Independent Advisory Council to the NDIS

Equitable access to the NDIS by people with cognitive impairment on the margins

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Independent Advisory Council to the ndis

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Purpose

To identify enhancements to current NDIS policy and practice to maximize equitable access for individuals with cognitive impairment who are 'on the margins' and who are traditionally under-represented in disability services.

Target Group

The Intellectual Disability Reference Group (IDRG) described 'people on the margins' as people with cognitive impairment who experience complex disadvantage associated with mental ill-health, insecure housing, the use of drugs and alcohol and/or contact with the child protection and/ or criminal justice systems. Parents with a disability (especially parents with a cognitive impairment), new arrivals and people of culturally and linguistically diverse (CALD) or Aboriginal background are also underrepresented in using disability services.

Development of the report

In preparing this paper, the IDRG engaged with a select group of leaders, academics and practitioners working with people on the margins to explain current NDIA practice, identify challenges and recommend enhancements. This report summarises the core issues identified in relation to people on the margins. Subsequent reports will take up additional issues related to specific marginalised groups. This advice was agreed to by the IAC with the recommendation that the target group be extended to people with cognitive impairment as the content and recommendations were seen as appropriate for this broader group.

People who contributed to the development of this paper are identified in Appendix A.

The IDRG acknowledges proactive steps taken by the NDIA to engage with people on the margins. These are described in current practice for each issue.

Summary of core issues

Outreach

There is a significant danger that NDIS outreach will fall short in engaging people on the margins unless effective processes are developed at the systemic, service and individual levels.

The Service Delivery Operating Model (SDOM) identifies Local Area Coordinators (LACs) as the first point of engagement. The fact that LACs will have a large caseload and may not have experience in engaging with unresponsive people on the margins is problematic. The challenge is further exacerbated by bilateral agreements outlining that people who are not

existing service users will have limited access to the Scheme until the third year, reducing the motivation for other service systems to make referrals.

The complexity of system interfaces further increases the challenge. Interface principles enable local flexibility to plan and coordinate streamlined services for individuals requiring multiple system responses. This can have a positive or a negative impact depending on the priorities of the area.

Finally, at the individual level, factors inherent in people on the margins such as not identifying as having a disability, lacking positive family support, using drugs and alcohol, being homeless, having poor mental health and histories of trauma, being skeptical of services and being seen as non-compliant and unmotivated mean that engagement will depend on active outreach by the NDIA.

Determination of eligibility, pre planning, planning and plan implementation

The NDIS faces many challenges in ensuring effective passage of people on the margins along the participant pathway.

At the systemic level, challenges include ensuring that there are multiple pathways into the NDIS that are transparent to the community, having a workforce with appropriate skills and experience to work with people on the margins and having effective coordination at the individual, service and systems levels.

At the service level, challenges include the assumption that mainstream agencies will provide a "warm referral" and will remain engaged with their clients until their plan is implemented.

At the individual level, challenges include:

a) collecting and accessing appropriate information to determine eligibility;
b) the assumption that participants consider staff from mainstream referrers as "allies" in the NDIS processes;
c) the difficulty in moving beyond crises to enable the participant to develop positive life goals and engage with concepts of choice and control; and
d) ensuring that flexibility is built into plans including ready access to plan review to accommodate rapidly changing needs.

Interface with Health Systems

There is concern that the NDIS will have little impact on the health and wellbeing of participants as a result of the inability of health systems to meet their responsibilities under

the National Disability Strategy and their obligations under the *Disability Discrimination Act 1992 (DDA)*. This will require rigorous collaboration and pressure at the systemic level to ensure health systems have an understanding of the requirements for specialist knowledge, skills and responsiveness to all people with cognitive impairment including those on the margins.

Key challenges include facilitating better uptake of the Medicare annual health assessment, ensuring that reasonable and necessary support includes support to access the advice of health professionals and ensuring that there is an infrastructure of expertise to address complex behaviours of concern.

