.

At the Roundtable, Michelle Henwood noted that the behaviour support process involves the following (as outlined in the NSW Behaviour Support Policy and Practice Manual) www.adhc.nsw.gov.au/sp/delivering_disability_services/behaviour_support_services/behaviour_support_policy_and_practice_manual

1. Risk assessment and safety planning.
2. Behaviour assessment - interview of the person and members of their support network, observation, file review, data analysis, formulation, recommendations.
3. Behaviour support plan - consult, draft, refine, seek approval for any restrictive practice.
4. Training and implementation support for informal and formal support providers.
5. Monitoring implementation and impact including data analysis, interview, observations and file review.
6. Review and refine behaviour support following the same process again.

This process must be complemented by highly skilled complex support coordination.

Henwood also emphasises that the assessment and planning process must consider and incorporate a range of professional perspectives and approaches, far beyond “behaviourist” theory. Practice has evolved significantly over time. A particular focus in the last 10-15 years has been trauma informed practice. Many people with complex behaviour support needs have experienced trauma and their behaviour may be related to how these experiences are impacting on them in the present. Traumatization can impact people’s capacity for learning, memory, problem-solving, and self-regulation amongst a myriad of other impacts.

For people with intellectual disability, the impact of the trauma can be exacerbated by their cognitive and communicative difficulties and the associated lack of appropriate support options. As such, positive behaviour support for people with intellectual disability must be trauma informed and trauma cannot be “treated” as a separate issue from their behaviour support.

Trauma informed practice is not only about direct support to the individual but applies to the entire support system.

Key underpinning tenets of trauma informed practice are choice, voice, safety, relationships, collaboration and person centredness. See the Taking Time Framework for supporting people with intellectual disability who have experienced trauma. www.adhc.nsw.gov.au/__data/assets/file/0004/340447/Taking_Time_Framework.pdf

The old system

Prior to the introduction of the NDIS, disability support in NSW was predominantly provided or funded by Ageing Disability and Homecare (ADHC) in the Department of Family and Community Services (FACS) NSW. There was also varying degrees of focus on behaviour support for people with intellectual disability in mainstream agencies including schools, Health, Juvenile Justice and Corrective Services.

Within the disability service system, ADHC was the predominant service provider for people with complex behaviour support needs whether people were living in supported accommodation or living with families. 55% of people with complex support needs (which included complex behaviour support needs and/or complex health needs) were living in ADHC supported accommodation. 16% were living in the family home. Only 12% were in NGO supported accommodation. (KPMG (2015), Market Analysis and Consultations to Inform the Safe Transition of People with Complex Support Needs to the National Disability Insurance Scheme, Unpublished)

A large proportion of the people in ADHC supported accommodation were in large residential centres but many others were in community group homes.

To be eligible for ADHC services, a person generally needed to have an intellectual disability within the traditional definition requiring an IQ below about 70, significant deficits in adaptive functioning and the disability arising before the age of 18. ADHC psychologists carried out these assessments.

ADHC had a statewide network of professional supports for people with intellectual disability. These included:

- Community Support Teams including behaviour support practitioners, speech pathologists and other professionals.
- Regional Behaviour Intervention Teams to back up Community Support Teams for people with complex behaviour support needs.
- The Statewide Behaviour Intervention Service which provided tertiary consultancy for people with particularly complex needs and wide ranging policy and practice development and training for disability workers and professionals.

There was also a comparatively small number of behaviour support practitioners, speech pathologists and other professionals employed by non-government service providers and private businesses.

NGO service providers were predominantly funded by block grants from ADHC.

ADHC provided disability sector leadership on professional governance and workforce development and leadership.

ADHC ran two specialist programs:

- The Community Justice Program (CJP) for up to 400 people with intellectual disability and very serious histories of offending. This program involved a range of supported accommodation from

drop-in support to highly structured and supervised group homes. Most of this accommodation was run by funded NGOs with a high level of case work, behaviour support and other professional input from a specialist team in ADHC. The CJP had strong intake links with Corrective Services and Juvenile Justice.

- The Integrated Services Program for a small number of people with complex cross agency needs. This was a joint program with NSW Health and NSW Housing.

ADHC also provided or funded:

- Some clinical health services including a chair in intellectual disability mental health at UNSW and regional psychiatry clinics led by psychiatrists with expertise in the mental health of people with intellectual disability
- A chair in intellectual disability behaviour support at UNSW

ADHC established collaborative arrangements with other agencies including a memorandum of understanding with NSW Health and collaborative multidisciplinary clinics for people with complex disability and mental health needs.

There was always a considerable shortfall compared with need in supported accommodation and behaviour support and other professional services. This meant that many people with complex behaviour support needs received very inadequate support.

However, ADHC was the crisis support and last resort support provider for people with complex behaviour support needs. It was not uncommon for a non-government provider to withdraw from supported accommodation for a person with complex needs. While residents of ADHC supported accommodation had no legal security of tenure, in practice ADHC accepted the political responsibility to continue to provide supported accommodation no matter how difficult it became. ADHC very rarely, if ever, withdrew supported accommodation from a person. The support arrangements may have been inadequate, especially during crisis periods, but at least the person had somewhere to live and some support.

In recent years, ADHC commissioned a number of valuable evaluations of behaviour support related initiatives including:

- The Specialist Training and Resource Framework for capacity development in emerging specialist issues.
- The Developmental Psychiatry Clinic which was a partnership between the Statewide Behaviour Intervention Service and the Children's Hospital at Westmead.
- The ADHC Client Monitoring and Review System.
- A proposed client monitoring and review system for NGOs.

These evaluations have not been published but may be valuable resources for the NDIA and NGOs.

The new system

The NDIS

If a person has intellectual disability and complex behaviour support needs, there is very unlikely to be any question about their eligibility to be a participant in the NDIS. The person then goes through an NDIS planning process to consider their goals and needs and arrive at a statement of participant supports which specifies

any general supports that will be provided to the person and “reasonable and necessary supports” that will be funded by the NDIS. General supports include supporting a person’s access to mainstream services and community resources.

As well as specific support plans for participants, the NDIS has an Information, Linkage And Capacity Building arm (ILC). This will consist of a national network of local area coordinators and funded projects of up to 2 years.

Transition of existing recipients of disability support from ADHC is governed by a bilateral agreement between the NSW and Australian governments. The agreement basically required that 37,000 people transition into the scheme in 2016-17 and a further 36,000 in 2017-18. There has been limited scope for new people to come into the scheme in that period but it is expected that a further 67,000 people will come in over time bringing the total number of participants in NSW from 73,000 to 140,000. The bilateral agreement is at [ndis.nsw.gov.au/wp-content/uploads/2015/07/Bilateral-Agreement-between-the-Commonwealth-and-New-South-Wales-2.pdf](https://www.ndis.gov.au/wp-content/uploads/2015/07/Bilateral-Agreement-between-the-Commonwealth-and-New-South-Wales-2.pdf)

There are working arrangements between the NDIA and NSW in relation to transition for participants with complex support needs.

In deciding what supports it will fund for a participant, the NDIA has to consider whether a support is most appropriately funded through the NDIS and not through other mainstream services as part of their universal service obligation or in accordance with reasonable adjustments required under discrimination law. (see section 34(f) NDIS Act).

COAG has agreed on a set of Principles to Determine the Responsibilities of the NDIS and other Service Systems which seek to make reasonably clear which service system is responsible for what support. These “interface principles” with tables of applied principles in relation eleven mainstream service systems are at www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf

The NSW Government has established the Integrated Service Response as a two year project providing Intensive support coordination for some NDIS participants who have complex cross agency needs.

In response to widespread dissatisfaction with the participant pathway, the NDIA has carried out a comprehensive review of the pathway and is currently developing a specific pathway for participants with complex needs. The NDIA is showing determination to ensure that the new pathway addresses participant concerns including about the need for clear information tailored to individual participants, personal and transparent plan development and development of a trust-based relationship with NDIA staff who need to be prepared for participants’ unique situations.

In the meantime, the NDIA has taken a number of initiatives in relation to complex needs including its Technical Advisory Team being available for specialist support for planners and providing practice guides. For children aged up to 6, the NDIA has developed the Early Childhood Early Intervention approach (ECEI). A family meets an “early childhood partner” experienced in early childhood intervention. The partner works with the family to determine the best supports for the child and family, identifies mainstream supports that can be used and, if required, helps the family to request NDIS access and develop a plan. The ECEI approach is available in areas where the NDIS is currently in operation.

The NDIS has a Quality and Safeguarding Framework which will be implemented in NSW from July 2018. The

full framework is at www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-quality-and-safeguarding-framework and the NDIS Amendment (Quality and Safeguards Commission and other measures) Act was passed by Parliament in late 2017.

The Framework is centred on an NDIS Quality and Safeguards Commission whose functions will include:

- Complaint investigation.
- Oversight of reportable incidents including abuse, neglect or serious injury to a person with disability.
- Monitoring NDIS provider compliance with conditions of registration.
- In relation to behaviour support:
 - Developing and implementing a competency framework for NDIS providers registered to provide behaviour support assessments and develop behaviour support plans.
 - Developing policy and guidance material in relation to behaviour support and the reduction of restrictive practices.
 - Overseeing behaviour support and restrictive practices.

