



**Family &
Community Services**
Ageing, Disability & Home Care

Leading Clinical Practice and Supporting Individuals with Complex Support Needs in an NDIS Environment

Options and considerations for New South Wales

Department of Family and Community Services –
Ageing, Disability and Homecare

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Contents

Page

1. Leading Clinical Practice and Supporting Individuals with Complex Support Needs in an NDIS Environment	2
2. Supporting individuals with complex needs under the NDIS	3
3. Key features of a best practice model in the NDIS environment	4
4. Key features of the NDIS approach – individual-level	5
4.1 Key feature of the NDIS approach (individual-level) – assessment	6
4.2 Key of the NDIS approach (individual-level) - planning	7
4.3 Key of the NDIS approach (individual-level) - support provision and plan management	8
4.4 Key of the NDIS approach (individual-level) - monitoring and review	10
5. Key of the NDIS approach – sector level	11
5.1 Key of the NDIS approach (sector level) – clinical consultant and tertiary advice and support	12
5.2 Key of the NDIS approach (sector level) – practitioner and sector capability development	14
6. Key features of the NDIS approach – system level	15
6.1 Key features of the NDIS approach (system level) – practice leadership and guidance, and research and practice development	16
6.2 Key features of the NDIS approach (system level) – clinical governance and regulation	17
7. Looking forward – developing a national clinical governance framework	18
8. Options for transitioning services	20
9. NSW CIG and discussions with the NDIS and the NDIA	21
Appendix A: Key stakeholders consulted	22
Appendix B: Understanding the target group	23
Appendix C: Supporting individuals with complex needs under the NDIS	25
Appendix D: Principles of supporting individuals with complex support needs	26
Appendix E: Key features of the NDIS approach for supporting individuals with complex support needs	27
Appendix F: Productivity commission perspectives	28
Appendix G: Contemporary supports for individuals with complex needs	29
Appendix H: References	30

1. Leading Clinical Practice and Supporting Individuals with Complex Support Needs in an NDIS Environment

Introduction

The Clinical Innovation and Governance (CIG) Directorate was requested by the ADHC Executive to explore the various functions that would be required in a new National Disability Insurance Scheme (NDIS) environment to ensure the establishment and continuity of best practice functions for individuals in NSW with complex support needs.

CIG is a leader in policy and practice across a number of specialist disciplines. The majority of the directorates' work aims to improve service and support responses that are available to individuals accessing disability supports, including those with highly complex support needs.

The implications of the move to the NDIS on the Department of Ageing, Disability and Home Care (ADHC) are substantial. As per the Heads of Agreement, there will be no disability services provided or funded by the NSW government. This paper provides an important opportunity to instigate discussion on key measures that should be built into the future disability support system for individuals with complex support needs. As well as the practice leadership and professional support that is required to enable practitioners to appropriately meet the needs of individuals.

Key functions such as

- Policy development
- Practice leadership
- Research
- Tertiary clinical support and consultation
- Capability and workforce development
- Safeguarding
- Outcomes, evaluation and Key Performance Indicators

Scope of Paper

This is a revised version of a paper developed in collaboration with KPMG and CIG that was presented to the ADHC Executive on 23 November 2013. This paper is based on consultations with key stakeholders and explores an approach for supporting individuals with complex support needs within the future NDIS.

Report structure

Rather than replicate existing systems and functions, this paper adopts a "blue sky" approach that is, a model of the best practice functions that would operate in an ideal world. Accordingly the paper is structured to draw on recommendations which capture and are reflective of a contemporary environment, lessons learnt from the productivity commission report, key papers and stakeholder engagement.

2. Supporting individuals with complex needs under the NDIS

The NDIS has commenced in five launch sites, and will progressively be rolled out nationwide over the period to 2018. A substantial amount of design and development work has already occurred to establish the NDIS and to provide the rules and guidelines which will govern its operations. Despite this there continue to be significant 'unknowns' such as: how individuals with complex support needs will be supported in each of the key stages of the NDIS client pathway and consideration of the system features and functions that need to be in place to ensure that the system is able to effectively respond to the needs of individuals with complex support needs.

Over the past twelve months there has been an increasing focus on groups of individuals with complex needs, with a number of papers developed to contribute to the discussion.

- Intellectual disability and people in contact with the criminal justice system (NSW CID, 2013)
- Healthcare of people with an intellectual disability (NSW Health, 2012)
- Provision of multiple and complex health needs for people with an intellectual disability (ADHC, 2013)
- Intellectual Disability and mental health (Mental Health Council of Australia, 2013)

Each paper highlights the challenges within the existing design for people with complex needs. The overarching themes of concern and the proposed solutions are consistent with the those core elements articulated by the United Nations (2013) and the Productivity Commission Report (2011). Broadly these include

- recognition that the needs of complex clients will not be adequately addressed through a generic pathway.
- that there is a need for a tiered approach to service delivery which addresses the needs of people with complex needs, which includes specialist services and a governance framework
- that agencies need to collaborate
- that a skilled workforce, using best practice is required for implementation

The implications for the NSW Government (ADHC) for the move to NDIS are therefore substantial. There is a need for a cultural recasting of the current siloed service provision across all agencies at a state and national level. As part of the transition ADHC is examining its role in direct service delivery, and considering how its role in areas such as policy and program management, sector development and support functions can be transitioned from a state-based disability service system to the NDIS.

The purpose of this paper is:

1. to provide an overview of the additional features and functions which should be in place to effectively support individuals with complex support needs – based on evidence of good practice and considering the underpinning principles for supporting individuals with complex support needs
2. to outline the key considerations *for the National Disability Insurance Agency (NDIA)* in further developing the NDIS approach with respect to individuals with complex support needs

Features and functions of the NDIS approach

An NDIS approach for supporting individuals with complex support needs is multi-faceted, and it is useful to think about the approach on three levels:

- i. At an *individual-level*, which relates the core features of the NDIS approach as they are applied to individuals with complex support needs
- ii. At a *sector (practitioner and organisation) level*, which relates to how the NDIS can support and facilitate the development of practitioners and organisations to effectively meet the needs of individuals with complex support needs
- iii. At the *system-level*, which relates to how the NDIS can provide the practice leadership, monitoring and oversight, and clinical governance and regulation for this cohort

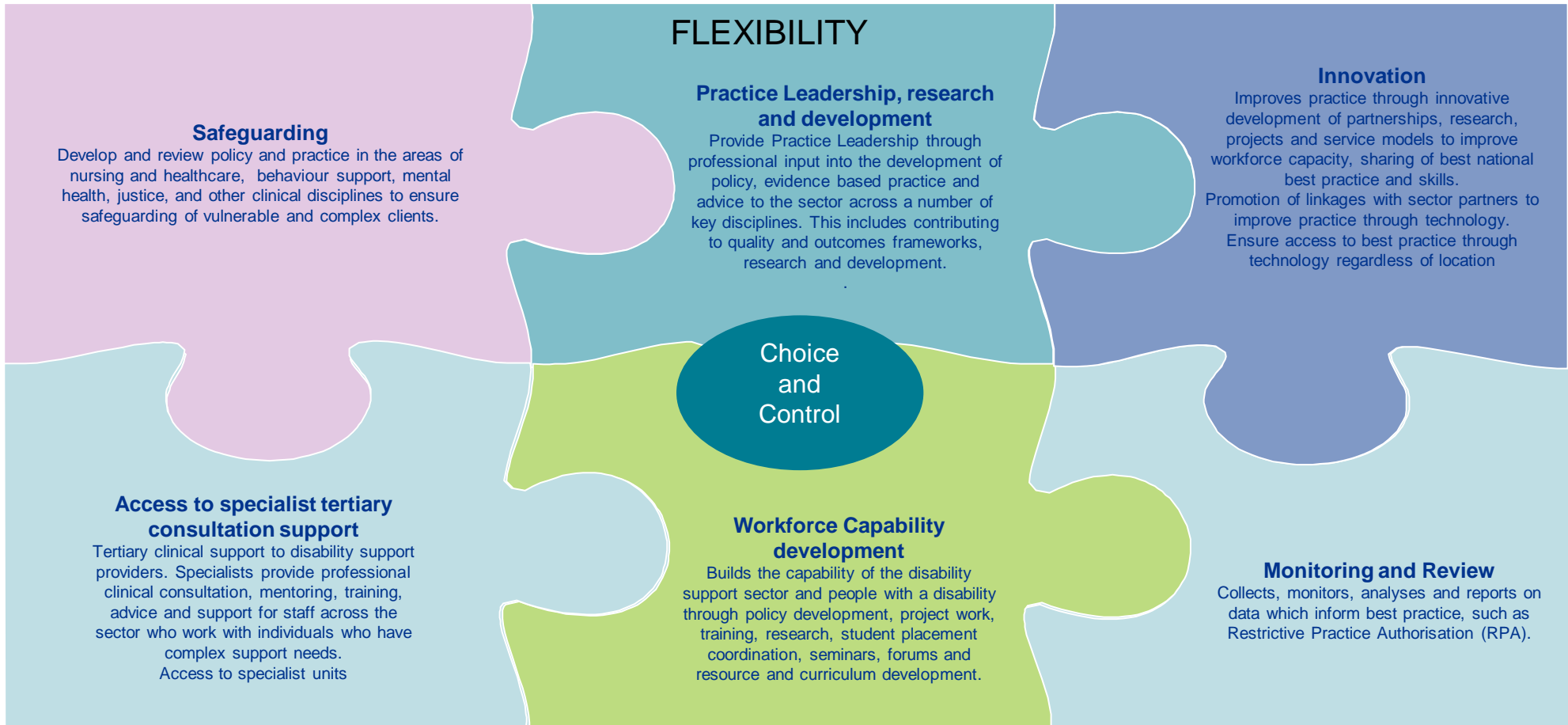
This paper has been prepared by Clinical Innovation and Governance (CIG) in collaboration with stakeholders and KPMG.