Recommendations in relation to outreach:

The IAC recommends that the NDIA:

1. Provides priority to people on the margins to the maximum extent possible over the next 2 years.
2. Strengthens communication and systemic pathways for referral from mainstream agencies into the NDIS including:
   a) providing clear messages to referrers that people waiting to become participants will be connected to mainstream agencies; and
   b) working closely with mainstream services and advocacy groups at the local level to foster access requests by people on the margins.
3. Conducts an outreach pilot in one or more of the existing trial sites, documenting strategies to enhance engagement with people on the margins.
4. Provides a specialist LAC role which will enable priority access for people on the margins.
5. Ensures that Information Linkages and Capacity building (ILC) provides services experienced in outreach and support for people on the margins.
6. Provides greater guidance as to a workable distinction between disability support to access mainstream services and the reasonable adjustment required of mainstream services for this target group. This may include:
   a) mapping the evidence base for relevant universal/generalist support measures available and the ways these are currently made accessible to people with cognitive impairment against the National Disability Strategy ;and
   b) exploring a specialist LAC role or Developmental Educators from the NDIS in offering assistance to people with cognitive impairment to access mainstream services.

Recommendations in relation to determination of eligibility, pre planning, planning and plan implementation

In relation to eligibility, the IAC recommends that the NDIA:

7. Supports the practice of emailing (rather than mailing) access requests so as to allow for the expeditious handling of access where appropriate.

8. Supports the development of a consistent approach in determining eligibility by benchmarking the application of functional capacity indicators by NDIS access team personnel.
9. Develops public material on when a young person or adult on the margins may be eligible to become a participant on an early intervention basis.
10. In collaboration with mainstream services and advocacy groups, monitors whether people on the margins may be being denied access to participant status due to the lack of evidence of impairment and functional capacity.
11. Promotes effective exchange of information to determine eligibility and provide reasonable and necessary support including:
    a) protocols for accessing the information;
    b) protocols to differentiate assessments by purpose and nature and hence their relevance in the NDIS planning processes.

Recommendations in relation to determination to pre planning, planning and plan implementation

The IAC recommends that the NDIA:

12. Develops a common framework to be used in pre planning, planning and plan implementation for people on the margins including:
    a) clear terminology to promote identification of the target group;
    b) specialist teams skilled at working with people on the margins;
    c) guidance to operationalise principle based decision making;
    d) identification and documentation of good practice;
    e) purchase of comprehensive needs assessments where necessary especially where lack of evidence of impairment and functional capacity impedes the determination of eligibility;
    f) the provision of capacity building in individual plans;
        i. flexibility responsive to rapidly changing circumstances including: support coordination to implement, monitor and provide ready access to plan review.
    g) the provision of for advocacy support for some individuals; and
    h) reference Packages that recognise that support coordination will be an ongoing requirement for some participants;
13. Ensures effective coordination including:
    a) the implementation of effective models of coordination at the system, service and individual levels; and
    b) the requirement that registered providers of support connection, support coordination and specialist support coordination services have the competence and experience to work with people on the margins.

The IAC recommends that the NDIA:
Builds pathways that support engagement for people on the margins including:

a) The development of specialist pre-planning and capacity building for people on the margins to facilitate the development of choice and control and positive life goals.
b) Recognition of the often crucial need for a trusted ally to support a person on the margins through NDIS eligibility, planning and plan implementation processes.
c) Communication and systemic pathways for referral from mainstream agencies into the Scheme.
d) The funding of organisations in the ILCB that have experience in capacity building, support for decision making and outreach to people on the margins.
e) Recognition of the value of a specialist LAC role for this target group or at least a senior LAC position that establishes relationships with mainstream agencies and builds systemic capacity to interface with multi systems.
f) Priority access to LAC for people on the margins.