The Commission will be independent from the NDIA but subject to direction by the Minister except in relation to particular individual cases.

Authorisation processes for restrictive practices will remain the responsibilities of States and Territories.

The Framework also emphasises the importance of the role of advocacy services, building provider capacity through an Integrated Market, Sector And Workforce Strategy and more rigorous quality assurance requirements for complex supports.

NSW withdrawal from disability service provision

In a parallel process to NDIS implementation, the NSW government is ceasing to be a disability support provider and has been tendering out to the non-government sector the disability services previously provided by ADHC.

Supported accommodation has been tendered out in packages generally comprising all of the supported accommodation in a geographical area. A range of NGOs have been successful tenderers. All of the ADHC community support teams, large residential centre professional teams, the Statewide Behaviour Intervention Service, practice Leaders in key professions, and student placement practice leaders have been transferred to The Benevolent Society. The Community Justice Program and Integrated Services Program are being separately tendered out.

While residents of supported accommodation and their families were given some input in relation to the tender out process, the choice of successful NGOs was ultimately made by the NSW government.

What the productivity commission says

In its recent report on NDIS costs, the Productivity Commission made the following relevant findings and recommendations:

- The scale and pace of NDIS rollout is highly ambitious and risks the NDIA not being able to implement the NDIS as intended.
- Groups at risk of having a less positive NDIS experience include those with complex and multiple disabilities and language and cultural barriers and people transitioning from the criminal justice

system, the homeless and the socially isolated.

- For types of disability that require specialist knowledge, there should be specialised planning teams and/or more use of industry knowledge and expertise.
- It is false economy to have too few resources for Information, Linkages and Capacity Building particularly during the transition period. Funding for the ILC should be increased to the full scheme amount of \$131 million for each year during the transition.
- Interface with mainstream agencies
 - The COAG Disability Reform Council (DRC) should make public the approach of the Australian, State and Territory Governments to providing continuity of support and the services they intend to provide to all people with disability. Arrangements for continuity of support should be made clear before full scheme implementation. The NDIA should report annually to the DRC on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to service access.
 - Each relevant COAG Council should have a standing agenda item to address how its services interface with NDIS supports. At review points of national agreements, governments should agree to specific commitments and reporting obligations that are consistent with the National Disability Strategy.
- Supply of providers
 - Thin markets will persist for some groups including some participants with complex, specialised or high intensity needs, or very challenging behaviour, from CALD or Indigenous backgrounds or who have an acute and immediate need for crisis care and accommodation. The NDIA should address thin markets by a range of approaches, including block funding and publicly releasing its provider of last resort (POLR) policy and market intervention framework discussed in the NDIS Market Approach Statement of Opportunity and Intent.
 - The supply of disability supports in the short term will not meet participant demand due to a combination of factors including rapid intake of the scheme, difficulties faced by participants to navigate the new markets, difficulties by providers to adjust quickly to the new market-based model, and underdeveloped market stewardship.
 - The COAG Disability Reform Council should immediately clarify and make public the roles and responsibilities of different levels of government with respect to market stewardship including clear and transparent reporting of specific actions and outcomes.
- The Australian, State and Territory governments should continue to fund disability advocacy organisations.
- The Australian government should remove the cap on staff employed by the NDIA. (Productivity Commission (2017) National Disability Insurance Scheme (NDIS) Costs. Study report. www.pc.gov.au/inquiries/completed/ndis-costs/report)

Opportunities, challenges and risks

The NDIS has many potential benefits for people with disability including people with intellectual disability and complex behaviour support needs:

- Once the scheme is fully implemented in NSW, access to support will be based on need rather than whether or not there are vacancies in inadequately funded services.
- The NDIS focus on choice and control provides promise of supports being tailored around a participant's goals and aspirations rather than just what is currently available.
- NDIS eligibility is based on a more flexible functional test than the traditional definition of intellectual disability that was used by ADHC.

- The early intervention and insurance base of the NDIS should provide for early action to prevent complex behaviour support needs arising or escalating.

If the NDIS works well, it will become much less likely that an individual will develop challenging behaviour and quality support should be able to address challenging behaviour before it becomes complex and entrenched.

However, as the NDIA readily acknowledges, there is a range of issues that need to be addressed to make the scheme work well for people with complex needs including development of a capable market of coordinators of support, development of a skilled workforce and market of providers, provider of last resort capacity, the participant pathway, provision for fluctuations in behaviour support needs, quick plan reviews, regional connections with services like mental health and justice, resolving boundaries with mainstream services whilst getting the right supports for the individual, and information sharing. For example, if a person is in gaol, NDIS planning should occur six months prior to release so that:

- A provider is in place who can gradually work with the person and build a relationship prior to release.
- Housing and any necessary health services are also in place.

The implementation of the NDIS and the parallel process of the NSW Government exit from service provision are raising many risks and challenges:

- **Equitable access** - Ensuring fair access to the scheme for people who will not proactively seek it out. And making the scheme work for people from Indigenous and CALD communities who had never had an equitable access to the disability services that have existed.
- **Evidence to meet the disability requirement** - If a person does not have evidence to meet the disability requirement for NDIS access, this can be difficult to obtain. The NDIA does not fund these assessments. These challenges can be particularly great for people in gaol. They tend to lack informal supports, it is difficult to do reliable assessments in gaol and there is a paucity of staff to either do assessments or assist the person to seek out any old assessments and to assist with access requests.
- **The planning process** - There has been widespread concern to date about the quality and consistency of the planning process and the adequacy of participant plans. There is a range of reasons for this concern including the extraordinarily fast pace of transition of the 73,000 existing recipients of disability services in NSW and the limited time and skills of NDIS planners.
- **Funding beyond frontline behaviour support** - Dowse and others (2017) report that the current NDIS funding model providing minimal capacity for services to provide other than a frontline behaviour support service with no funding for skill development of providers.
- **Rapid response to changing needs** -The NDIS planning process being able to respond to the unpredictability and fluctuation of an individual's needs over the period of a plan.
- **Quality and coordination in a choice focused market** - Ensuring quality and coordination of professional and other supports in a market approach where an individual is faced with complex decisions purchasing a range of discrete services.
- **Challenges in choice and control** - Difficulties in choice and control over goals and services where an individual has narrow horizons and experience (and perhaps a background of trauma) and a lack of adequate informal supports to assist with choice and control.
- **Trauma related needs** - For people with a history of trauma, especially young people who have been in state care as children, ADHC used to accept responsibility for their holistic support needs. There is a reported tendency for the NDIA to seek to hive off trauma related needs as the responsibility of the mental health system without due regard for whether the trauma is leading to ongoing

psychiatric impairment and reduced functional capacity. Very inadequate therapy and core supports are then being offered.

- **People with justice system involvement** – Making the NDIS work for people charged with criminal offences. In NSW, the ADHC Community Justice Program provided a clear pathway and collaborative relationship with Corrective Services to allow access to disability support as people moved towards leaving gaol. There has been no such clear structure with the NDIS. In contrast, Juvenile Justice NSW reports positive engagement with the NDIS, particularly for young people on community based orders, and now having 56 young people as participants who were not receiving services from ADHC. The successes flowed from Juvenile Justice psychologists being able to do assessments of disability and good relationships between Juvenile Justice staff and the NDIS. Juvenile Justice is quite a small agency and has done a lot of training with its staff. In Corrective Services, the challenges are much greater with very large and increasing numbers in gaol and very limited disability professional staff.
- **Early Childhood Early Intervention** initiative is reported to have a range of practical problems.
- **Children with very complex needs** - Making the scheme work for families, children and young people with extremely complex and high risk behaviours. In the past, some of these children were provided supports through Voluntary Out Of Home Care managed by ADHC or intensive multi-disciplinary supports collaborating across all settings. There is a risk that these children will now be placed in the Child Protection system which is very poorly equipped to meet their needs.
- **Maintaining continuity of worker/person relationships** when a person has periods in gaol or hospital and NDIS funding stops. People with histories of broad social disadvantage find it hard to form trusting relationships. Quality providers work hard to develop these relationships but they are interrupted by imprisonment or hospitalisation and resultant interruption of funding leading to staff moving on.
- **Exit of ADHC** - In view of ADHC having been the predominant disability service provider for people with complex behaviour support needs, there is an open question about whether the non-government sector will be able to fill this gap. ADHC has sought to safeguard this in the tender out process through means including two years continuity of pay and conditions for staff of transferred services. Only time will tell whether those safeguards were adequate.
- **NGO behaviour support systems** - Previously ADHC provided a considerable amount of systems development, consultation, and professional development to NGO's around behaviour support systems and professional governance or NGOs could purchase this from specialist private agencies. Organisations now report that they are finding it very difficult to pay for these inputs with the current funding model.
- **Crisis and last resort providers** - Who will fill the crisis and last resort support provider role that ADHC has filled to date? In practice, this has been accepted as a core public service responsibility. With ADHC closing, this role is ending.
- **Workforce and markets** - Beyond the implications of ADHC closing, there is a broader concern about workforce and availability of providers. There has never been an adequate support worker or professional workforce to meet the needs of people with complex behaviour. There needs to be a strategy to maintain and build this workforce. At present, the danger is that the workforce will go backwards due to the combination of ADHC closing and other factors noted in the report from the Markets and Workforce table discussion below.
- **Suitable accommodation** - Will NDIS funding structures ensure a supply of suitable and safe physical accommodation? For example, where an option with extra safety features may be required as a temporary measure to support stabilisation of a person's situation. The Roundtable did not specifically address the issue of supply of suitable accommodation. CID is further considering this issue.