3. Key features of a best practice model in the NDIS environment

Overview of a best practice framework

There were six major functions identified, which form the core of good practice. These are described in Figure 2 and include: safeguarding, practice leadership, research and development, innovation, access to specialist tertiary consultation support, workforce capability development and monitoring and review. These features form core elements for state and national application

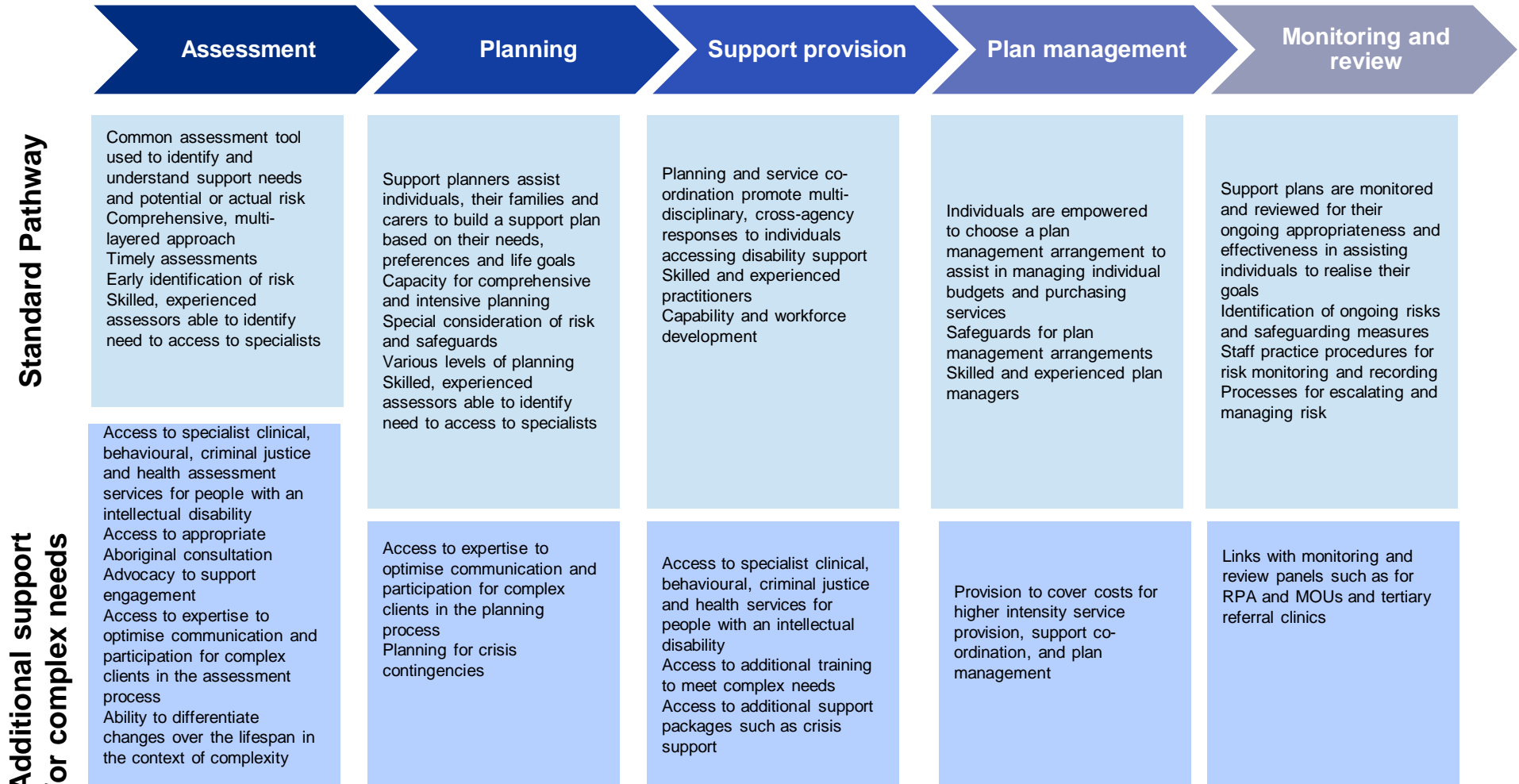
Figure 1: Functional overview of a best practice framework



4. Key features of the NDIS approach – individual-level

The next section outlines the key features and functions of the NDIS approach at the ‘individual level’. Diagram 1 below sets out a best practice NDIS client pathway and summarises specific considerations for supporting individuals with complex support needs. It is important to recognise that entry is likely to be on a standard pathway but at any point an individuals’ needs may necessitate them requiring additional support. Engagement and early identification are needed as well a system that is flexible and responsive.

Table 1: NDIS client pathway and key considerations for individuals with complex support needs



4.1 Key features of the NDIS approach (individual-level) – assessment



Features of the NDIS approach

The NDIS Operational Guidelines, and *Planning and Assessment Toolkit* outline the process and guidance for conducting the needs assessment and planning stages with individuals. The Guidelines and Toolkit will apply to all people who are deemed eligible for the NDIS, including individuals with complex support needs.

There are, however, some additional elements which should form part of the NDIS approach to needs assessment for individuals with complex support needs:

- recognition that some individuals may be reluctant to engage with the NDIS such as those from an Indigenous background or those who have been in contact with the criminal justice system. Consequently the approach to assisting them into the pathway may need to be different
- assessments should be a comprehensive, multi-layered and tiered
- given that many individuals with complex support needs have a multiplicity of needs it is important that assessment is conducted in an integrated, planned, and timely manner
- early identification and comprehensive assessment of need should be key components of the assessment function for individuals with complex support needs. A system which is reactive to risk alone will do little to build a resilient service.
- skills and capabilities of assessors who conduct assessments for individuals with complex support needs should be more advanced - assessors should have:
 - specialised skills and knowledge (for example, experience in working with augmented communication systems, complex behaviour intervention, mental health, knowledge of the criminal justice system and knowledge of specific therapeutic interventions which have good validity for individuals with a range of support needs)
 - Ability to differentiate changing needs over the lifespan in the context of complexity
 - experience in working with and conducting assessments with this cohort (and target groups – for example young people leaving care, people with mental

health issues or people at risk of or involved in the criminal justice system)

- access to specialists who can conduct additional assessments or provide input into the assessment process for an individual (eg clinical psychologists, psychiatrists, behaviour intervention specialists and other clinical professionals) . *It is noted that this has been incorporated into the NDIS operational guidelines.*
- Access to specialist units with residential assessment capability with expertise in intellectual disability.

Additional considerations for the NDIA

Where should this function be placed?

- The assessment function has been identified as a core function of the NDIS, with assessors either being employed or contracted by the NDIA.
- It will be important to employ and/or contract assessors with the experience, skills and capabilities to conduct assessments with individuals who have complex support needs. It will also be important for the NDIA to consider how and where it will source specialised input into the assessment process for individuals with complex support needs. Specialist units could be collocated in existing service models such as health
- Considering the complexities involved in delivering comprehensive assessments for this group, there will need to be flexibility built into the time-limits for completion of assessments.

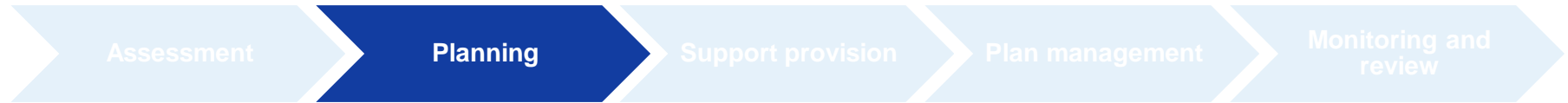
How should it be funded?