Recommendations in relation to the interface with Health systems:

The IAC recommends that the NDIA:

2. Facilitates better take up of the Medicare annual health assessments for people with cognitive impairment.
3. Establishes robust systems for collaboration with mental health and drug and alcohol services.
4. Negotiates with the health system to ensure more responsive systems of support for people in hospital and community health settings.

Introduction

The Intellectual Disability Reference Group (IDRG) was convened in 2015 to provide advice to the NDIS Independent Advisory Council (IAC; the Council) on best practice in enabling people with intellectual disability to lead ordinary lives included in their community. The topic of *Equitable Access by People on the Margins* is one of the issues the IDRG identified as requiring attention. The IAC determined that the advice could be broadened to focus on all people with cognitive impairment, not just intellectual disability.

The purpose of this paper is to identify enhancements to current NDIS policy and practice to maximise equitable access for individuals with cognitive impairment who are on the margins and traditionally under-represented in disability services.

The IDRG used a number of indicators to identify this target group of people with intellectual disability. They are well described by ARROS in its recent case studies *Supporting people with intellectual disability on society's fringe in the context of the NDIS* (2015):

People on the margins refers to individuals with intellectual disability who are society's fringe because of their experiences of homelessness, the criminal justice system, out of home care, poor mental health or substance abuse issues. They often have few informal supports such as friends or family, or mainstream supports. A history of trauma and other social disadvantages may result in complex behaviour that can further isolate them in society, both in terms of informal supports and access to specialist and mainstream supports.

People with intellectual disability living on the fringes of society have needs that remain unarticulated. There are a number of reasons for this, largely related to their disability. Limitations in intellectual functioning may mean they articulate their needs differently, limitations in social skills may mean they lack informal supports to help them identify and articulate their needs, a desire to 'be like everyone else' may mean they do not identify with the disability labels others may use to define their needs.
(ARROS, 2015, 3)

This paper does not address specific issues related to parents with disability, children in child protection systems and people of Culturally and Linguistically Diverse (CALD) or Aboriginal background. These issues will be the subject of subsequent work.

In the preparation of this paper, the IDRG engaged with a select group of leaders, academics and practitioners working with people on the margins to explain current NDIA policy and practice, identify challenges and recommend enhancements. Appendix A identifies members of the group.

This paper summarises the key issues identified in relation to outreach, determination of eligibility, pre-planning, planning and plan implementation and interface with justice and health systems.

1. Outreach

Current practice

Responsibility for outreach and linkages

The NDIA's Service Delivery Operating Model (SDOM) employs a range of strategies for outreach, with a primary role for Local Area Coordination (LAC), Information Linkage and Capacity building (ILC) and engagement teams for this essential function. The bilateral

agreements signed with New South Wales and Victoria provide time ahead of the phasing schedule for work with mainstream agencies to ensure an understanding of the NDIS and interface principles as well as enable the NDIS to understand the environment and participants.

Many people on the margins require significant support from trusted allies to engage with the NDIS.

Features of the Service Delivery Operating Model that aim to address these requirements include:

- the use of data to identify complexity in a person and thereby allocate the person to a specialist team;
- the use of support coordination to implement the plan and build the capacity of the participant; and
- the ultimate transfer of the participant to an LAC who is able to maintain ongoing contact as required.

Support for people on the margins who will not become participants

People who are ineligible to become participants, including people in need of episodic support, remain the responsibility of mainstream agencies. In the Service Delivery Operating Model it is the role of the LAC to work with people to connect them with mainstream support and work with mainstream agencies to ensure they understand interface principles, are inclusive and have capacity to support people with disability.

Challenges

Self-identification of disability

Research demonstrates that some people with cognitive impairment do not identify as having a disability (Dowse et al 2014). Many experience complex disadvantage associated with the use of drugs and alcohol, mental ill-health, insecure housing and contact with the child protection and/or criminal justice systems. Issues associated with complex disadvantage pre-date the NDIS where services had little incentive to refer the person to disability supports because of a lack of resources and appropriate available pathways and mechanisms for referral. The NDIS however provides new opportunities and incentives for engagement including the opportunity for reasonable and necessary support for those who are eligible and the increased awareness in the general community, with a “no wrong door” policy contributing to more community support.