- **New gaps in health services and supports for offenders** – The NSW government contracted to hand over its whole disability budget to the NDIS without excluding money that was being used for services that the NDIS will not fund. This includes regional specialist psychiatry clinics which have proved a vital complement to the role of disability professionals in assessing and responding to complex behaviour support needs. Also, the NDIA is tending to take a narrower view of its role in relation to people with offending behaviour than has the ADHC Community Justice Program.
- **Lack of clarity on the respective responsibilities of the NDIS and other service systems** and, in some circumstances, people losing necessary supports that were formerly provided by ADHC but which the NDIA sees as the responsibility of mainstream services.
- **Defunding of advocacy services** – Having agreed to transfer its whole disability budget to the NDIS, the NSW Government plans to stop funding individual and systemic advocacy services in June 2018.

In the years during which NDIS implementation and ADHC exit from service provision have been occurring, there is in fact evidence of a significant decline in the quality of behaviour support.

Professor Julian Trollor holds the Chair in Intellectual Disability Mental Health at UNSW and runs a tertiary clinic for people with intellectual disability and complex behaviour and mental health problems. Professor Trollor has observed a marked reduction in quality of the behaviour support being provided to people who come to his clinic over the last 2.5 years.

A long term advocate and guardian reported at the Roundtable how the quality of service provided to the woman to whom she advocates has declined markedly over the last two years as the non-government organisation has prepared for NDIS implementation. Staff turnover has increase from 10% to 80%. The number of casual staff is enormous. This triggers the woman's behaviours of concern and she can end up hospitalised. She is on significant medication and is not coping with the stress. She has gone back to being incontinent which has only happened twice in the last 10 years. Advocacy for this woman remains vital.

Key areas for action

In Appendix 1, we set out the issues highlighted by each table group and their recommendations to address those issues. The NDIA and other agencies should find those recommendations valuable.

Here, we highlight key issues for CID emerging from the Roundtable and its surrounding context.

The participant pathway

CID strongly welcomes the new general participant pathway and the agency's current work on a tailored pathway for participants with complex needs.

Some key issues to be addressed in the complex needs pathway are:

Equity of access

The NDIS needs to actively reach out and not assume that people can easily find their way onto the NDIS path. I have something I want you to do. I want you to ask yourself

What can I do to reach out?

What can I do, fix or change to help someone with complex needs get the good life they deserve and not be left behind?

(Michael Sullivan, opening address at the Roundtable)

There are many people with intellectual disability and complex behaviour support needs who live isolated lives on society's fringe and who are unlikely to be aware of or seek access to the NDIS. Related to a lack of disability support, members of this group are often in contact with the criminal justice system. They tend to be distrustful of government agencies due to a history of negative experiences and cautious about accepting the label of "disability". If this group is to have equitable access, there needs to be a well-coordinated system of outreach and engagement and support for people to enter the scheme and/or access other mainstream services and community supports. This system should be a partnership between the ILC and mainstream agencies and advocacy services who, in some cases, are well-placed to support people into appropriate supports.

At each step of the NDIS pathway, it may be necessary for a new player, for example a planner or coordinator of support, to take time to establish a trusting relationship with the person. Quite often, mainstream agencies will not be well placed to establish these relationships because of the person's history with the agency. Modes of communication in these efforts to engage people must be varied and capable of meeting the communication needs of each individual.

See CID's position statement on equity of access at www.nswcid.org.au/images/pdf/Fringe_posn_statement_150315.pdf

The pathway being responsive to the person's current circumstances

This issue arises in a range of situations including for people who are in contact with the criminal justice system. If a person is currently facing charges and potentially detention in custody, the pathway needs to be responsive by ensuring that a plan is in place by the time the court will be making a decision about remand or a custodial sentence. The person will then have an equitable opportunity to avoid detention as would people without disability who face criminal charges.

Similarly, if a person is in custody, the planner will need to be prepared to visit the person in gaol. Corrective Services NSW reports major difficulties with planners understanding of issues for people with intellectual disability in the justice system and willingness to spend time to come to the gaol to work with the person on planning.

The challenge of choice and control

People with intellectual disability and complex behaviour support needs face major challenges in exercising choice and control due to factors including the impact of the disability on the person's understanding of the NDIS pathway and their life options and goals, the impact of histories of trauma and a lack of adequate decision supports and advocacy whether from families or other supporters.

Through the ILC and participant plans, the NDIA should provide for capacity building and independent support in decision-making. Where advocacy is available, it can also assist the person and/or family supporters.

Assistance needs to take account of the communication needs of each individual. People may present as strong verbal communicators whilst actually requiring significant support with both receptive and expressive language.

Families of children have a formal role in choice and control and families of adults commonly have important roles as well. Families, especially disadvantaged families, commonly need capacity building and support to carry out these roles and this needs to be provided through the ILC and participant pathway.

Where, despite maximum efforts, a person cannot currently be supported to make their own planning decisions, the NDIA should consider appointing a nominee within the safeguards of the nominee system. If no appropriate nominee is available, the NDIA or other existing supports should consider an application for a guardianship order.

Skilled planners

It is essential that planners for a person with complex behaviour support needs have specific skills in communicating with the person, in understanding the person's needs and what can and cannot be expected of mainstream services, and in making good judgements. NDIS planning may be informed by reference packages and a range of other general rules. However, each participant is a unique individual with unique life circumstances and living in locations with a range of variables in factors like available community and mainstream supports. All planners, and especially planners for people with complex needs, must have the capacity to make good judgements about how to take all those factors into account in arriving at a participant plan. Planners need to be able to make good judgements in relation to the input from current support providers, respecting their knowledge of the person but also considering their conflict of interest.

There need to be subspecialties including planners with specific skills in disability support for:

- Children and young people – Planners need to understand issues like childhood development and family systems.
- People with complex mental health needs as well as intellectual disability.
- People involved with the criminal justice system - In relation to this group, the joint standing committee of the NDIS has gone so far as to recommend that, “the NDIA establishes an NDIA unit specialising in the interaction of the Scheme with the criminal justice system”. www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report (Recommendation 23)

Planners also need access to advice from high level independent behaviour practitioners and other professional expertise where needed.

Informed and collaborative planning

To decide what are reasonable and necessary supports for a person with complex behaviour support needs, the planner will commonly need a range of information from a range of people, including the person and their informal supports, disability professionals and other services working with the person, for example schools, health and justice services. With consent, planning should be a collaborative process with the person at the centre but with other relevant players having input. If this does not occur, planning may proceed on false assumptions in relation to disability support needs and in relation to the supports that can be appropriately expected from other agencies.

Shortcuts such as involving a person's current key disability support worker in planning are inadequate. The quality of key workers and their information bases vary enormously.

If planning occurs in a collaborative way, it is much more likely to lead to collaborative and concerted implementation of the plan than if it is perceived as something imposed by the NDIA. This is especially important if the NDIA looks to mainstream services to provide supports that have to date been provided by ADHC.

At the same time, the process needs to be alert to the conflict of interest that existing support providers will have.

If strong, collaborative planning is to occur, considerable time may be required from NDIS service providers and the financial implications of that for the providers need to be considered by the NDIA. Providers already claim that they put considerable unremunerated hours into planning processes and reviews.

The need for multiparty input to the planning process would be reduced if the NDIA moved towards plans that were much less prescriptive about use of the total plan budget than is currently the case.

Time in the planning process

The planning process will often need to be very time intensive for a person with complex behaviour support needs. However, this will be time well spent if it leads to the person's needs being well met so that crises, escalations of support needs and urgent plan reviews are less likely.

Behaviour support cannot be quick and dirty

The allocations in a plan for behaviour assessment and support and other related inputs such as speech pathology need to be realistic to take account of the time commonly required to provide quality behaviour support. This includes:

- the behaviour support practitioner developing the plan in close liaison with the person and their family,
- training and supporting informal and formal support workers to implement the plan,
- ensuring collaborative action by the range of relevant disability and mainstream professionals and services,
- urgent strategy development and training for issues that were not anticipated, and
- regular plan reviews

There are many reports of a general allocation of 10 hours a year for behaviour support which is generally extremely unrealistic for a person with complex behaviour support needs. This results in lengthy service delivery gaps and high risks while plan reviews are sought. The problems could be alleviated if the NDIA moved to greater flexibility in use of overall plan budgets rather than, for example, specifying a particular maximum number of hours for behaviour support.

Any reference packages that are used for people with complex behaviour support needs must reflect the time and skills required and be readily departed from on the basis of individual circumstances.

Expert consultancy

For people with particularly complex needs, there should be funded access to tertiary behaviour support practitioner skills and a panel including representatives from relevant agencies, independent professional experts and an advocate supporting the individual. This panel could provide a fresh set of eyes and seek to break down logjams in cross agency action.

This kind of panel could also play a valuable role in the planning process itself, in reviewing draft plans of people with very complex needs.

Tertiary skills are currently available in a small number of private practitioners and the former Statewide Behaviour Intervention Service which has been transferred from ADHC to The Benevolent Society.