- Given this is a core function of the NDIA, assessment should be funded through the NDIA operational budgets. Specialist assessments should also be funded by the NDIA directly, with payments for each individual assessment.

Other considerations

- It will be important for the NDIA to work with jurisdictions during the transition stage to harness the skills, capabilities and experience of skilled assessors which already exist within jurisdictional service systems.

4.2 Key features of the NDIS approach (individual-level) – planning



Features of the NDIS approach

As previously noted, the NDIS Operational Guidelines, and *Planning and Assessment Toolkit* outline the process and guidance for conducting the needs assessment and planning stages with individuals. Using the outcomes of the assessment and in consultation with the individual, a plan that reflects the goals and aspirations of the person will be developed by the planner who assists the person to make choices and decisions about the supports they will require.

Some additional elements that should form part of the NDIS approach to planning for individuals with complex support needs include:

- communication support where required to enable the individual to participate as fully as possible in the planning process
- recognition that the planning process will be more intensive than planning for other groups – it will involve multiple conversations with an individual and their family, carers or others in their support network, and liaising with other practitioners and clinicians who may already be involved in a person's life
- consideration of risks and safeguards incorporating empowerment and risk enablement strategies in individuals' support plans, including contingencies for crisis management
- allowing for different levels of planning, including planning with the person (and the development of a single plan), as well as the development of specific strategies and behaviour support plans
- recognition that planners need to have more advanced skills, knowledge and experience in working with individuals who have complex support needs
- ensuring planners have timely access to specialists who can provide input into a person's plan as needed

Additional considerations for the NDIA

Where should this function be placed?

- The planning function has been identified as a core function of the NDIS, with planners being employed by the NDIA.
- It will be important to employ planners that have experience, skills and capabilities to work with individuals with complex support needs, and to recognise their skills and experience through more senior grading structures. It will also be important for the NDIA to consider how and where it will source timely specialised input into the planning process for individuals with complex support needs.

How should it be funded?

- Given this is a core function of the NDIS it should be funded through NDIA operational budgets. Access to specialist input should also be funded by the NDIA directly, with payments on a per-episode basis.

Other considerations

- Continuity of contact with the NDIA is an important consideration for this group, ideally minimising the number of practitioners a person has to work with during the assessment and planning phases, and potentially having a single assessor/planner.
- It will be important for the NDIA to work with jurisdictions during the transition stage to harness the skills, capabilities and experience of planners who work with this cohort group within jurisdictional service systems.
- Invest in market development – NDIA to collaborate with ADHC during transition planning on a market strategy to recruit and employ skilled planners and determine how to ensure that access to specialists is built into the future planning function

4.3 Key features of the NDIS approach (individual-level) – support provision and plan management



Features of the NDIS approach

Individuals with complex support needs typically have a breadth and depth of need that requires multifaceted and complex responses from a number of practitioners, agencies and sectors. Integration and coordination of supports by the various providers and agencies outside the formal disability service system is also critical. Joint support should be provided in a positive, person centred way and seek to ensure that the experience for the individual is as coordinated as possible, enabling the individual to exercise choice and control over how support is provided.

Multi-disciplinary and trans-disciplinary approaches and cross-agency collaboration are key areas of focus for integrated support provision. NDIS approaches to planning and service coordination, as well as funding mechanisms for supports, need to facilitate:

- Trans-disciplinary practice – encompassing the sharing of roles across disciplinary boundaries so that communication, interaction, and cooperation are maximised among practitioners.
- Multidisciplinary approaches - involving practitioners from different backgrounds and disciplines working together collaboratively and in a coordinated way, while each staff member remains within the boundaries defined by their discipline or professional background.
- Multi-agency collaboration - involving practitioners from different agencies working together effectively so that they can share information and knowledge, participate in joint planning and delivery of support services and to adapt service provision for these individuals

Providers also need to be able to access specialist (tertiary-level) advice, input and resources to enable them to effectively support individuals with complex support needs, particularly where there are significant risks to the person or service provider. The level of skill and expertise in this area has developed over time and has resulted in units such as the Clinical Innovation and Governance Directorate (NSW) and similar units, such as the Office of the Senior Practitioner (Victoria), in other jurisdictions.

Additional considerations for the NDIS

Where should this function be placed?

- There is no expectation that the NDIA will be a provider of supports or have a role in coordinating supports or managing a person's plan. This will be the role of the sector (or 'market').
- There is some question about the appetite, willingness and capability of the market to play a significant role in supporting individuals with some of the most complex support needs, and this was noted in the Productivity Commission's report. While a market can develop and be supported to develop, the Productivity Commission raised the possibility of the need for a 'safety net' function or 'provider of last resort'. The idea of a safety net function should be considered, though the function does not need to be undertaken by the NDIA – it can, for example, be undertaken by a number of providers separately and specifically funded to take on this safety net role and could build on existing services such as in the justice or health systems.
- Given the intensity of the plan management and coordination function for individuals with complex support needs, this function may need to be undertaken by the NDIA, and potentially linked with the planning function to ensure continuity of contact with a single plan/coordinator.
- Sustained and skilled workforce development and training is critical to the successful delivery of these functions and consistency of the interventions. Training to be reflective of current research and best practice in close partnership between training organisations and the sector. Specialist units could serve dual purpose of providing expert advice and training.

How should they be funded?

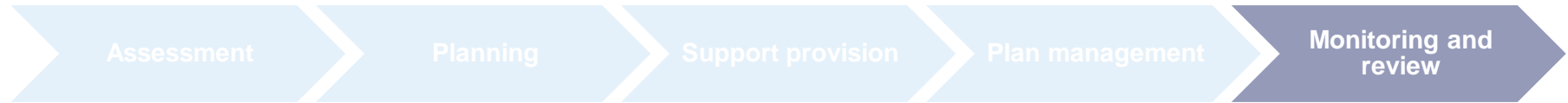
1. Most supports for individuals with complex needs can be funded on an individual basis (that is, from a person's funding package), to enable choice and flexibility. It will be important that specific support needs are considered in the planning phase and an allocation for these supports is built into an individual's funding package.
2. There may be some very targeted or specialised supports which could be block-funded to ensure that there is sufficient capacity in the market to respond to needs as they arise.

4.3 Key features of the NDIS approach (individual-level) – support provision and plan management (continued)



3. Explicit recognition of the higher intensity and cost of support coordination and plan management for individuals with complex support needs – both in the development of an individual's funding package, and the fee/price schedules for providers. It is critically important that fees/prices are realistic so that provider revenues adequately cover their costs of providing support – particularly in a market where few providers are willing or have the capability to support individuals with complex needs.
4. Additional support for providers who support individuals with complex support needs to ensure that they have the critical infrastructure and staff skills and capabilities required, and potentially to provide an 'additional incentive' for providers to provide supports to individuals who have more complex needs.
5. It should also be recognised that the willingness and capability of the market to take on additional service delivery roles for this cohort group is likely to be limited at this stage, and there is a real risk that transition of these services and functions to the non-government sector will not be fully successful. Explore options for the funding of other state government agencies to assume responsibility for direct services, such as Mental Health. Transition will require capacity building and willingness of services to take on these functions and in delivering effective responses for this group

4.4 Key features of the NDIS approach (individual-level) – monitoring and review



Features of the NDIS approach

Monitoring and review of a person's plan needs to occur on an ongoing basis. The plan manager will need to consider the appropriateness of support and ensure it continues to be relevant and provide benefit to the individual in meeting their support needs, goals and aspirations. Most importantly the review and monitoring process should assess the effectiveness of the services being provided in achieving the stated aims and supporting the individual with a disability to achieve their goals. Plans should be monitored to ensure they are consistent with current best practice. Where there are issues identified the plan should be revised.

For individuals with complex support needs, the ongoing monitoring of risk will be required. This includes how changing circumstances or behaviours are impacting on an individual or their family, carers, and those in their support network. For the NDIS there should be agreed processes for:

- regular review of support provision
- identification of ongoing risks and safeguarding measures
- staff practice procedures for risk monitoring and recording
- processes for escalating and managing risk.
- managing changes over the lifespan
- evaluating outcomes for the individual

For individuals with complex support needs a formal review and comprehensive reassessment should occur regularly (based on an agreed cycle identified during the assessment and planning stages and/or based on identified 'trigger points'), and may also involve a formal reassessment of risk. There should also be processes for acknowledging when more frequent reviews should take place in certain circumstances and, again there needs to be clarity for NDIS support planners and plan managers on the frequency and trigger points for a review of a person's plan and support arrangements.