The challenge associated with the need for identification of disability in order to access NDIS

support rests with both the NDIS and interface agencies. The NDIS has a responsibility to ensure the availability of services in ILC that are experienced in outreach and supporting people on the margins. Interface agencies have a responsibility to recognise the impact of disability and make reasonable adjustments.

Self-identification of disability

Being reliant on mail for access requests

The practice of mailing access requests to identified potential participants has been developed to maintain a register of access requests. Referring agencies spend significant time and effort in convincing people on the margins (especially those who do not identify as having a disability) that the NDIS will provide assistance that will be beneficial. At times, the moment of recognition of the value of becoming an NDIS participant may be brief and the slow turn around that results from using Australia Post to mail access requests means that the person has changed their mind by the time the access request arrives. The use of email to expedite the process of applying to the NDIS is likely to be more successful.

Being reliant on mainstream services for a 'warm referral'[1]

Mainstream services often do not respond appropriately to people with cognitive impairment, viewing people on the margins:

as non compliant, unmotivated, attention seeking and other labels that identify the behaviour without attempting to understand the underlying needs that these behaviours are attempting to express or respond to. (ARROS, 2015, 4)

The lack of understanding of the role cognitive impairment plays in a person's behaviour raises concern as to their willingness to take the time and effort required for the warm referral necessitated by people on the margins. The challenge is widespread given that all interface principles require systems to work together at the local level to plan and coordinate streamlined care and support for people with disability. While local flexibility is critical, without further guidance in relation to a workable distinction between disability support to access mainstream services and the reasonable adjustment required of mainstream services for this target group, flexibility can lead to lack of consistency and an excuse for reluctant systems to avoid the time and effort required.

Where a mainstream service does identify a person's need for disability support, a range of factors may impede a warm referral. These include the very limited timeframe a justice agency may have, a lack of mandate to work with the person, and historically based cynicism about whether disability services will make a meaningful response to a referral.

Advocacy groups tend to be well equipped to link their clients to disability support but are only available to a very small percentage of people on the margins.

Phasing of people who are not current service users

Bilateral agreements in NSW and Victoria require transition of existing clients with limited access for new participants prior to the third year of the Scheme. This means that engagement with people on the margins who have not been disability service users will be complicated because of the delay in enabling them to become participants. The emphasis on transition of existing clients will impede the development of a culture of outreach to people on the margins.

Demands on LACs will inhibit time required to engage people on the margins

The large caseloads of LACs and their involvement in NDIS planning will make it difficult for them to take the time and effort required to engage people who are reluctant or resistant to engage. In addition, it is difficult to imagine that LACs will have the time required to work with mainstream agencies to enhance their capacity to provide services responsive to and inclusive of people on the margins.

2. Determination of eligibility, pre-planning, planning and plan implementation for people on the margins

2.1. Determinations of disability

Current Practice

The *National Disability Insurance Scheme Act 2013* (NDIS Act) states that a person must meet both the age and residence requirements and one of either the Disability or Early Intervention requirements to meet the access criteria..

To assist in streamlining access decisions, the CEO has directed that where a person:

- has a certain diagnosis (listed in Appendix A to the Operational Guideline dealing with the disability requirement); or
- is currently receiving supports from certain state programs (listed in Appendix C of the same Operational Guideline);

decision-makers generally will not require further evidence that the person meets the disability requirement, as people in those two situations will have already been assessed as having a disability that meets the elements of the disability requirements.

A second list has been provided (at Appendix B of the Operational Guideline) to assist decision-makers where a person has a condition that satisfies part of the test and evidence

is only required in relation to functional capacity.