Allowing for fluctuations in needs

The support needs of people with complex behaviour support needs can escalate quickly, suddenly and unpredictably. Plans should include a buffer amount to allow for immediate responses to such escalations and there needs to be a process for extremely urgent plan reviews.

Continuity of support when a person is imprisoned or hospitalised

NDIS funding should continue at least to the extent of allowing for maintenance of trusted relationships between support workers and participants. Where interruptions in support are an inherent part of service provision, such as for people with serious histories of offending, the NDIA should consider providing continuity and/or block funding to avoid market failure.

Coordinators of support

Implementation of a plan for a person with complex behaviour support needs is commonly a challenging and time-consuming role. Coordinators of support need both the skills and the time to perform these roles adequately. The supply of skilled and independent coordinators of support needs urgent development.

Integrated Service Response

This NSW Government project is focused on a small number of people with complex needs that cut across the NDIS and mainstream services. The project is trialling a system for coordination between NDIS services and those of mainstream agencies. The NSW Government and the NDIA should closely monitor the project, adjusted it with initial learnings and then consider an ongoing role for it.

Last resort and crisis providers

The NDIA needs a robust structure for ensuring that there is always a suitable provider and accommodation available for a person in crisis and/or where a suitable provider cannot readily be found. This includes situations where an existing provider withdraws on the basis that it feels unable to meet the person's needs. Over time, this could be a recurring situation in relation to people whose supported accommodation has been transferred from ADHC to the non-government sector. Crisis providers will also be needed where a person will otherwise face imprisonment or hospitalisation for want of appropriate disability support.

On tap physical accommodation options need to include a range of highly modified or purpose-built settings designed to address safety issues in a minimally restrictive way.

The NDIA also needs clear systems to respond to crises facing people who have not yet become participants, for example where a family carer dies or the person is inappropriately taken to hospital where the family carer can no longer cope. The NDIA should make provision for urgent interim access requests and plans with a view to a fuller planning process say a month later.

A greater focus on outcomes

There is much to be said for the NDIA developing an outcomes framework for planning so that anticipated outcomes for the participant are identified in their plan and reviews include a stocktake on outcomes achieved and why they have or have not been achieved. An outcomes framework for people with complex behaviour support needs would have to be carefully designed and implementation would require sophisticated planner skills. There are often complex individual reasons beyond the quality of support that impact on actual outcomes.

An outcomes framework should apply across the range of disability and, if possible, mainstream supports a person receives.

Interplay with other pathways

If the NDIA develops other specialised pathways, for example for Indigenous Australians or people with psychosocial disability, the pathway for an individual may need to be an amalgam of two or more pathways.

Recommendations

1. In the development of the complex needs pathway, the NDIA should:
 - a. Ensure a robust system of outreach and engagement with people with complex needs who are unlikely, of their own initiative, to seek out NDIS access. This system should include:
 - i. designated time of local area coordinators who have skills in outreach and engagement,
 - ii. funding of grounded community groups through the ILC,
 - iii. close liaison with advocacy services,
 - iv. close liaison with State government agencies and mainstream community organisations which are likely to have contact with marginalised individuals with disability, and
 - v. assistance to obtain assessments needed for NDIS eligibility.
 - b. Ensure that the pathway is responsive to individual circumstances, for example the need to have a plan in place before a court makes a decision about diversion from a custodial sentence.
 - c. Ensure that the pathway is well linked with other specialist pathways the agency is developing, including that for Aboriginal and Torres Strait Islander participants.
 - d. Ensure that participants and, where relevant, their family supports have access to capacity building and independent support in decision-making. This should occur through funded ILC services, advocacy where available, and funding in participant plans.
 - e. Where, despite maximum effort, a person cannot be supported to make their own planning decisions, the NDIA should appoint a plan nominee and, if necessary, instigate an application for a guardianship order.
 - f. Ensure that planners for people with complex needs have the requisite skills, including having subspecialist planners for children and young people, people with complex mental health needs and people involved with the justice system. Planners need skills to make good judgements about individual plans rather than starting from rules of thumb about hours of behaviour support and being overly reliant on reference packages.
 - g. For people with very complex needs, draft participant plans should be reviewed by an expert panel including independent expert professionals and advocates.
 - h. Planning should be based on a broad information base and collaboration, with the participant at the centre. Whilst being alert to conflict of interest, the process should include input from disability professionals and mainstream services working with the person.
 - i. Planning should move to a greater focus on outcomes to be achieved by disability and, if possible, mainstream supports, with the NDIA developing an enhanced outcomes framework in collaboration with advocacy, disability service provider and mainstream agencies.
 - j. Plans should provide increased flexibility in use of overall plan budgets rather than, for example, specifying a particular maximum number of hours for behaviour support.
 - k. As a matter of the greatest urgency, the NDIA should establish crisis provider and provider of last resort arrangements including a range of suitable physical accommodation.
 - l. Planning should allow a quick and flexible response to unfolding individual circumstances through:
 - i. greater flexibility in relation to use of total funding, for example less specificity in relation to a set amount for behaviour support,
 - ii. consideration of a buffer amount in a plan which is available where circumstances change, and
 - iii. allowing for continuity of support and maintenance of trusted relationships with support workers where a person is imprisoned or hospitalised.
 - m. Through individual plans and/or block funding, ensure capacity for access to tertiary behaviour support practitioner skills and an expert advisory panel.

Supply and quality of workforce and providers

People with complex needs need skilled and thoughtful professionals working for them. In every part of their NDIS journey, from initial contact to plan in place and beyond. What happens in this NDIS journey will be mirrored by the goodness or lack of good in that person's life from then on.

(Michael Sullivan, opening address at the Roundtable)

Ultimately, this may be the biggest challenge facing the NDIA in meeting complex behaviour support needs.

A skilled workforce is needed across the board - local area coordinators, planners, coordinators of support, behaviour support practitioners and other disability professionals, and direct support workers. There is a current shortage at all these levels in workers skilled to meet complex behaviour support needs. The demand for these workers will increase with the implementation of the NDIS but at present the supply of them in NSW is arguably declining.

Mainstream agencies also need to address these workforce skills including in schools and the health and justice systems.

Similarly, there is already a thin market of provider organisations to work with people with complex behaviour support needs and this situation may be exacerbated by the withdrawal of ADHC from being a service provider. There was a political imperative for ADHC to meet complex needs. There is no such imperative for the non-government providers to whom services have been transferred.

Providers also report they no longer have the financial capacity for systems vital to good practice in behaviour support including risk identification, peer review, and complex case review.

Recommendations

2. The Department of Social Services, in collaboration with the NDIA, NDIS Quality and Safeguards Commission and State and Territory Governments, should take urgent action to ensure an adequate and skilled workforce to work with people with complex behaviour support needs. This workforce development is required across the spectrum from local area coordinators, planners, coordinators of support, managers and staff of providers, behaviour support practitioners and other relevant professionals. Workforce development must include tertiary education and ongoing mentoring and skills development in the workplace.
3. The NDIA should take action to ensure an adequate supply of provider organisations for people with complex behaviour support needs including through consideration of incentives, adequate pricing for direct supports and block funding.

People with intellectual disability and a psychiatric condition

Many people with intellectual disability and complex behaviour support needs will have psychiatric conditions. If a psychiatric condition is likely to be permanent and results in a substantial reduction in functioning, then it may be equally relevant as the intellectual disability to whether the person meets the disability requirement for NDIS eligibility and to the reasonable and necessary support needs that flow from the disability.

A common example here is where a person has a history of trauma giving rise to an ongoing psychiatric condition.

In the past, intellectual disability and health professionals have not had to focus on the impact of a psychiatric condition when considering a person's eligibility for ADHC services. Now, they should focus on both the intellectual disability and the psychiatric condition.

Recommendations

4. The NDIA should provide clear public information in relation to the evidence required for eligibility where a person has both an intellectual disability and a possible disability related to their psychiatric condition.

Early Childhood Early Intervention

While the ECEI approach was seen as having a range of positives, there is major concern about how it is working in practice with reports of families being turned away if they do not have a diagnosis for the child and services being consumed with planning but with families being confused by the system and not being able to access services.

Here is the best opportunity to address developing complex needs before they have established. Anecdotal reports suggest that this opportunity is being missed with the roll out of the ECEI and the blurring of responsibilities and defensiveness of parallel service sectors.

For example, there needs to be a very strong focus on transition to school planning with families, ECI, schools and health services working in partnership to ensure a wraparound service that meets the child's needs.

Recommendations

5. The NDIA, in collaboration with State and Territory government agencies, should develop and implement a framework to ensure realisation of the potential of the ECEI approach to provide early intervention to children who have or can be foreseen to develop complex behaviour support needs.

Interface issues

The National Disability Strategy, Disability Inclusion Act NSW and discrimination law call on mainstream agencies to enhance their responses to people with disability. Much of CID's advocacy over the last 20 years has been directed at mainstream agencies, most particularly the Australian and NSW Departments of Health. People with intellectual disability face stark health inequalities including, in NSW, 38% potentially avoidable deaths compared to 17% in the general population. www.bit.ly/2v9cgFz CID and our advocacy partners have had some significant successes with health agencies including getting into Medicare items for annual health assessments for people with intellectual disability, NSW Health adopting a Service Framework to Improve the Health Care of People with Intellectual Disability and specific material in the 5th National Mental Health Plan. However, much remains to be done.

