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Complex Disability (with Complex Support Needs): Engagement, Reasonable and Necessary Supports, and Cost Drivers

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4 April 2017

scope

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1. Overview

The NDIS is premised on the right to citizenship - to have full social and economic participation in Australian life.

There is a risk that the very group of people for whom the Scheme is life changing may be left behind.

Their voice not heard, their aspirations and opportunity to live an ordinary life limited.

This paper is an attempt to elevate that voice and engender a conversation to reach a common understanding of the ways in which a person with multiple and complex disability requires support to engage in the NDIS journey.

It is critical that the multiple factors (and the interactions of these factors) experienced by people with complex disability and the impact that these are likely to have on a person's participation in the Scheme are understood.

This paper provides contextual information on the following three areas:

1. Engaging people with complex disabilities to participate in the NDIS.
2. Determining the reasonable and necessary supports for complex disability.
3. Cost drivers to support people with complex disability to live an ordinary life.

Case studies from Scope's East and West Divisions are included to illustrate the breadth of complex disability.

Complex disability is not particularly well defined and is often used interchangeably with complex (support) needs. Complex support needs arise from interrelationships between individuals, environments and systems[1]-[2], and often result from multiple and concomitant issues. Complex disability can include any combination of disability and physical health/ medical conditions, mental health problems, challenging behaviour, alcohol or drug issues[3]-[4], contact with the criminal justice system, Aboriginal or Torres Straight Islander background, use of augmentative and alternative communication, a history of being placed in (or leaving) state care (i.e., child protection services)[5], homelessness or being at risk of homelessness. It is well documented that people with disability have poorer health than the general

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[1] Collings, S., Dew, A., & Dowse, L. (2016). Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. *Journal of Intellectual and Developmental Disability, 41,* 272-276.
[2] Dowse, L., Wiese, M., & Smith, L. (2016). Workforce issues in the Australian National Disability Insurance Scheme: Complex support needs ready? *Research and Practice in Intellectual and Developmental Disabilities*, 3, 54-64.
[3] St Vincent's Hospital. (2013). Young Adult Complex Disability Service [Brochure]. Melbourne, Australia: Author.
[4] Disability Justice Project. (2017). Support planning for people with complex needs. Retrieved from http://www.disabilityjustice.edu.au/supporting-people-with-complex-needs.
[5] Department of Family and Community Services. (2014). *Leading clinical practice and supporting individuals with complex support needs in an NDIS environment*. New South Wales, Australia: Author.

population[6] and higher rates of premature death[7]. They experience a range of secondary conditions, co-morbid conditions and age-related conditions[8], and experience high rates of mental illness[9]. People with acquired brain injury are over-represented in the criminal justice system, and there are large numbers of children with disability in out-of-home care[10]. Consequently, many people with disabilities will have complex support needs.

2. Engaging people with complex disability to participate in the Scheme

If not appropriately supported, people with complex disability will not make it into the NDIS.

There are likely to be challenges for people with complex disability engaging with the Scheme (i.e., knowing that the Scheme exists, determining eligibility, identifying needs, and making decisions about services from which to access supports). Many potential participants have little knowledge about the Scheme, particularly those who do not have family or other supports, are socially marginalised, homeless or are not currently using disability services[11].

Even though information about the NDIS is available in various formats, many people are not likely to understand this information without some support, which will affect their access and participation to the Scheme. Easy English, for example, whilst accessible to many people with disability, requires a support person to help the person read, understand, and process the information. The same issues are likely to arise with other formats that have been used to share Information about the Scheme (e.g., video and audio clips).

Not all people with complex disability will have people who can support them to understand information (and then act on it) and it is difficult for advocates and others to assist someone with comprehension and communication if they do not know the person well. To ensure that people with complex disability are aware of the NDIS, considerable outreach and face-to-face communication will be required in order to engage with people[12]-[13]. It should be noted that for people with complex disability comprehension and response to information will be an issue throughout the whole process (eligibility, assessment, planning and implementation).

[6] Hollins, S., Attard, M. T., Von Fraunhofer, N., & Sedgewick, P. (1998). Mortality in people with learning disability: Risks, causes, and death certification findings in London. *Developmental Medicine & Child Neurology, 40*, 50-56.
[7] World Health Organization. (2016). Disability and health [Brochure]. Retrieved from: http://www.who.int/mediacentre/factsheets/fs352/en/
[8] Ibid.
[9] Borthwick-Duffy, S.A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. Journal of Consulting and Clinical Psychology, 62, 17-27.
[10] Snow, P., Mendes, P., & O'Donohue, D. (2014). *Young people with a disability leaving state care - Phase 2 report*. Melbourne: Monash University.
[11] O'Connor, M. (2014). The National Disability Insurance Scheme for people with mild intellectual disability: Potential pitfalls for consideration. Research and Practice in Intellectual and Developmental Disabilities, 1, 17-23.
[12] Collings, S., Dew, A., & Dowse, L. (2016). Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. *Journal of Intellectual and Developmental Disability, 41,* 272-276.
[13] O'Connor, M. (2014). The National Disability Insurance Scheme for people with mild intellectual disability: Potential pitfalls for consideration. *Research and Practice in Intellectual and Developmental Disabilities, 1,* 17-23.