People who are not covered by either appendix are not in any way prevented from accessing the Scheme – the appendices relate only to how evidence is collected. People not already covered can provide evidence of their disability from their doctors, allied health workers or education professionals.

The NDIS is aware that many people on the margins will need support to access the Scheme.

To this end the NDIA seeks to work closely with other government and non-government systems to ensure staff understand the NDIS and are able to assist their clients to engage, including assisting with the provision of documentary evidence necessary to meet access criteria. These systems include among others:

- child protection;
  criminal justice:
- juvenile justice;
- mental health;
- and homelessness services.

Challenges

It is often a challenge to collect or access appropriate information in relation to people on the margins. Although the NDIS has data integration authority with Commonwealth agencies (which reduces the impost on people and the service system to provide information) the data is often inadequate to provide the level of information required.

Many people on the margins will have no existing assessment of their impairment or functional capacity and may not have a health or education professional able to provide such an assessment.

In addition, it is sometimes difficult to access historical records and people may not provide accurate and full personal histories.

The application of functional capacity indicators by NDIS access Team personnel as part of determining eligibility is subject to variability across individuals and locations. Equity requires consistency.

Some people on the margins might be eligible to become participants on an early intervention basis but this is currently not clear.

2.2. People on the margins are supported by NDIA and outsourced planners are skilled at working with people on the margins

Current practice

SDOM identifies 20 per cent of participants as requiring intensive and super intensive support to engage with the Scheme and plan and implement their support. Differential strategies are planned to support effective engagement.

Practice is variable across trial sites. Barwon uses specialist teams with expressions of interest being sought from staff interested in working with this target group. The intent is to identify staff who are comfortable working with people on the margins, have strong experience in working in interfaces, and can build enduring relationships with people on the margins as well as with interface agencies. The good practice in Barwon is built on long standing systemic experience in Victoria in working with this group.

Challenges

There are challenges in ensuring planner competencies and training reflect requirements of working with people on the margins. Recent work by the *Intellectual Disability Behaviour Support Program* at the University of NSW (UNSW) identified key worker competencies as including social justice principles, an understanding of community inclusion, strengths based approach and cultural competence, communication and negotiation skills, motivational interviewing and practice that is person centred and reflective (*Intellectual Disability Behaviour Support Program*, 2015).

A further challenge is finding people with the appropriate skills and experience to provide support to people on the margins. Often people with the necessary knowledge and skills in working with this target group are employed in systems other than disability such as criminal justice, drug and alcohol or mental health.

2.3. People on the margins are supported by a trusted ally through NDIS eligibility, planning and plan implementation processes

Current practice

The engagement team of the NDIA outreaches to interface agencies but relies on these agencies to make referrals and support engagement with NDIS.

The NDIA works with individuals one by one and even in the context of specialist teams in Barwon, planners have needed to call in formal advocacy support for some individuals.

Challenges

People on the margins may be passive or even resistant in the referral process and lack a

"trusted ally" to support them. The NDIA may perceive staff from other service systems as allies but participants may have a different view. For example participants may view staff from the justice system as someone who may breach their parole or staff from mental health services as the person who gives injections. Staff from other agencies are more likely to be perceived as trusted allies where they have a long standing relationship with the person or establish their role as being clearly on the side of the individual, for example advocacy agencies.

Current expectations that mainstream agencies will remain engaged with the client until the person has engaged with planning and plan implementation processes are unrealistic given their limited mandates with clients and heavy workloads.

Pathways between service outlets of mainstream agencies and the NDIA are not yet well developed and this inhibits the implementation of processes that best engage people on the margins.

2.4. People on the margins are assisted to develop concepts of choice and control and positive life goals

Current practice

There is recognition that when people lead chaotic lives and are involved with multiple systems, there is a danger that the focus is to resolve crises and that concepts of choice and control and positive life goals take second place.