Mainstream agencies must continue to increase their accessibility and appropriateness of services for people with disability.

Taking the education system as another important example, reports from two NSW inquiries in 2017 highlighted the inadequacies of the school system for students with disability and made wide-ranging recommendations for reform:

- Report of the Legislative Council committee inquiry Education of Students with a Disability or Special Needs in NSW
www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6114/170921%20-%20Final%20report.pdf
- NSW Ombudsman Inquiry into Behaviour Management in Schools, Special Report to Parliament
www.ombo.nsw.gov.au/news-and-publications/publications/reports/community-and-disability-services/nsw-ombudsman-inquiry-into-behaviour-management-in-schools-august-2017

However, in some spheres, the delineation of responsibilities is not clear. Also, major problems arise where the NDIA takes a narrower view of its role than ADHC did.

There are specific problems in NSW where ADHC was funding services that the NDIA does not see as within its responsibility. The obvious case is a range of health services including regional specialist psychiatry clinics which are very relevant to people with complex behaviour support needs. The NSW Government needs to accept responsibility for maintaining the functions of these health services. Failure to do so will lead to poorer health and increased disability support costs. In relation to specialist psychiatry, if a person needs access to this and cannot get it, their behaviour support needs are likely to escalate.

There are also difficult questions in relation to the Community Justice Program which has been funded by ADHC. The NDIA appears to be taking a narrower view of its responsibility than did the CJP based on a false dichotomy between challenging behaviour which is the responsibility of the NDIS and offending behaviour which is seen as the responsibility of the justice system. This dichotomy assumes that offending is not related to a disability whereas in fact offending is commonly related to reduced functional capacity in communication, social interaction, learning or self-management. The NDIA also appears to be making incorrect assumptions about the role that justice services play for offenders generally in relation to therapeutic programs and support to avoid reoffending.

The applied principles for justice in the COAG Principles to Determine the Responsibilities of the NDIS and Other Service Systems say that “Other parties” are responsible for:

- Cognitive and psychiatric assessments for court sentencing or diversion.
- Accessible legal assistance
- “Offence specific interventions... which are not clearly a direct consequence of the person’s disability”.
- “Intensive case coordination ... where a significant component of the case coordination is related to the justice system”.
- Early identification and primary intervention programs.

But justice services commonly do not perform these or other stated responsibilities.

In this field, CID argues that the interface principles are not consistent with the test in the NDIS Act on which they rest, namely whether supports are most appropriately funded through the NDIA and not through other mainstream services as part of their universal service obligation or in accordance with reasonable adjustment required under discrimination law (Section 34(f)).

The justice interface principles do note “that the NDIS interface with justice is complex” and that lessons learned from the NDIS trials will assist Governments to refine them.

See the submissions of CID and Australians for Disability Justice to the joint standing committee on the NDIS at www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth

The joint Parliamentary committee on the NDIS has considered the role of the scheme in relation to people in the justice system and recommended that the NDIA:

- Urgently clarifies what approved supports are available to NDIS participants in custody and how it monitors and ensures NDIS participants access the supports they are entitled to while in custody.
- Establishes an NDIA unit specialising in the interaction of the Scheme with the criminal justice system.
- Develops a specific strategy to deliver culturally appropriate services for Aboriginal and Torres Strait Islander people with disabilities who are in the criminal justice system

www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report

Respective responsibilities for children with disability in voluntary out of home care is also a challenging issue. Many of these children are in out of home care because families have found it extremely difficult to meet their complex behaviour support needs. There have been ongoing negotiations between the NSW Government and the NDIA on these issues.

For young children, there needs to be consistent implementation of NDIA responsibilities under the Early Childhood Development interface principles including for specialist support and training for school staff in support needs of a student with disability including specialised behaviour support.

Interagency collaboration should be promoted based on:

- Strong local systems between the NDIA and mainstream agencies.
- Collaborative initiatives across professions and agencies, for example as currently occurs in NSW via joint clinics between children's mental health services and disability services.
- A no disadvantage approach – A person should not be deprived of necessary supports by the introduction of the NDIS and NSW Government exit from disability service provision.
- Collaborative negotiation in determining what is funded by the NDIS and what is provided by mainstream agencies, taking account of individual and local circumstances. The core issue is whether a support is most appropriately funded through the NDIS and not through other mainstream services as part of their universal service obligation or in accordance with reasonable adjustments required under discrimination law. (NDIS act, section 34(f)) CID argues that section 34 calls for a more individual consideration than that currently set out in the interface principles.
- Capacity to escalate situations to a senior group able to problem solve and make out of guideline funding and service decisions.
- Shared KPIs and outcome measures.

Recommendations

6. The NSW Government should ensure ongoing enhancement of the accessibility and appropriateness of mainstream services for people with intellectual disability and complex behaviour support needs including through:
 - a. the disability inclusion plan scheme required by the Disability Inclusion Act NSW, and
 - b. ensuring that NSW Health maintains the functions of health services previously funded by ADHC.
7. The NSW Government should ensure the continuation of the ADHC Community Justice Program as

a community based and disability support focused program including meeting any funding shortfall arising from NDIS implementation.

8. The NSW Government and the NDIA should promptly resolve their respective responsibilities for holistic support of children and young people in voluntary out of home care.
9. The NDIA and State government agencies should continue to build collaborative relationships at individual and systemic levels including through:
 - a. mainstream agency input to individual planning,
 - b. ensuring that a person is not deprived of necessary supports while State agencies and the NDIA resolve demarcation issues,
 - c. applying the Principles to Determine the Responsibilities of the NDIS and Other Service Systems taking account of individual and local circumstances rather than treating the principles as establishing sharp lines of demarcation, and
 - d. establishing a shared outcomes framework.
10. The Australian and State and Territory Governments should review the Justice section of the Principles to Determine the Responsibilities of the NDIS and Other Service Systems.

Beyond the group home

One of the opportunities that the NDIS should provide is for much more individualised choices of accommodation and support options than the traditional group home model. The way the NSW Government has gone about moving out of service provision and closure of institutions has not taken this path. Group homes and institutions were the predominant form of supported accommodation provided by ADHC. ADHC is devolving its remaining institutions into group homes. It is also finalising a process of transferring its existing group home accommodation to non-government providers on a “continuity of care” basis which includes the provider having five or ten year leases of the houses and options to renew those leases.

In the 1980s, group homes were widely developed as a much preferable option to large institutions. As the years have gone by, the limitations of group homes have become very apparent with people often having no choice about with whom they live and major limitations on individual choice and privacy within the household. Group homes have particular problems for people with complex behaviour support needs due to issues of compatibility between residents and major difficulty for staff in meeting complex individual needs within a group environment.

The NDIS planning pathway for each resident of a group home should specifically consider the person’s goals and aspirations in relation to their living arrangements and whether the group home arrangement is meeting the person’s needs. A thorough support model assessment should occur. www.adhc.nsw.gov.au/sp/delivering_disability_services/behaviour_support_services

Alternative and more individualised accommodation should be considered and pursued.

Where there is stark evidence that a person’s current accommodation is not meeting their needs, for example because of critical incidents or the provider seeking to withdraw, there should be a specific focus on identifying and pursuing the most appropriate accommodation support arrangements for the person.

Recommendations

11. The NDIA planning pathway should include specific consideration of whether a person's current accommodation is able to meet their goals and needs with a view to seeking out more appropriate accommodation where appropriate.
12. As a top priority, where there is clear evidence that a person's accommodation is not able to meet the person's goals and needs, the NDIA should ensure systems to provide the person with appropriate accommodation.

Residency agreements

NDIA Terms of Business say that providers of supported disability accommodation must offer a written service agreement to residents including requiring the provider to give a participant "a minimum of 90 days notice before the participant is required to vacate unless short notice is required to address the risk of harm to the participant or others". providertoolkit.ndis.gov.au/sites/g/files/net3066/f/ndis_terms_of_business.pdf

This clause is most unfair especially in circumstances where there may be a risk of harm which flows from the failure of service providers to provide appropriate behaviour support. Commonly, alternative accommodation options are in short supply.

The central focus should be on changes of accommodation being consensual focused on moving to a better option rather than eviction by a support provider.

The NDIA needs to reconsider its requirements for service agreements to address these issues and otherwise make the agreements fair for people with disability.

CID strongly objected to contracts prepared by ADHC to be used by accommodation and support providers in supported accommodation being transferred by ADHC to the non-government sector. ADHC then made some changes to the contracts. See the two CID blogs on this issue at www.nswcid.org.au/blog/

ADHC is now consulting on proposed legislation to regulate the relationship between residents of supported accommodation and accommodation providers.

www.facs.nsw.gov.au/about_us/news/public-consultation-for-improving-disability-resident-protections-in-supported-group-accommodation

CID's commentary on the proposals in the ADHC consultation is at www.nswcid.org.au/blog/let-s-make-sure-this-is-about-residents-rights.html

Recommendations

13. The NDIA should review its terms of business in relation to service agreements with a view to ensuring that agreements are fair to participants with complex behaviour support needs, in particular in relation to circumstances in which a person may be evicted from their home.
14. The NSW government should ensure that its proposed legislation for residency agreements in supported accommodation is fair to participants with complex behaviour support needs, in particular in relation to choice of new residents and circumstances in which a person may be evicted from their home.