It will be important that the monitoring and review process utilises external input where needed– for example in the form of regional specialist review panels of

practitioners/clinicians – to provide input and advice to the NDIA in the monitoring and formal review of a person's support plan and support arrangements.

Additional considerations for the NDIA

Where should this function be placed?

There is no detail provided in the NDIS operational guidelines relating to monitoring and review. It is assumed that plan managers as well as the NDIA (support planners) will have a role in monitoring and review of a person's plan and support arrangements. Given the complexity and intensity of support and coordination for this cohort, and the risks that may be present, it is suggested that the monitoring and review function sit with the NDIA for this cohort group.

How should it be funded?

There should be a specific component of a person's funding package (or plan management allocation) relating to monitoring and review, and for individuals with complex support needs this allocation should reflect the additional frequency and intensity of this function.

Other monitoring and review structures, such as specialist regional/local review panels, should be funded separately by the NDIA. Client monitoring and review systems can be used to illustrate the value and benefits of having an intensive and coordinated approach to monitoring and review for individuals with complex support needs. Considering the complexity and intensity of support and co-ordination for this cohort the NDIA should assume responsibility for the monitoring and review of support plans for this cohort. Experience can be drawn from the UK's 'Risk Enablement Panels', to establish 'risk panels', where specialist are convened to develop, review and monitor support plans and safeguards for individuals who are at high risk of harm to themselves or others.

5. Key features of the NDIS approach – sector-level

The next section outlines key features and functions of the NDIS approach at the 'sector-level'. Diagram 2 below summarises *tertiary clinical* support and *capability development*, along with special considerations for supporting individuals with complex support needs.

Table 2: 'Sector-level' features of the NDIS approach and key considerations for individuals with complex support needs



5.1 Key features of the NDIS approach (sector-level) – clinical consultation and tertiary advice and support

Tertiary clinical consultation, advice and support

Practitioner and sector capability development

Features of the NDIS approach

The NDIS operational guidelines have focussed on individual-level components of the NDIS. There has been little focus to date on aspects of the NDIS approach relating to tertiary-level clinical consultation, advice and support for practitioners and organisations working with individuals who are most at risk or whose support needs are highly complex. This is a critical component of the future disability support system (and any contemporary disability support system).

Features of tertiary-level clinical consultation, advice and support function that should be considered for the future NDIS service system include:

- An ability for practitioners working with an individual with complex support needs to be able to access specialist advice and external input into the design and delivery of specific aspects of a person's support arrangements, typically where there are challenges and risks.
- Availability of one-on-one professional supervision and mentoring for practitioners to develop their skills and capabilities to work with an individual with complex support needs (again focussing on specific aspects of a person's support arrangements).
- Tertiary-level clinical consultation, advice and support needs to complement and contribute to the development or delivery of effective service responses. There should be a focus on practitioner-to-practitioner interaction.

Further, tertiary-level clinical consultation, advice and support is intrinsically linked to and builds on other functions, including practitioner and sector development, practice development and research and practice leadership functions, with each function contributing to the effectiveness of the others.

Additional considerations for the NDIA

Where should this function be placed?

There is some potential for the market to provide tertiary-level consultation, advice and support. There are some examples of private sector providers of tertiary-level clinical consultation. In order for the market to take on a much more significant role extensive market development and support is required over time.

As noted above, there is also some value in linking tertiary-level consultation capacity with practice development and research and practice leadership functions. This could be achieved through a 'centre of excellence' or a 'hub-and-spoke' approach where:

- Centre(s) of excellence or 'hubs' could provide practice leadership and coordinate research and practice development activities in a particular area of practice, such as intellectual disability and mental health, behaviour support. Centres/hubs could be placed in a university (and for NSW could potentially build on existing University Chairs).
- A network of specialist practitioners could be established across the country who are closely aligned or connected with the centre/hub, and who will provide tertiary-level clinical consultation, advice and support in their areas of specialty/area of practice. Specialist practitioners could be employed by the centre, and/or be employed by disability provider organisations ('the market') which have been specifically funded for the role. (It could be more efficient for specialists to be funded directly by the NDIA and this would ensure standards and priorities are established).

How should they be funded?

- While tertiary-level consultation typically relates to an individual's support arrangements, it may be unwise to fund this function through individual funding package arrangements. To do so may create a barrier or disincentive for practitioners accessing tertiary-level consultation or advice, particularly where an individual does not agree or where the cost is substantial and as a consequence impacts on the level of other supports that can be provided.

5.1 Key features of the NDIS approach (sector-level) – clinical consultation and tertiary advice and support (continued)

Tertiary clinical consultation, advice and support

Practitioner and sector capability development

- A more sensible funding mechanism may be for the NDIA to fund tertiary-level consultation on a traditional block-funded basis. Block-funding (and sufficient levels of funding) is also likely to improve the level of interest in the market for providing this function.

As noted above, there are two broad options for the NDIS relating to the clinical consultation and support function: move to a centre of excellence or hub-and-spoke model (with universities, linked with practice leadership, practice development and research), or transition of this function to the sector.

- Establish centre(s) of excellence or 'hubs' which have regional capacity to deliver and contribute to tertiary clinical consultation, capability development, practice leadership, research and practice development. NDIA could build on existing work with universities and learning from the SBIS and the Queensland Centre of Excellence model. This could be a quasigovernmental service where services are paid for by the NDIA.
- NDIA and CIG work together to establish a network of multidisciplinary specialists, which is linked to the centre/hub, and can provide tertiary clinical consultation in local jurisdictions. This option was recently discussed at the National Roundtable on the Mental Health of People with Intellectual Disability.
- Establish a national network of specialists whose tertiary services can be purchased by the NDIA in regional locations as needed, particularly when existing arrangements are at high risk of breaking down.
- Invest in further developing the existing market and develop an appropriate funding mechanism ('fee for service' or block-funding through a competitive tender) and quality framework for these services.
- Develop a consortia of leading non-government agencies who have state-wide coverage and capacity to provide regional tertiary responses as needed.

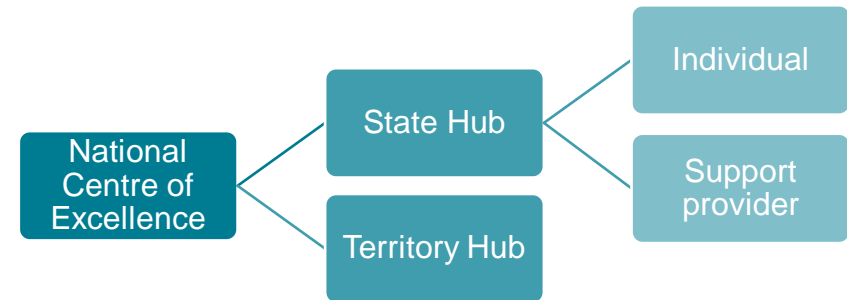


Figure 2: Centre of Excellence – hub and spoke model of tertiary service provision

5.2 Key features of the NDIS approach (sector-level) – practitioner and sector capability development

Tertiary clinical consultation, advice and support

Practitioner and sector capability development

Features of the NDIS approach

Complementing tertiary-level consultation and support is a focus on developing the practitioner workforce more broadly to support individuals with complex support needs, and developing the sector that will support this cohort group. This includes:

- Providing input into ongoing specialised learning and development opportunities and formal education and professional supervision for practitioners
- Promoting best practice through delivering formal education and other learning and development opportunities
- Supporting and providing opportunities for on-the-job training and development with senior-level practitioners and experienced providers for new graduates and less-experienced practitioners, and facilitating (and funding) student placements
- Supporting providers to maintain and grow practitioner capacity and capability to support individuals with complex support needs

Considerations for the NDIA

Where should this sit and how should it be funded?

- Coordinating and leading the development of the practitioner workforce and the sector to support individuals with complex support needs (and developing the workforce and sector more broadly) is a core function that should be funded and led by the NDIA.
- It needs to be recognised that practitioner and sector development relies on strong partnerships and networks with formal education providers (universities), professional associations, private training providers, and with support providers who will need to provide the opportunities for on-the-job training (for students and new graduates).