The NDIA uses support coordination or support coordination intensive in plans to assist participants to both negotiate systems as well as build capacity to begin to experience choice and control and positive life goals. Recent practice in Barwon demonstrated use of detailed planning (one over four weeks, one over eight weeks and the third over 12 weeks) to identify positive life goals and support for choice and control distinct from day to day crises.

Challenge

Choice and control without capacity building for people on the margins may reinforce negative choices. The Good Lives Model [2]used with offenders with intellectual disability is an example of capacity building that seeks to engage people on the margins in building positive lives.

Siloed service systems can be barriers to rather than enablers of the best solutions.

2.5. Planning for people on the margins is supported by access to information from a range of relevant sources including a comprehensive, multifaceted assessment where needed

Current practice

For 70 per cent of people in contact with the access team, there is a need to seek further information either in order to complete access determination or to set the reference package. The NDIA proactively seeks information from whatever sources are able to be identified. Where formal permission to access information is not provided in the initial access request, the NDIA works with the individual to obtain the information.

Independent assessments are only used where there is no existing information available. The NDIA does not have a policy on payment for such assessments. Barwon has however recently paid for in-depth assessments related to behaviour (in-depth functional behavioural analysis), related to child protection and in a leaving care processes.

In the Hunter, consent has sometimes been a barrier to further assessment. This has not been an issue in Barwon where individuals have had informal support or a formal guardian.

Challenges

There is a need for clarification of the nature and purpose of exchanged information, to distinguish between information for access and assessment from information about service type and usage. Information shared between agencies is of variable quality. Many participants will be unaware of information stored on their files and may challenge its veracity.

2.6. People on the margins have flexibility built into their plans and ready access to plan review to accommodate rapidly changing needs

Current practice

The NDIA recognises that people on the margins will be part of the 20 per cent of people who need intensive or super-intensive support in the process of streamed planning in the SDOM. In addition support coordination or specialist support coordination is built into the plans of people on the margins to assist with plan implementation and monitoring and to facilitate ready access to plan review as required.

In Barwon for example, the specialist team works with a smaller number of participants. There is an expectation that the planner will have a level of oversight of the participant

(supporting plan review as required) as well as relationships with the agencies with which the participant engages.

Challenges

A key challenge includes ensuring the SDOM provides flexibility in relation to planning for people on the margins who often have unstable lifestyles marked by unpredictable crises.

In addition, it is important to ensure there is recognition of the ongoing need for support coordination for some participants.

2.7. People on the margins are supported by effective models of coordination at the individual, service and system levels

Current practice

The NDIS support catalogue includes a number of items aimed at assisting participants to implement their plans as a pathway to achieving their goals. These items include:

- Support Connector – a role that provides time limited assistance to strengthen the participant's ability to connect with informal, mainstream and funded supports and to increase the capacity of the participant to maintain support relationships, resolve service delivery issues and participate independently in NDIA processes
- Support Coordinator – a role that provides assistance to strengthen participants' abilities to connect to and coordinate informal, mainstream and funded supports in a complex service delivery environment. This includes resolving points of crisis, developing capacity and resilience in a participant's network and coordinating supports from a range of sources
- Specialist Support Coordination – a role that provides support coordination within a specialist framework necessitated by high level risks in the participant's situation. This support is time limited and focuses on addressing barriers and reducing complexity in the support environment while assisting the participant to connect with supports and build capacity and resilience. Specialist support coordination usually gives way to support coordination.

Support coordination is built into all plans of people on the margins and assists the participant to build their own capacity as well as negotiate within their network, with their services and across service systems.

Challenges

The term support coordination has multiple meanings across service systems. It is possible that the support coordination provided by a registered provider may not meet the expectations described in the role.

The system coordination anticipated in the Council of Australian Governments' (COAG) interface principles usually assigns responsibility for system coordination to parties other than the NDIS. The fulfilment of these responsibilities is often not a high priority.