Governance, quality and safeguards

The NDIS Quality and Safeguarding Framework has potential to provide considerable safeguards to people with complex behaviour support needs.

The implementation of the framework needs to have a central focus on the reduction and elimination of the use of restrictive practices. In 2014, Australian, State and Territory Disability Ministers endorsed the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector. www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-framework-for-reducing-and-eliminating-the-use-of-restrictive-practices-in-the-disability-service-sector The implementation of the NDIS generally and the Quality and Safeguards Commission in particular need to be squarely focused on implementation of this framework.

A key issue for the Quality and Safeguards Commission will be the development of a competency framework for providers of behaviour support. Dowse and others (2017) make a range of important comments relevant to this issue and conditions on provider registration (pages 16 – 17, 21 and 25-26).

In implementing the framework in NSW, specific consideration is needed on two fronts:

- Ensuring that valuable functions performed by the NSW Ombudsman are not lost in the new safeguarding arrangements. Issues that need to be addressed include
 - The scrutiny of the NSW health system that the NSW Ombudsman has performed as part of its role of reviewing deaths of people with disability in supported accommodation. While the Quality and Safeguards Commission will receive reports of deaths, it does not have jurisdiction in relation to the NSW health system in the way that the NSW Ombudsman has
 - The community visitor scheme - This scheme has been very valuable for providing specifically skilled visitors to residences where people with complex behaviour support needs live. This monitoring and active watchdog function must be maintained into the future.
- Authorisation of restrictive practices - While the new Quality and Safeguards Commission will have a range of roles in relation to restrictive practices, the role of authorisation remains to be addressed under NSW law. To date this has occurred by the interplay of ADHC policy and the role of the Guardianship Division of the NSW Civil and Administrative Tribunal. The NSW Law Reform Commission is currently completing a review of the Guardianship Act. It is vital that authorisation of restrictive practices continues to be required through an independent statutory process such as guardianship.
- ADHC played important roles in providing practice leadership, professional development and resource development across the range of professions relevant to behaviour support. It also funded the chair in intellectual disability behaviour support. These roles need to be maintained through the Quality and Safeguards Commission and/or other systems established by the NDIA.

Data systems are needed to collect and analyse data in relation to the quality of supports provided to people with complex behaviour support needs both through the NDIS and through mainstream agencies.

Recommendations

15. The NSW Government should ensure that the establishment of the NDIS Quality and Safeguards Commission does not leave gaps in roles previously performed by the NSW Ombudsman including in relation to scrutiny of the NSW health system and ongoing auspicing of the community visitor scheme.

16. The NDIA and the Quality and Safeguards Commission should ensure ongoing performance of roles previously played by ADHC in relation to people with complex behaviour support needs including practice leadership, professional and resource development and research.

Advocacy

Related to its handing over of its whole disability budget for NDIS participant plans, the NSW Government currently plans to cease funding of disability individual and systemic advocacy and independent information services on 30 June 2018. This funding is approximately \$13 million year. The Australian government currently provides approximately \$6 million a year for advocacy in NSW. If the NSW government proceeds with its plans, there will be a fundamental reduction in the availability of advocacy in NSW.

Various participants in the Roundtable from outside advocacy emphasised the importance of ongoing individual and systemic advocacy for people with complex behaviour support needs. The Australian Government, the Senate and the Productivity Commission have all called on the NSW Government to continue to fund advocacy.

Recommendations

17. The NSW government should continue to fund individual and systemic disability advocacy at least to the level currently funded.

Ongoing development of programs, policies and practices

CID argues that the best outcomes are achieved if programs, policies and practices are developed in close consultation with people with intellectual disability, their families and other advocates. In this sphere of complex behaviour support needs, we also argue that the NDIA and other agencies need to work in active consultation with independent thinking professionals and researchers skilled in meeting complex behaviour support needs. If this does not occur, agency practices may be ill-informed and impractical.

Recommendations

18. In ongoing development of programs, policies and practices for people with complex behaviour support needs, the NDIA, the Quality and Safeguards Commission and the Department of Social Services should act in close consultation with representatives of people with intellectual disability and skilled disability and health professionals.

Appendix 1 - reports from table discussion groups

Each table group was asked to consider the following questions in relation to its table topic:

1. What are the most important issues to be addressed by the NDIA and other service systems?
2. What are the most important actions to make the NDIS and related service systems work better?

Each table had a chair who fed back verbally at the Roundtable and then provided a written report. The feedback does not necessarily reflect the views of particular table members or the agencies that they represent.

NDIS Planning Process

General

Issue: Generally, the table felt that many of the issues around NDIS planning resulting in poor quality plans and the need for plan reviews were related to:

- Limited resources – eg staff
- Timeframes – eg KPIs regarding plan approval
- Communication and transparency about the planning process

Action/Solution:

- Increase staffing
- Rework the bi-lateral agreements to lower KPI levels
- NDIA release accurate information about the planning process eg questions asked at the planning meeting

NDIA development of new planning process and the role of families, guardians and advocates

Issue: Example situation - Multiple children with disability in family and single parent (mother). Mother has to provide considerable evidence to prove that she could not complete tasks (eg take child to appointment) because of the need to provide care for other children with disability. How do you ensure plans for multiple family members or people living in group homes are complementary?

Action/Solution:

- Draft plans – Participants should be able to review plans before approval. They would be able to pick up inconsistencies and lower review rate.
- Two planning meetings – The gap between meetings would allow for processing time and participants to come to the next meeting with follow up questions and information. Planner could review documentation between meetings. At second meeting, planner/LAC could review plan ideas and check these with participant.
- Multiple plans developed at the same time
- Planner Specialist training for planners

Adequate Funds for behaviour support (including supervision and mentoring), therapy, transport? And reference packages

Issue – Example behaviour support situation - Comprehensive supporting evidence is submitted to NDIS for participant with very complex needs to ensure they have adequate funds for behaviour support. Funding package returned with limited funding for behaviour support.

Solution –

- Ensure the reference package is accurate (by providing accurate information about age, disability and level of function).
- People with complex needs often have more than one disability that significantly contributes to support needs. Reference packages have limited utility in these cases. NDIA should enhance the planning questions to modify the reference package to ensure it is more accurate for people in this situation.

Transport issue – Limited access to transport in regional areas, limited transport options and limited funds in plan to cover costs. Public transport may be impractical for people with complex needs.

Action/Solution:

Creative solutions needed.

Allowance for foreseeable crises

Issue: 'Contingency' funding is not built into plan.

Action/Solution:

- Planner empowered to put extra funding into plan to cover this (eg \$5000). Funds could be quarantined unless needed.
- Planner/LAC training to identify participants who may need this consideration.
- Service providers cover cost of crisis from current funds. Immediate plan review requested. Service providers would need to have confidence and trust that their crisis support will get refunded by the NDIA. Having a Local Point of Contact with the NDIA may instil this confidence.

Plan Implementation

Support coordination

- This critical role need sufficient hours and better agreement about the roles – scope, quality standards, accreditation and registration.
- Improvements in these areas could better manage conflicts of interests where the coordinator of supports works within a wider provider service, where there is a thin market with few choices, and where the participant lacks experience or exposure to choice options.
- The centrality and intensity of the role need to be reviewed. A coordinator of supports won't ever be described as a case manager but the role does need to pick up the centrality and sometimes the intensity of that type of role. It needs to be the linker of services.
- Quality and accessible workforce to be able to deliver the promises of the role.

Other important actions

- Review of service agreements - The purpose and legalities of service agreements are unclear. At the moment, agreements look like a set of conditions on the participant, most are inaccessible and cover

detailed information about the person's interaction with the service beyond the terms of the NDIS plan.

- Operationalise the state interface principles around an individual participant - Get high level agreements about how state agencies / NDIS should be working together so that there is knowledge about how to respond at the ground level when a person requires assistance
- Monitoring coordinator of supports and other provider claims - have they provided the service they are claiming payment for?
- Accountability:
 - an articulated audit process for providers
 - registration process – Ensure providers understand core competencies and that those who cannot provide a quality service drop out of registration

Marketplace and workforce

Capacity issues

Skill and experience of workers and providers as well as lack of volume across all segments of the sector.