Other considerations

- As well as coordinating student and graduate placement programs, Government has traditionally *provided* student placements and opportunities for new graduates to develop skills in supporting individuals with a disability in a real-world environment. With the move away from government service provision towards provision of supports by the sector, these opportunities are diminished. It will be important for the NDIA to consider how it can create the right incentives (financial and other) for non-government providers to provide student and graduate opportunities

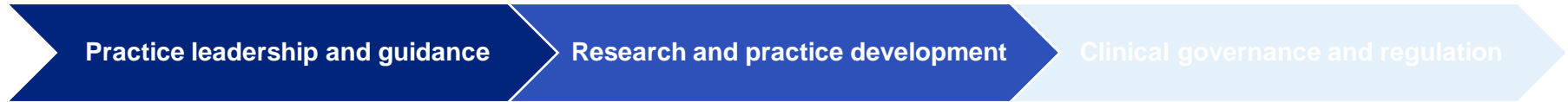
6. Key features of the NDIS approach – system-level

The next section outlines key features and functions of the NDIS approach at the 'system-level'. Table 3 summarises *practice leadership, research and practice development* and *clinical governance*, all people with a disability should have access to the following best practice framework

Table 3: 'System-level' features of the NDIS approach



6.1 Key features of the NDIS approach (system-level) – practice leadership and guidance, and research and practice development



Features of the NDIS approach

In any disability service system there needs to be clear and evidence-based direction, guidance and leadership provided to practitioners to promote good practice and continuous improvement in practice.

It will be important that the following features are incorporated into the NDIS approach:

- Strategic advice, input and guidance from recognised practice leaders to inform policy development and to provide guidelines (such as core standards) and resource materials for practitioners to implement best practice
- Contributions and support to conduct research into effective disability support models, support practices and safeguarding mechanisms
- Evaluating system outcomes through collecting, monitoring and evaluating administrative data
- Foster innovation and best practice dissemination and development across the disability sector
- Effective practice leadership provided by practitioners who have maintained a level of clinical work, or provided by a team/unit with direct clinical responsibilities

Considerations for the NDIA

Where should these functions sit?

As noted earlier in this report, there is value in linking tertiary-level consultation capacity with practice development and research and practice leadership functions – potentially through a ‘centre of excellence’ or a ‘hub-and-spoke’ approach where:

- Centre(s) of excellence or ‘hubs’ provide the practice leadership and coordinate research and practice development activities in a particular area of practice

- A network of specialist practitioners is established across the country who are closely aligned or connected with the centre/hub, and which provide tertiary-level clinical consultation, advice and support in their areas of specialty/area of practice.

An alternative approach would be for the practice leadership function and coordination of research and practice development activities to sit firmly within government (the NDIA), with links to universities and research centres as is the case currently.

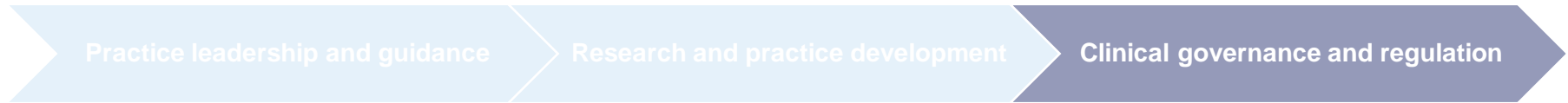
How should they be funded?

Funding for these functions should come from NDIA operational budgets, and/or through specific NDIA budget line items where funding is allocated directly to centres/hubs if this option was considered feasible.

There is a significant opportunity for NSW along with counterparts in other jurisdictions and the NDIA, to lead or contribute to the development of the ‘practice leadership and guidance’ and ‘research and practice development’ functions.

A key facilitator of practice leadership, practice development role and research is provided by the two University Chairs recently established in NSW. The ability to continue to contribute will be dependent on recurrent funding.

6.2 Key features of the NDIS approach (system-level) – clinical governance and regulation



Features of the NDIS approach

In any disability service system there needs to be a clear clinical governance and monitoring framework and regulation in order to:

- ensure high standards of support provision, promote continuous practice improvement, and create and maintain an environment that supports clinical excellence
- provide an environment which upholds the rights and dignity of people with a disability
- administer specific regulatory and legislative requirements (particularly in relation to restrictive practices) which may risk impinging on the rights and dignity of people with a disability
- provide oversight of quality assurance frameworks including registration/accreditation/practice standards, complaints mechanisms, and grievance procedures
- facilitate a safeguarding approach that embody 'risk enablement' and 'empowerment' principles in planning and support provision
- monitor the professional development and skill requirements of the disability sector workforce.
- work with the sector to continue to build a skilled workforce
- work with the professional associations to promote self regulation of best practice standards
- work with training organisations to embed a culture which promotes best practice and clinical excellence

This applies to all people with a disability, not only those with complex support needs, though is particularly important for this cohort.

Each jurisdiction currently has their own clinical governance framework and approach to regulation and monitoring, as well as a different legislative bases for these governance practices. A clear and consistent framework is necessary, however, NDIA should take into account these contextual differences and ensure the future framework aligns with a contemporary, person-centred approach to disability support.

Considerations for the NDIS

Where should this function be placed and how should it be funded?

- This is a core function of the NDIS, and as such should be funded through the NDIA operational budget.

Other considerations

- The extent to which the NDIS can be consistently applied across jurisdictions needs to be further examined in light of the different legislative and regulatory bases, as well as the degree of consistency which is desirable across jurisdictions. The NDIA will also need to determine what role states and territories will play in clinical governance and regulation moving forward.

There is a significant opportunity for NSW, along with counterparts in other jurisdictions to lead or contribute to the development of a clinical governance framework for the NDIS, building on the extensive experience, skills and knowledge which exists within CIG.

7. Looking forward. Developing a national clinical and governance framework

National Clinical and Governance Framework

Given that the NDIS will move from a state-based to a national disability support system, there is an important opportunity to explore a model for delivery of clinical innovation and governance services and supports in the future.

This report acknowledges that in conjunction with direct service provision to individuals, there are a range of functions that are essential to ensuring that people are effectively supported in the future service environment, including:

- Tertiary clinical consultation, advice and support
- Practitioner and sector capability development
- Practice leadership and guidance
- Research and practice development
- Clinical governance and regulation

Currently these functions are being delivered in a diverse range of ways across jurisdictions. Considering the move to a national disability support system, it is an opportune time to explore how these functions could be delivered within a national framework.

Considerations for the NDIA

Clinical Innovation and Governance (ADHC) in NSW currently plays a critical role in protecting the rights and safety of individuals accessing disability supports, as well as promoting good practice and continuous quality improvement. The NDIA will replace existing disability support systems and should therefore be responsible for a national clinical innovation and governance framework that provides evidence-based direction, guidance and leadership for delivery of quality disability supports.

In developing a strategy for delivering clinical innovation and governance functions, the NDIA should consider:

- **Maximising and leveraging the experience, skills and knowledge of existing state-based clinical innovations and governance functions through**
 - retaining skilled specialist and practitioners
 - early collaboration on strategies for workforce expansion and development
 - joint development of a national clinical innovation and governance framework and structure.
- **Federal jurisdiction over clinical innovation and governance functions through a 'hub and spoke' model of service delivery to states and territories where:**
 - the NDIA establishes, governs and regulates policies and practices related to disability supports (i.e. restrictive practice authorisation)
 - a national 'centre of excellence' or 'hub' sits with and is funded by the NDIA and oversees the functions of tertiary clinical consultation, capability development, practice leadership and research and practice development, which are delivered through 'satellite' centres or hubs in each jurisdiction
 - existing clinical governance leads in each jurisdiction transition to become the 'satellite' centres or hubs under the new structure that deliver the functions listed above.