Cross sector coordination is at best patchy and will be further complicated when state governments move out of disability service provision. Cross sector coordination is however essential to ensure that people on the margins get the range of services and supports from the NDIS as well as mainstream agencies. Failure of other sectors to provide access to quality services will increase the cost of disability support and hence addressing cross sector coordination is fundamental to NDIS sustainability.

Increasing research and literature in relation to cross sector coordination and the NDIS propose models that address issues at the system, service and individual level. (Centre for Disability Research & Policy, 2014 and Intellectual Disability Behaviour Support Program, 2015)

3. Interface with Health

3.1. Disability support to access and follow the advice of health professionals.

Current experience and practice – research for intellectual disability

Australian and international research convincingly demonstrates unacceptable unmet physical and mental health needs in children, adolescents and adults with intellectual disability (Lennox 2014). Unrecognised and poorly managed health conditions greatly exceed prevalence in the general population. People with intellectual disability die younger than other Australians: seven years younger for those with mild intellectual disability and 20 years younger when disability is severe or profound (Lennox 2014). Health assessments have been demonstrated across three Australian randomised trials to improve GP recognition of unmet health needs in people with intellectual disability. This means that the highest level of evidence supports the implementation of health assessments for this group.

Research indicates that between 20 to 40 per cent of people with intellectual disability have mental disorders including schizophrenia, being two to four times more prevalent than in the general population. Established risk factors for mental disorders commonly exist for people with intellectual disability including social exclusion, poverty, contact with the justice system, misuse of drugs and alcohol, poor physical health and intellectual disability itself (ABS, 2010).

Research shows that people with intellectual disability have very poor access to mental health care. When there is access to care, the care is often not appropriate. Mental health professionals lack training and lack access to specialists in intellectual disability mental health. (Trollor, 2014, NSW Council on Intellectual Disability, 2014)

A recent data linkage study of 680 NSW adult prisoners with intellectual disability found that 60 per cent had a diagnosed mental disorder and that 70 per cent had a substance use disorder. Forty five percent had both of these conditions (Baldry and others 2012 and communication with Professor Baldry).

Offenders with intellectual disability have poor access to treatment for drug and alcohol problems. Treatment services tend to see themselves as ill equipped to work with people with intellectual disability and see their programs as unsuitable. (Simpson et al. 2001)

Experience

Many health practices and facilities have policies and practices that are not inclusive of people with cognitive impairment.

Many people with cognitive impairment have trouble accessing general health services. They may be able to make an appointment but need support to communicate with the health professional, make informed decisions about treatment options and implement the treatment into their daily lives.

For people on the margins, there are particular problems due to poor access to and skills in mental health and drug and alcohol services.

Many people with cognitive impairment experience significant challenges when admitted to hospital. Parents are often expected to support a son or daughter with disability for the entire period of their hospitalization.

NDIS practice

The NDIS provides support for participants to use health services and implement the advice of health professionals through support for daily living.

NDIS funded support workers are able to visit a participant in hospital to maintain social support but it is the responsibility of the health system to provide daily living support while the participant is in hospital.

Challenge

An annual health check is an important evidence based intervention to improve the health outcomes of people with intellectual disability. Most state disability departments ensure health assessments are available to people with intellectual disability within their states. As states and territories cease to provide services, health assessments may not be readily available or promoted for use.

Historically, state and territory governments have developed and fund structures and expertise to address complex challenging behaviour and related mental health needs. These will disappear in some states and territories once state governments cease providing services under the NDIS. These issues will be canvassed in detail in the IDRG work on support for people with complex behaviours

People with cognitive impairment in custody have high rates of mental disorder and substance abuse and treatment services see their programs as ill equipped to cater for

them.