Caused by:

- Rapid releasing of everyone from waiting lists – workforce cannot keep up
- Increased funding support to some people
- Turn-over of staff due to challenges working in the new environment, staff leaving to work in adjacent sectors
- Staff burn out – including dealing with billable hours KPIs
- Poor job security and predictability due to casualisation of the workforce
- Difficulty billing for sessions completed by a student – cash flow issues
- Lack of availability of staff to fill vacancies

Outcomes:

- Limitations to business development and growth
- Quality and safeguards implications
- Risks to participants
- Risks to other staff and community
- Regional and remote areas particularly at risk
- Culturally and linguistically diverse workers and workers with learning difficulties find documentation hard to understand
- Slowing of capacity building opportunities across the sector

Solutions:

- Coordinated state based/national workforce strategy
- Subsidized student placements
- Recommended rates of supervision/mentoring/professional development across all segments of the sector including direct support workers
- Collaboration between NDIA and the Universities - has potential to offer low cost services for participants and placement opportunities for students.
- NDIS and provider documentation to be easy to read and understand

Low confidence of providers

Caused by:

- Significant burden of admin that comes with working with NDIA managed clients
- Sudden policy shifts that affect business cash flow and planning
- Inadequate funding in plans to satisfactorily complete required work = challenge to ethics in terms of quality of work or loss of income as business completes work unpaid
- Frustrations of working with planners and LACs who do not understand level of complexity
- Slow systems for plan reviews and crisis situations
- Volume of follow up and chasing up NDIA which is unfunded
- Cost of registration for some businesses (Third Party Verification)

Outcomes:

- Businesses leaving sector completely
- Businesses diversifying their income to take less NDIS funded clients
- Businesses holding off moving into the sector
- Businesses choosing to prefer referrals from people who are self-managing
- Reduced choice for participants
- Reduced capacity within the sector

Solutions:

- Dedicated specialist planners for this group
- A return to individualised funding rather than prescribed hours for service (often 10 hours)
- Stabilisation of policy
- Responsive plan reviews
- Refined admin processes
- Improved responsiveness of NDIA to enquiries

Providers unable to be sourced for people with complex issues

Caused by:

- Risks to staff and other residents – affecting providers own workforce capacity and possibly loss of income if other customers move on
- Perceived lack of funding to support person adequately – leading to Quality and Safeguarding issues
- Risks to property – further loss of income
- Risk to reputation – if situation becomes challenging, provider reputation is at risk
- Lack of resource for training, supervision and mentoring of staff

Outcomes:

- Person is homeless
- Person remains in custody
- Person remains in hospital
- Person is supported by less skilled workers
- Person experiences more restricted practices
- Person is unnecessarily medicated
- Providers unable to maintain their workforce

Solutions

- NDIA to purchase placements with a range of providers who agree to accept referrals of people with complex needs.
- Investment to these providers to upskill and support their workforce
- Adequate funding to be provided for the provider
- Comprehensive collaboration between all relevant agencies

Children and Young People

Early Childhood Early Intervention

- Currently, we are running a 'mixed model' as not all NSW services have transferred to the NDIS. This has led to difficulties for families trying to access ECEI. The tender for gateway closed recently, and the process needs to be resolved quickly to minimise impact on families and children.
- We need to re-instate ECEI as per Policy, noting its intent. There should be some flexibility in pricing so that children can be funded according to individual need, as needs in this cohort are highly disparate.
- We need to be mindful of the pressures brought on NGOs to change the way they operate to bring them into line with the requirements of the NDIS. The messaging of the peak appears to have been "Do what you've always done", but the NGOs will need more assistance than this.
- There is an issue of capacity across ECEI providers – quality of service is highly variable.

Actions – Look at practice standards; examine data relating to complaints and feedback; examine the NDIA's work across sectors; explore how the NDIA provides training and supervision around ECEI practice.

- Apparently, some have suggested access to ECEI for newborn babies. The feeling of this group was that in the first few months of life, the focus should be on the family accepting and adjusting to the diagnosis and supporting parents to form healthy attachments to their child. The family should be given the space to think 'baby first, disability second'.
- There may be a case for having an ECEI pathway for Aboriginal children beyond 6 years of age. This would need to be carefully considered alongside Ability Options and Land Council initiatives. It could be valuable if ECEI services worked with an older child and community where there were few or no alternate services on the ground in that area. This could provide a better cultural fit than seeking services some distance from home and community.

Transition to school planning

When planning a child's transition to school, there needs to be some moderation of expectations of the school system. Health, ECEI and the Department of Education need to work in partnership to ensure a 'wraparound' service that meets the child's needs but is viable for the school. Commonly, parents who have had extremely high levels of support for their child prior to school entry, eg access to 1:1 behavioural therapy, are disappointed and angry when the school cannot replicate similar levels of support. With strong contributions from all parties, goal setting and planning would be better informed and the family and service provider systems would move forward collaboratively.

Other important actions to make the NDIS and related service system work better

- Acknowledge the essential interface between family and service system.
- Ensure planning is undertaken collaboratively (and involves family, community and school).
- There must be a planning goal around going to school. If there is not a school-specific goal in the plan, it is likely that critical supports will not be available when required.
- Clarify roles and responsibilities between sectors, in particular clarify responsibilities for behaviour

support between the NDIS, out of home care and schools – Who should deliver it, who trains those responsible for implementation, what happens when best practice requires behaviour support is delivered across settings in a reliable and consistent way? Note that “Specialist support and training for school staff related to the specific personal support needs of a student with a disability, including specialised behaviour intervention and support” is a Responsibility of NDIS in the Principles to Determine the Responsibilities of the NDIS and Other Service Systems (COAG).

- In the context of NDIS planning, stakeholders must flag any knock-on needs relevant to school so that behaviour support requirements can be met in that context too.

Observation by group:

As a sector, we need to be thinking more collectively, not as specific states and territories. This would mean most agencies would have to adjust both thinking and operations. It is a responsibility of all of us, not just the NDIA, to think creatively about co-design and co-responsibility. We need to be funding conjoint work.

Justice interface

Problems

- Greater difficulty and delay in getting disability support services which are essential to put together a support plan to get a diversionary order from the court.
- Increased difficulty and delay in getting disability support when a person with cognitive disability has been charged with a crime has resulted in some people being unnecessarily remanded in custody.
- If person is in prison and does not have an NDIS plan or needs a plan review to set up an adequate disability support plan, there is no clear system to get this done quickly and the person can spend a long time in prison
- Many people with intellectual disability do not know they have a disability until they come into contact with the justice system.
- Most people we see in the criminal justice system with disability do not know about or understand NDIS. Some of these people have had services at some time in the past but are not at the same address and have not been contactable.
- Some people with complex needs are not taken up by services – the market is not responding to their needs.

Solutions

- An early intervention response to kids with challenging behaviour at school can minimise the escalation of offending and support needs. A pattern of school suspension in high school is a definite warning signal.
- ILC seems a very piecemeal approach at present. ILC could have an outreach approach to people with disability who are isolated and without personal support. These people need active assistance to understand, accept and apply for NDIS. Advocacy services such as the Intellectual Disability Rights Service provide this assistance to some people at present but a more systematic and statewide approach is needed.
- Key issue is that the services system including NDIA and providers must be able to identify crises and give priority and response to situations where delay will exacerbate the crises. The risk of going to prison due to lack of disability support should be recognized and responded to as a priority response situation with a clear pathway. This requires collaborative relationships between criminal justice workers, the NDIA and disability support providers.
- A clear pathway to enable people with disability to apply for NDIS and get a plan developed while they are still in prison. This means someone from NDIA coming into the prison to get things started.

- Recognise that people with intellectual disability, who are in contact with the justice system need significant hours of support co-ordination in their packages because it is almost a given that things will go wrong and they will need assistance to get things right again.
- Enhance skills in NDIA and support providers to understand challenging and offending behaviour and that the two are intertwined and impacted by disability. In NSW, a lot of gains have been made in this area over the past 20 years and must not be lost.
- Develop a strategy to develop workforce capacity to work with people with complex needs who are in the criminal justice system. This is the biggest challenge. If necessary, provide incentives for providers to deliver high quality services to this group.

For a thorough discussion of issues in the role of the NDIS for people with criminal justice system involvement see

- NSW CID (2014) Participants or Just Policed? -guide to the role of the NDIS with people with intellectual disability who have contact with the criminal justice system
www.nswcid.org.au/images/pdf/Participants_or_just_policed_614.pdf
- The submission of Australians for Disability Justice to the NDIS joint standing committee
www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions

Health interface

The group mapped its responses to a modified 3AQ (ie a 4AQ) accessibility framework in healthcare. This included consideration of:

1. Availability
2. Accessibility
3. Acceptability
4. Appropriateness
5. Quality

Availability

Problem – Poor availability of clinical health services for people with complex needs, and their limited interaction with NDIS supported services

Solution – Continue efforts to equip mainstream services, and develop more specialised intellectual disability health services.

Problem – Lack of uniformity about how health services at all levels interact with NDIS related supports.

Solution – Develop and test innovative service models, testing various ways in which multidisciplinary teams engage (virtually, and in real life) and the way in which they engage clinical staff within health

Problem – Concern over the loss of clinical health supports that historically were funded by ADHC

Solution – Being worked on by Premier and Cabinet and New South Wales Health.

Accessibility

Problem – Barriers to access health services are accentuated for people with complex support needs

Solutions – All generic health accessibility initiatives should also consider the complex needs space. Plus, specific initiatives are required around those with specific complex needs. There is a very big need for case

managers to work closely with health staff.

Acceptability

Problem – Inadequate inclusion of the voice of people with intellectual disability in the equipping of the health sector and its interactions with NDIS.

Solution – Increase the presence, visibility and voice of people with intellectual disability in peer support programs, joint interagency forums between Health and NDIS, and in developments in health service policy and service innovation

Appropriateness

Problems

- Lack of uniform understanding of trauma informed practices as they apply to both disability and health service provision
- Lack of ability of current frameworks to address the level of complexity experienced by some people
- Lack of KPIs which support interagency work
- Lack of specific focus or KPIs in relation to people with complex needs
- Lack of flexibility in NDIS funding arrangements so that they can be responsive to unstable or changing needs, where funds may need to be redeployed or more funds sought
- Lack of persistence in behaviour support, eg a thorough behaviour support plan may be developed but the implementation of the plan is not sustained beyond an initial period and the problems repeat themselves.