7. Looking forward. Developing a national clinical innovation and governance framework

Benefits and implications of a national structure

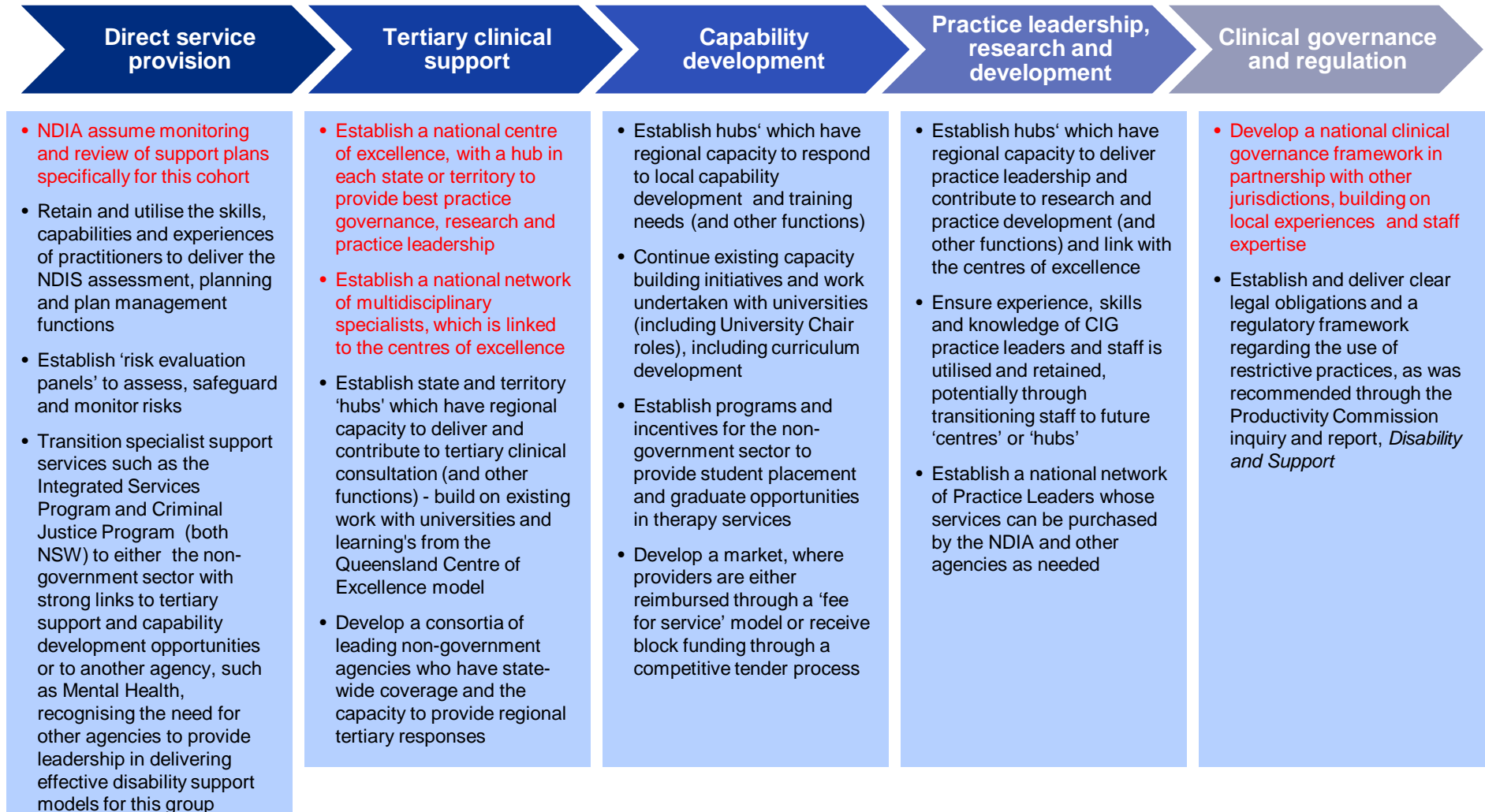
Moving toward a national structure for delivering clinical innovation and governance functions has a range of benefits for individuals accessing support, as well as for the service system as a whole. A national model will promote:

- **Consistency in quality and access** – a national framework aims to provide individuals (those residing in rural, remote or metropolitan areas) with equal access to supports that embody quality and best practice across the disability support system regardless of their location
- **Choice** – individuals' ability to move to a different state or locality will be enhanced under a national model, where the same level of clinical support should be delivered in all states and territories and where the same best practice principle can be expected
- **Effective safeguards and risk management** – protecting the rights and safety of individuals is a key concern and should be recognised as a national priority to ensure everyone has access to the same safeguards
- **Collaboration** – national connectivity should drive shared learning and development of a national 'community of practice' among leaders in clinical innovation and governance
- **Advancement in practice and research** – the skills and experiences of Australia's leading practitioners, peer-consultants, researchers, academics and key stakeholders will be leveraged to support the ongoing development of effective service models and interventions
- **Cost efficiencies** - leveraging the existing workforce and sharing resources across jurisdictions will strengthen capacity and should save on costs of training and capability development over the long term. Efficiency created by the reduced need to duplicate resources, procedures and overarching policies will allow more time for innovation .

8. Options for transitioning services

Table 4 summarises the options for transitioning current services and establishing clinical governance and innovation within the future configuration of disability support under the NDIS. Suggested NDIS (black) versus NDIA actions (red) are listed below

Table 4: Summary of options for transitioning services



9. NSW CIG and discussions with the NDIS and the NDIA

With the launch sites now established and roll out underway, it is timely to engage greater discussion about clinical service provision.

Under the suite of Stronger Together initiatives and now Ready Together, NSW demonstrated a vision and commitment to reforming the provision of disability service within NSW prior to NSW implementation. This forward thinking places it well ahead of other states whose thinking is still in its comparative infancy. The past few years of having to operationalise the reform agenda places CIG well to lead such discussions nationally.

Unlike agencies in other jurisdictions, CIGs' scope of operations and its practice leadership represent all major clinical/ allied health disciplines including behaviour support and the criminal justice system.

CIG has strong links with the University sector and has seeded two University Chairs in; Intellectual Disability and Mental Health and in Behaviour Support.

CIG has strong links in research, policy and governance and has invested in workforce development through its Student Unit.

By contrast, Queensland's quasi-government model is focused largely on behaviour support, as are Victoria and South Australia. The other states and territories are smaller concerns.

The NSW commitment to reform and the closure of large residential centres, provides an opportunity to

- Undertake an review of NDIS assessments completed on the client with complex needs at Stockton and map any gaps in assessment, planning or support with the view of developing case studies to assist in further discussions with the NDIS design team
- Monitor and review learning's from the transition of residents from Kanangra as a representative sample of people with complex needs with regard to community service provision

Based on these findings and concurrent to these projects CIG has initiated formal discussions with members of the NDIS design team to raise the profile of individuals with complex needs.

It is hoped that the next step in these discussions will enable a meeting with the NDIA with the recommendation being that CIG be endorsed to progress national discussions on the support needs of individuals with complex needs in the NDIS environment and to

- Undertake discussions regarding the development of centres of excellence or 'hubs' of expertise (liaising with other jurisdictions and the NDIA to ensure there is some coordination and no duplication)
- Undertake market development activities to ensure that the sector has the skills, capabilities, resources and infrastructure to take on this function, building on existing clinical consultation capacity that already exists

Appendix A: Key stakeholders consulted

Below is a list of the stakeholders who were consulted to support the development of this options paper.

List of key stakeholders consulted	
Stakeholder	Position
Anne Skordis	Executive Director, NDIS Design and Transition, Ageing Disability and Home Care, NSW Department of Family and Community Services
Craig Layton	Director, Stronger Together 2 , Program Management Office, Ageing Disability and Home Care, NSW Department of Family and Community Services
David Dossetor	Senior Staff Specialist, Director for Mental Health SCHN; Clinical Associate Professor, University of Sydney
Frank Lambrick	A/Senior Practitioner, Disability, Office of Professional Practice, Victoria Department of Human Services
Jacqui Astolfi	Director, Strategic Capability, Ageing Disability and Home Care, Department of Human Services, NSW Department of Family and Community Services
Jim Simpson	Jim Simpson, Senior Advocate, NSW Council for Intellectual Disability
Julian Troller	Chair, Intellectual Disability Mental Health; Head, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Medicine
Karen Nankervis	Professor and Director of the Centre of Excellence for Behaviour Support, University of Queensland; Adjunct Professor, RMIT University
Scott Holz	NSW State Manager, National Disability Services
Sebastian James	A/Deputy Regional Director Southern Region, Ageing Disability and Home Care, NSW Department of Family and Community Services
Vivienne Riches	Psychologist and Clinical Associate Professor, Sydney Medical School, The University of Sydney, Centre for Disability Studies

Appendix B: Understanding the target group

Understanding the target group

The purpose of this paper is to explore current and future functions that are needed to provide ongoing effective and quality disability support. A large focus of the paper is on the group of individuals accessing disability services who, in addition to having a disability, have complex support needs and who require responses that the service system is not always structured and able to provide.

It is therefore important to outline the characteristics of the target group and to identify the causes or factors which contribute to 'complexity', in order to have common terminology and definitions.

Factors which contribute to complexity of support need

Complexity of support need is not an issue in and of itself – it only becomes an issue when the formal service system is not able to adequately respond to or meet an individual's support needs. An individual may be seen as 'complex' or 'challenging' to the service system because the service system is not structured, organised, resourced or otherwise able to respond to their needs.

There are some common features or characteristics of individuals with complex support needs who do 'challenge' the service system. Rankin and Regan (2004) suggest that the complexity of support needs results from:

- a breadth (or range) of need – multiple factors (more than one) that are interrelated or interconnected
- depth of need – profound, severe, serious or intense needs.

For many individuals with complex support needs, their unique combination of personal characteristics and the circumstances in which they live interact in such a way that without timely and effective service responses they or others are at immediate risk, or may become at risk. However, services have often found this group difficult to define which has contributed to continual issues in providing optimal care and support for this cohort.