Recommendations by NDIS Systems

Service Delivery Operating Model:

The IDRG recommends that the NDIA:

1. Provides priority to people on the margins to become new participants to the maximum extent possible during surge.
2. Develops a common framework to be used in pre planning, planning and plan implementation for people on the margins including:
    a. clear terminology to promote identification of the target group;
    b. specialist teams skilled at working with people on the margins;
    c. guidance to operationalise principle based decision making;
    d. identification and documentation of good practice;
    e. purchase of comprehensive needs assessments where necessary especially where lack of evidence of impairment and functional capacity impedes the determination of eligibility'
    f. the provision of capacity building in individual plans;
    g. flexibility responsive to rapidly changing circumstances, including:
        (i) support coordination to implement, monitor and provide ready access to plan review
    h. the provision of advocacy support for some individuals.
3. Ensures effective coordination including:
    a. the implementation of effective models of coordination at the system, service and participant levels; and
    b. that registered providers of support connection, support coordination and specialist support coordination services have the competence and experience to work with people on the margins.
4. Provides greater guidance in a workable distinction between disability support to access mainstream services and the reasonable adjustment required of mainstream services for this target group. This may include:
    a. mapping the evidence base for relevant current universal/generalist support measures available and the ways these are currently made accessible to people with cognitive impairment against the National Disability Strategy (NDS).
    b. exploring a specialist LAC role or developmental educators from the NDIS to offer assistance to people with cognitive impairment to access mainstream services.

Access

The IDRG recommends that the NDI supports the practice of emailing (rather than mailing) access requests so as to allow for the expeditious handling of access where appropriate.

1. Supports the development of a consistent approach in determining eligibility by benchmarking the application of functional capacity indicators by NDIS Access Team personnel.
2. Promotes effective exchange of information to determine eligibility and provide reasonable and necessary support including:
    a. protocols for access to information; and
    b. protocols to differentiate assessments by purpose and nature and hence their relevance in the NDIS planning processes.
3. monitors whether people on the margins are being denied access to participant status due to the lack of evidence of impairment and functional capacity, in collaboration with mainstream services and advocacy groups,.

Engagement

The IDRG recommends that the NDIA:

4. Develops public material outlining the circumstances in which a young person or adult on the margins may meet the early intervention requirements to become a participant.
5. Strengthens communication and systemic pathways for referral from mainstream agencies into the NDIS including:
    a. providing clear messages to referrers that people waiting to become participants will be connected to mainstream agencies; and
    b. working closely with mainstream services and advocacy groups at the local level to foster access requests by people on the margins.
6. Develops specialist pre-planning and capacity building for people on the margins to facilitate the development of choice and control and positive life goals.
7. Recognises the often crucial need for a trusted ally to support a person on the margins through NDIS eligibility, planning and plan implementation processes.
8. Conducts an outreach pilot in one or more of the current trial sites documenting strategies to enhance engagement with people on the margins.

Interface and Scheme Practice Approach

The IDRG recommends that the NDIA:

9. Facilitates better uptake of the Medicare annual health assessments for people with cognitive impairment.
10. Establishes robust systems for collaboration between the NDIS and mental health services.

Negotiates with the health system to ensure more responsive systems of support for people in

hospital and community health settings

Information, Linkage and Capacity Building (ILCB)

The IDRG recommends that the NDIA:

1. Provides a specialist LAC role or at least a senior LAC position that establishes relationships with mainstream agencies and builds systemic capacity to interface with multi systems.
2. Provides priority access to LAC engagement for people on the margins including establishing relationships with organisations in touch with people on the margins (e.g. homelessness, housing, mental health, drug and alcohol and post release services).
3. Ensures the ILCB provides services experienced in outreach, capacity building and support for people on the margins including the provision of support for police and court processes and support to meet court imposed conditions for people with disability who are not participants.

Reasonable and necessary support

The IDRG recommends that the NDIA:

4. Provides capacity building in all plans of participants on the margins.
5. Ensures flexibility of plans responsive to rapidly changing circumstances including support to implement, monitor and provide ready access to plan review.

Scheme Actuary

The IDRG recommends that the NDIA:

6. Ensures that Reference Packages recognise that Support Coordination will be an ongoing requirement for some participants.

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