Solutions to these problems required major change in the way in which people with high complexity are funded and supported.

Quality

Problem – NDIS funding framework is not based on clear outcomes expectations. This can be a disincentive and may not encourage quality and improvement

Solution – Create a framework for monitoring impact of NDIS on the individual and those around them, and on related services sectors.

Problem – We don't easily identify people with intellectual disability (including those with complex support needs) in health care, and this makes it hard to provide reasonable adjustments

Solution – An intellectual disability flag, though this is acknowledged as being a potentially contentious issue

Problem – Lack of data on health, health outcomes and other outcomes for people with complex support needs

Solution – Data infrastructure that allows a better understanding of people with complex support needs and their health (and other service system) related interactions and needs. Make available the capacity to link data from the NDIS including basic information about participants and their packages to linkage agencies and researchers. Data can be used effectively to monitor impacts of enhancements in service provision eg specialised ADHC programs

Problem - Lack of shared understanding and definitions of complex needs between health and disability services; strong demarcations of what is and is not funded; fear that the historical siloing that had occurred

between disability and health services may be reinstated under the current funding and demarcation dispute. Solutions - Potential options for enhancing collaboration and interagency goodwill included: further development of interagency working groups at a local level; changing the way NDIS engages with clinical services in planning and funding decisions; providing the capacity for clinicians to interact with the NDIS system for example a web-based portal to input to NDIS participant planning; and generally developing a stronger consultation framework relating to NDIS plans, especially those around behaviour supports and where a person has a serious mental illness and is seeking funding for related supports.

Governance, Quality and Safeguarding

What are the most important issues to be addressed?

- Knowing the residual functions in relation to people with disability in NSW post June 2018.
- Clarifying the arrangements for authorisation and consent for restrictive practices in NSW post June 2018.
- Improving the quality and consistency of behaviour support.
- Improving the engagement and involvement of participants in their behaviour support and quality of service – availability and quality of decision supports.
- Getting a coordinated and comprehensive quality and safeguards framework in place to commence on 1 July 2018.
- Leadership across disciplines that are important in a collaborative approach to people with complex support needs (including speech pathology, physiotherapy and occupational therapy).

What are the most important actions to make the NDIS and related service systems work better?

- There are opportunities for cross-collaboration across regulators/oversight agencies, with the establishment of the NDIS Quality and Safeguards Commission and continued work of the NSW Ombudsman (re oversight of NSW public sector agencies) and Australian Ombudsman, etc. Collaboration will need to be supported by strong information sharing arrangements and collaborative work practices.
- Improving the quality and consistency of behaviour support – The intended role of the Senior Practitioner in the NDIS Quality and Safeguards Commission should assist with this (noting intended competency framework, approval of behaviour professionals, etc). However, behaviour support guidance and plans must be coupled with training and implementation support – there are questions about how providers will meet the costs of compliance (training, reporting, supervision).
- Ensuring informed consumers – Providing a greater focus on enabling participants to understand their behaviour and other supports and to feed back on the quality of their supports/services. Decision supports are critical for participants to be able to provide this input.
- Ensuring that there are strong and well-understood links across service systems for people with complex needs, and identified leads. The risk of shared responsibility is that no-one takes the lead. As Michael Sullivan noted, 'All needs to be connected, and with a focus on basic human rights'.
- Practice leadership across disciplines – the NDIS Senior Practitioner will provide the lead in relation to behaviour support, but better outcomes for individuals will occur where there is a collaborative and multidisciplinary approach to assessment and support. The need for a 'Centre of Excellence' has previously been argued – are there opportunities for the Senior Practitioner to provide the lead across practice areas that are more broadly relevant to behaviour support?
- Access to advocacy support for people with complex support needs, particularly in relation to mainstream services (including justice, health and education).

Appendix 2 – elements of good practice in behaviour support

- Person centred and goal-directed - The person is the driver of their own behaviour support and involved in all aspects where it is safe and they are able to do so; their personal goals underpin the professional direction; specific sub-goals related to behaviour support are articulated and agreed; the balance of “Important To” and “Important For” is skilfully considered in the approach.
- Outcome measurement framework/approach - Outcome measures are identified that are genuinely meaningful and valued by the person; additional quality of life measures are added; as well as measures that capture the outcomes for the support people and the broader system (eg. the organisation) to achieve sustainable change for the person.
- Holistic and integrated - Collaboration between the person, supports and all professionals result in one assessment process, one plan (or connected complementary plans), one implementation and review process
- Multidisciplinary supports are part of an overarching support plan - This usually requires highly skilled and intensive support coordination
- A systems approach: assessment and planning considers all aspects of the systems supporting and impacting on the person, informed by systems theory.
- Capacity to respond in crisis - This includes immediate strategy review, staff training, debriefing, professional input to medical reviews and crisis support model development/adaptation and more.
- Always based on assessment - A solid formulation is the key to understanding the person and their support needs and should underpin the behaviour support plan. For people with complex behaviour support needs, it is usually far more than a simple analysis of current presentation, but rather connects multiple aspects of the person’s past experiences and current circumstances to produce a hypothesis which informs all aspects of the plan.
- Assessment (and review) includes comprehensive medical review to identify any physical or mental health conditions that may be contributing to the behaviour.
- Always identify and address risks first - This aims to maximise people’s safety while the more comprehensive assessment process is undertaken.
- Appropriate selection of professional and support workers informed by experience required, professional governance structures (especially supervision), and analysis of past supports.
- Draws from multiple professional perspectives shared in team discussion together with the person and key support people.
- Evidence-based:
 - Sustainable in the system: embedded in a person’s support system
 - Trial and error review, refine, try again.
 - Acceptance that change may be slow and incremental.
 - Easy to understand: Simple but sophisticated
 - Intensive implementation support for informal and formal supports
 - Competency assessed training for behaviour support practitioners, support workers and implementers
 - Consistent across systems and settings

Appendix 3 – roundtable participants

Robyn Bale	Executive Director, Learning and Wellbeing	Department of Education NSW
Courtney Bellemore	Information and Inclusion Officer	CID
Amanda Brickwood	Regional Coordinator/NDIS Appeals Officer	Disability Advocacy NSW
David Briggs	Advocacy and Policy Officer	CID
Tracey Carroll	Branch Manager, Integration and Support	Department of Social Services
Maria Circuit	Parent advocate	
Melissa Clements	Director, Disability, Learning and Support	Department of Education NSW
Janene Cootes	Executive Officer	Intellectual Disability Rights Service
Belinda Epstein-Frisch	Advocate and consultant	
Steven Davison	Director, Social Policy Implementation	Ministry of Health NSW
Louise Farrell	Director, Priority Programs Unit, Social Policy Branch	Ministry of Health NSW
Cathy Fiden	Facilitator	CID
Stephanie Gunn	Deputy CEO	NDIA
Katrina Halpin	Portfolio Manager - Therapy & NMT Services	Sal Consulting
Judy Harper	Advocate and Board Member	CID
Michelle Henwood	A/Director Statewide Specialist Services	The Benevolent Society
Joanne Hewitt	Executive Director Disability	The Benevolent Society
Steve Kinmond	Disability Commissioner and Deputy Ombudsman NSW	Ombudsman NSW
Kathrina Lo	Deputy Secretary	Department of Justice NSW
Peta MacGillvray	Solicitor	Children's Civil Law Service, Legal Aid NSW
Ruth Marshall	Principal Psychologist	Juvenile Justice NSW, Department of Justice
Kathryn McKenzie	Director Disability	Ombudsman NSW
Paul Miller	Director, Quality and Safeguards Section	DSS
Sarah Morton	Director, Integrated Service Response	NSW Health
Helen Nugent AO	Chair	NDIA
Justine O'Neill	Acting Public Guardian	NSW Public Guardian
Con Papadopoulos	Director, Child Development Service	Royal North Shore Hospital and Neurodevelopmental and Behaviour Paediatrics Society of Australasia

Meg Parsons	A/Manager Technical Advisory & Complaints	NDIA
Vince Ponzio	Director of Mental Health, Children and Young People	Ministry of Health NSW
Tony Pooley	Senior Manager State Operations	National Disability Services
Caroline Reed	Executive Director NDIS Reform	Department of Premier and Cabinet NSW
Chantelle Robards	Consultant	CID
Diane Shaw	Parent advocate	
Jim Simpson	Senior Advocate	CID
Melinda Smith	Coordinator Cognitive Disability Services	Justice Health & Forensic Mental Health Network NSW
Philip Snoyman	Director Statewide Services OS&P	Corrective Services NSW
Rachel Spencer	Information and Inclusion Manager	CID
Michael Sullivan	Vice Chairperson	CID
Samantha Taylor	Executive Director, NDIS Implementation	Department of Family and Community Services NSW
Julian Trollor	Director, Department of Developmental Disability Neuropsychiatry	UNSW
John Walsh AM	Board Member	NDIA
Leslie Watson	Portfolio Manager -Clinical Practice	Sal Consulting
Amanda Wood	Principal Psychologist	Real Therapy Solutions
Tracy Wright	CEO	CID
Wayne Zahra	Life Style Mentoring Services Manager	Disability Services Australia