Common factors which contribute to complexity of support need (and which challenge the service system) are include in Table 1.

Table 5: Factors contributing to complexity of support need

Personal Factors	Situational Factors
<ul style="list-style-type: none"> • multiple disabilities • Profound/severe intellectual disability • dual diagnosis – intellectual disability and mental health concerns, including personality disorders • alcohol and/or drug issues • high medical needs or significant deteriorating health conditions (such as chronic respiratory disease or cancer) • behaviours involving harm to self or harm to others • experience of trauma or neglect 	<ul style="list-style-type: none"> • a lack of natural supports and support network • a breakdown in carer arrangements • Indigenous background • leaving statutory care • homelessness • involvement in or at risk of contact with the criminal justice or forensic system • youth disengagement from the education system • multiple agency involvement and difficulties accessing services in a coordinated way across a range of service systems • intensive resource and high cost care and support • history of inadequate, inappropriate and or misdirected therapeutic support

Appendix B: Understanding the target group

Defining 'individuals with complex support needs'

The following definition recognises the complex interplay between multiplicity of conditions and support needs, the degree of severity or impairment and the interrelationship between the individual's circumstances and their environmental or situational factors.

Within this paper, the terminology used when referring to the target group is: individuals with complex support needs, which is defined as individuals:

- who have a disability and are experiencing (or are at risk of experiencing) multiple and interrelated conditions or factors which contribute to an intensity of support need. Examples of these conditions or factors include: multiple disabilities, severe/profound intellectual disability, dual diagnosis, significant medical conditions or significant deteriorating health conditions, behaviours involving harm to self or harm to others, alcohol and/or drug issues, and issues relating to past experience of trauma or neglect

AND/OR

- who are experiencing (or are at risk of experiencing) one or more situational factors that impacts on the complexity of their support needs or the ability of their natural supports to meet their needs. Examples of situational factors include a lack of natural supports, family/carer stress, a breakdown in carer arrangements, young people who are leaving care, involvement in the criminal justice or forensic system, and multi-agency involvement in supporting an individual

AND

- who challenge the service system's capacity to respond to their support needs because of its structure, inability to work integrate across several agencies, organisation or resourcing, and or because of difficulties that the individual and service providers have in communicating with one another. Communication difficulties can result from language barriers or a lack of Alternative and Augmentative Communication methods as well as systemic barriers with sharing information across agencies.

It should be noted that the use of the term 'complex' in this report refers always to the nature of an individual's support needs, not to the individual themselves, and is not

intended to be used as a label for an individual (i.e. 'complex individual').

Defining 'challenging behaviours'

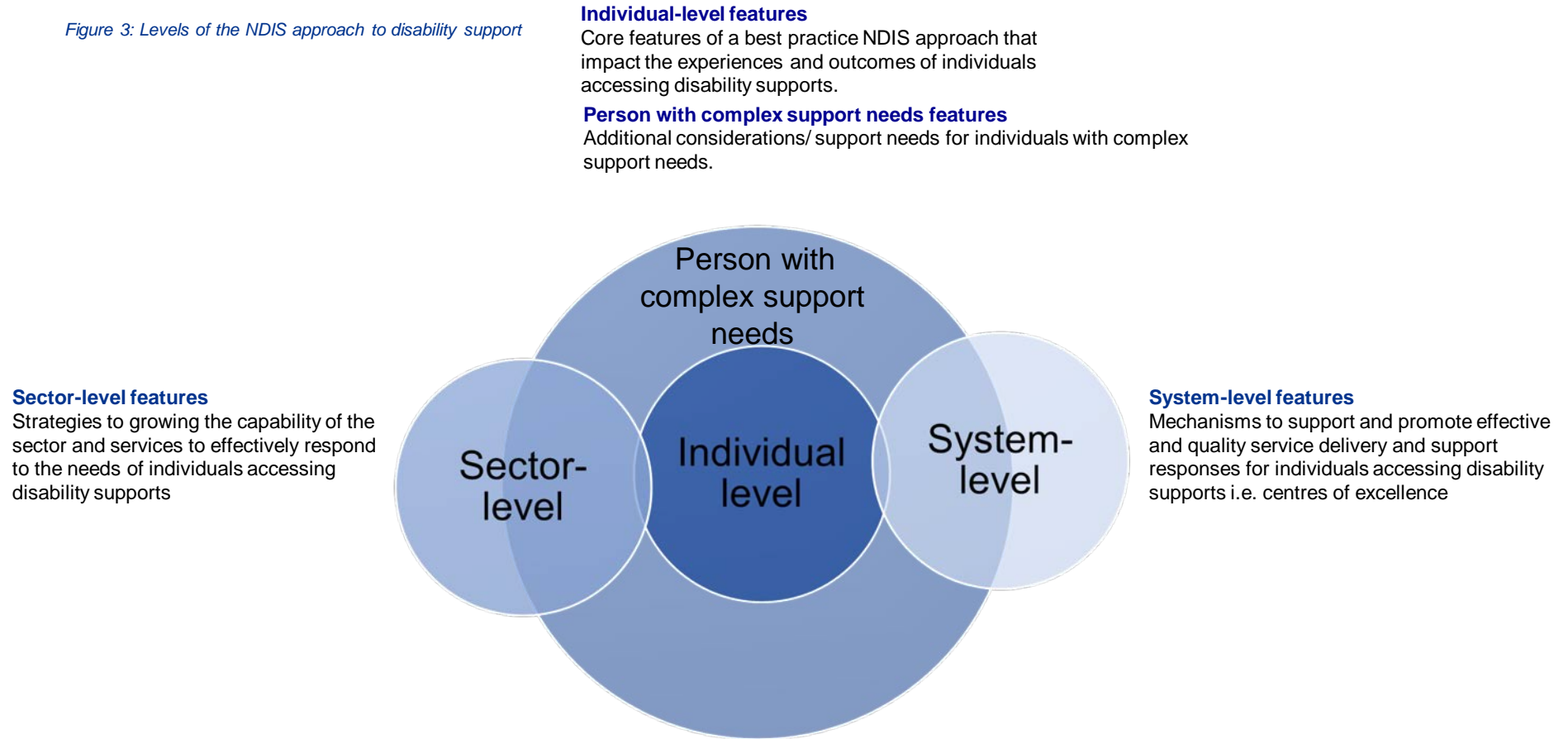
Some individuals who have complex support needs may also present to services with what have been termed as 'challenging behaviours'. For the purposes of this report the meaning of this term draws on the definitions described in the relevant literature which illustrates that behaviour is challenging when it threatens the quality of life or physical safety of the individual, others or the community*. The term is used to describe behaviour that interferes with an individual's support and daily life. The intensity, frequency and/or duration of these behaviours can often lead to responses that attempt to restrict behaviours or result in exclusion from services.

*Banks, R, Bush, A, Baker, P, Bradshaw, J, Carpenter, P, Deb, S, Joyce, T, Mansell, J Xenitidis, K, 2007, *Challenging behaviour: a unified approach - Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices*, Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, accessed 2 October 2013 at:

http://www.bps.org.uk/sites/default/files/documents/challenging_behaviour_-_a_unified_approach.pdf

Appendix C: Supporting individuals with complex needs under the NDIS

Figure 3: Levels of the NDIS approach to disability support



Appendix D: Principles of Supporting Individuals with Complex Support Needs

Supporting individuals with a disability in a contemporary environment

Supporting individuals with complex support needs occurs within a broader service system. This section outlines the key features that should make up a contemporary disability service system, within which support and practice relating to individuals with complex support needs occurs.

Rights-based approach

The United Nations Convention on the Rights of Persons with Disabilities reaffirms that people with a disability enjoy the same human rights as everyone in society, and prohibits discrimination against people with disability in all areas of life*. It recognises that individuals that have a disability have the right to participate fully in society and to direct their own lives by exercising control over the services and supports they need.

A contemporary disability environment sees people with a disability as individuals and partners in service delivery, and provides them with a greater degree of control over the services they receive.

The reorientation of disability service systems across Australian jurisdictions and internationally – including the person-centred reforms in NSW and the National Disability Insurance Scheme – have sought to enhance choices and opportunities for people with a disability, and are premised on this rights-based framework.

Outcomes-focus

Supporting individuals with a disability in a contemporary environment is focussed on improving outcomes for individuals in their community, personal and family life and is designed to assist individuals to exercise choice and control over their life decisions and the supports and services they receive.

This includes maximising opportunities for social inclusion and community connectedness and participation in employment and education for people with a disability in accordance with the individual's goals and aspirations – to ensure that individuals are able to take their place in society and participate in economic and community life to the best of their ability.

Individuals are at the centre of decision-making

At the core of a contemporary disability service system is a person centred approach which places the person at the centre of decision making and enables greater choice and control over decision making about formal supports they require and how to best use informal support networks.

Staff work collaboratively with individuals to facilitate and enable the individual to make informed choices.

One of the mechanisms to give effect to this is individualised funding, which is utilised to support increased levels of choice and control for individuals. This includes a choice for individuals with respect to direct payment and self management options for funds.

Individuals are also involved in the design, development and delivery of supports to ensure they are relevant and tailored to their needs and goals.

Individuals can access a range of mainstream, community and specialist supports to meet their needs

In a contemporary disability service system, individuals are able to access a range of supports and services which are tailored to their needs at different life stages and transition points. These supports and services include mainstream and community-based services as well as specialist (disability) supports, together with a focus on how to best strengthen family and other natural support networks.

High priority is placed on early intervention to improve quality of life, increase independence and plan for future needs.

Ease of access and navigation

In a contemporary system there are clear client pathways through easily identifiable access and entry points, providing information to individuals and their family, carers, and those in their support network so that they can make informed choices, and providing clear, transparent and consistent assessment processes.

Continuous improvement

In order to achieve the best outcomes, disability services and systems should build-in mechanisms for continuous improvements based on the best available evidence, and progress should be monitored and evaluated. This requires an infrastructure that supports, monitors and evaluates outcomes and a skilled workforce to implement this system.

* United Nations, *Convention on the Rights of Persons with Disabilities and Protocol*, accessed 14 September 2013 at <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> accessed .

Appendix E: Key features of the NDIS approach for Supporting Individuals with Complex Support Needs

National Disability Insurance Scheme – key features

Disability support in Australia is undergoing a substantial transformation through implementation of the NDIS. The Australian government has committed to a full rollout of the scheme by 1 July 2018, which has been championed by the NSW government.

Concurrently ADHC has invested heavily in new directions for disability support through *Stronger Together*, *Stronger Together 2* and now *Ready Together*. These reforms are fundamentally changing the way supports are chosen, delivered, funded and governed, which has many implications for individuals using disability services, and in particular individuals who have highly complex support needs.

Importantly aspects of this new approach will move the system toward a more contemporary environment in which to support individuals.

This section outlines some of the key features of the NDIS approach to disability support, which represent significant changes for individuals, families, carers, service providers and Governments.

Self directed support and individualised funding

The NDIS is based on a social insurance model and promotes self-directed support and individualised funding arrangements. In this person-centred approach, funding is allocated to individuals, families and carers to design a suite of supports that are aligned with their personal goals, needs and preferences.

This will be a shift away from the traditional model of funding services through a block-funding system, toward one that is person-driven *and* funded. This will substantially alter how service providers financially manage their organisations. Sustainability in the new market relies on delivering the types of supports that individuals need and *want* to purchase.

Choice and control

At the core of the NDIS reforms is a commitment to putting people with a disability at the centre of decision-making about their lives. This means empowering individuals, families and carers to make choices about the supports and services they access and to have control over the way in which those supports are delivered.

Person-centred planning

A key step in the NDIS service pathway is person-centred planning, which moves away from the traditional model of fitting individuals into existing services and toward a tailored and flexible approach to support planning. Under the NDIS support planners will provide resources and decision supports to encourage people to participate in the planning process by identifying their life goals and aspirations, and building a support plan that suits them best.

Safeguarding provisions

Individuals will be operating in a very different market in the future. Many safeguards that occur through traditional funding agreements between government and service providers will be dissolved and individuals will be entering into a direct purchasing relationship with service providers. In this new environment there is a need for greater decision support and safeguarding mechanisms that minimise the risk of harm to individuals, protect their right to be safe and empower them to achieve choice and control over the types of supports and services they receive. There are ongoing discussions at the national and state level to develop and implement safeguards that align with the National Disability Insurance Agency's (NDIA) new way of delivering disability supports.

Growth and competition

The NDIS will instigate unprecedented growth in the disability support sector through: competition resulting from a new demand-driven market; a substantial injection of new funding; and high levels of recommissioning of government-funded services to the non-government sector. The new market will mean increased competition and an expected increase in the number of service options for individuals.

* NSW Government, *National Disability Insurance Scheme fact sheet* (2013) accessed 14 September 2013 at http://www.adhc.nsw.gov.au/data/assets/file/0018/270342/NDIS_fact_sheet_june_2013.pdf

Appendix F: Productivity Commission Perspectives

Productivity Commission perspectives

The Productivity Commission's 2011 inquiry and report on *Disability Care and Support* * provided the precursor to the establishment of the NDIS. The report provided a comprehensive review of the potential risks and benefits of an NDIS and recommendations for its implementation. This includes commentary about the implications of the reforms in relation to individuals with complex support needs. This section highlights the range of issues and considerations identified in the report that are important to consider in designing an approach for effectively supporting individuals with complex needs.

Restrictive practice

Restrictive practices are authorised (RPA) in response to circumstances where individuals are at high risk of harming themselves or others. The Productivity Commission acknowledges that this creates the potential for misuse of these practices and recommends that the NDIA should deliver clear legal obligations on service providers regarding the use of restrictive practices with specific ongoing monitoring measures (p 503). Progress has been made in achievement national consultation as to ? Best practice approaches to RPA

State-level safety nets

The Productivity Commission reports that in some cases there may not be providers who are willing or able to provide support to clients with highly complex support needs or challenging behaviours . The report illustrates that in such cases, 'state and territory government agencies may be the only tenable service provider ' (p 53). They suggest that the NDIA 'would need to fund such services on a fee-for-services basis, taking into account capital costs' (p 53). In a state where no residual services will be provided by government, this presents challenges to build a market appetite and readiness.

Block-funding arrangements

The Productivity Commission explores the use and necessity of block funding to guarantee services in areas where the market may fail to deliver them efficiently. The report states that 'In some cases, the potential market for disability service may be too small to support the competitive provision of specialist disability support services under a consumer choice model (in particular under choice of package arrangement where approved service providers must be used)' (p 522).

The report points out that this 'may occur for individuals with very complex needs or very challenging behaviours — potentially resulting in under-servicing and unmet need' (p 522). The report illustrates that 'block funding through competitive tender is one way of addressing this' (p 522). This is a particular challenge in rural and remote areas and may require an innovative rethink of service provision utilising technology to fill gaps.

Monitoring quality

A quality framework with nationally consistent practice standards and a complaints mechanism will be implemented alongside the NDIS. The Productivity Commission stresses that the framework should be an important safeguarding measure and protect the rights of people with a disability. In relation to these quality settings the Productivity Commission states that 'Independent state-based statutory organisations (such as the Office of the Public Advocate) should continue to function as an avenue of complaint, investigation and recommendation', with an advisory role to the NDIA (page 52). The challenge here is developing and implementing a robust framework with evidence based indicators that measure outcomes.

Workforce issues

The capacity to provide expanded services and quality support for individuals with complex support needs will require extensive recruitment and training of new staff, including support workers and clinical professionals. The Productivity Commission acknowledges that requirements for training should take into account the needs of those using disability services and that some staff will need highly specialised training, particularly for certain functions, such as restrictive practices, therapeutic services, and behaviour intervention. The report recommends that the NDIS agency undertaking research into effective training programs and the Australian government should examine obstacles to workforce training and provide subsidies or scholarships where necessary (p 50). Building on existing partnerships with TAFE and the University sector to include disability content and practicum's into their curriculum will assist in workforce preparedness.

* Productivity Commission (2011) *Disability Care and Support*, Report no. 54, Canberra accessed 14 September 2013 at <http://www.pc.gov.au/projects/inquiry/disability-support/report>

Appendix G: Contemporary Supports for Individuals with Complex Needs

Innovative services and evidenced based practice

There is greater emphasis on developing innovative services and new service development is increasingly informed by robust research and an evidence base as to the best approaches to disability support.

Planning should be prospective, embracing new and developing technological advances which enhance practice, links in communicating with sector partners and enabling access to best practice service regardless of an individuals physical location.

Collaboration and partnership

In a contemporary system services should recognise the importance of working together collaboratively and in partnership in order to respond more effectively to the needs of individuals and to improve the integration, coordination, responsiveness and accessibility of services and supports.

Skilled and competent workforce

An essential component of a contemporary good practice disability service system is a skilled and competent workforce able to deliver supports in a manner which gives effect to choice and control in the everyday lives of individuals. This involves an ongoing sector wide commitment to recruitment and retention of staff through offering appropriate training, and clinical supervision, in addition to innovative partnerships and strong links with training organisations.

Appendix H: References

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