Information about the Scheme can be accessed in a number of ways including online, visiting an NDIS office, or via phone. These methods of accessing information are, however, not necessarily conducive to people with complex disability. For example, many people with disability, particularly complex disability, do not have access to the internet[14]. The general population who do not have access to the internet at home may access it elsewhere (e.g., libraries, internet cafes), however, people with complex disability cannot access these as easily (e.g., due to severe physical disability, those in the criminal justice system).

Literacy and computer skills are also likely to be low in people with complex disability, particularly in those who disengaged from the education system early (e.g., those in or having left out-of-home care, people of Aboriginal or Torres Straight Islander background), making it even more challenging to navigate the system.

Once a person learns about the Scheme, potential participants still need to navigate the system to determine eligibility. Currently, potential participants can use the NDIS Access Checklist (formerly known as My Access Checker), call the NDIS or visit an office. At a minimum, using the NDIS Access Checklist requires access to the internet, literacy and computer skills.

Calling or visiting the NDIA presents similar problems outlined above and requires self-advocacy and communication skills that many people with complex needs do not have[15]. Whilst a family member may check eligibility on behalf of people with complex disability, not all families have the resources, skills or confidence to do this. Further, not all people with complex disability have people in their lives who can advocate on their behalf. In order for people to effectively activate the system to help them achieve their goals, they will need the right skills or supports[16]. People with complex disability will need a competent and committed advocate who is knowledgeable about the person, their skills and abilities, and life circumstances. Advocates or supporters will also need to be knowledgeable about the various service systems (and how to navigate these), in order to understand what is possible, available[17] and considered 'reasonable and necessary' supports.

2.1 NDIS assessment and planning

There is a need for the NDIS assessment and planning processes to cater for and empower people with complex disability to explore and understand their choices. These processes can have major consequences on how people with complex disability are able to engage with the NDIS. In the UK, participants who had individualised budgets reported that they needed

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14 Australian Bureau of Statistics. (2012). Profiles of Disability, Australia 2009. Retrieved from: http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4429.0Main+Features100142009
15 Collings, S., Dew, A., & Dowse, L. (2016). Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. *Journal of Intellectual and Developmental Disability, 41*, 272-276.
16 Soldatic, K., van Toorn, G., Dowse, L., & Muir, K. (2014). Intellectual disability and complex intersections: Marginalisation under the National Disability Insurance Scheme. *Research and Practice in Intellectual and Developmental Disabilities, 1*, 6-16.
17 Clift, K. (2014). Access to the National Disability Insurance Scheme for people with intellectual disabilities who are involved in the criminal justice system. *Research and Practice in Intellectual and Developmental Disabilities, 1*, 24-33.

support with the assessment process as they risked under-estimating their support needs, especially if they had a disability that resulted in fluctuating needs[18]. Support was also needed for planning as people were not accustomed to thinking broadly about their needs and had difficulty imagining any arrangements or services beyond their current experiences[19]. These findings suggest that decision-making support will also be critical in order for people to exercise choice and control.

It is likely that people in Australia who receive individualised budgets through the NDIS are likely to experience similar problems with assessment and planning, and will require extensive support to be able to develop their goals and aspirations, particularly those who do not have many supports (e.g., family or others) or advocacy skills. Indeed, Clift (2014) demonstrated that it took 12 hours to support a person with intellectual disability (who does not have self-advocacy skills or informal supports) through the NDIS application, assessment, planning and implementation process[20]. It should be noted that even family or other informal supports might find it difficult to advocate on behalf of the person with disability, and articulate their needs or aspirations[21].

Given some of the issues that have been outlined, NDIA assessors and planners working with people with complex disability, will need to have more advanced and specialised knowledge and skills. These include knowledge of alternative and augmentative communication, behavioural support, decision making support, chronic disease processes (e.g. diabetes), medical conditions (e.g., epilepsy), and combined impacts of intellectual, physical and sensory impairment. This is to ensure that needs are accurately assessed and from which individualised support plans can be developed.

Assessors will need sufficient time to develop rapport with the person and build trust[22]. They will also require access to specialists/ specialised services that can conduct additional assessments (e.g., clinical/ medical, criminal justice, behavioural), as required, and to provide expert advice. Given the potential for the circumstances of people with complex disability to change rapidly, a process (and sufficient funding) that allows for the regular review of plans and supports is required. Because of these complex needs, enhanced coordination of supports is also required.

Adults and children with complex disability often require services from multiple service systems. It is critical that the planning and implementation between these systems is integrated. For example, best practice requires that children are supported in their natural

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[18] Rabieee, R., Moran, N., & Glendinning, C. (2009). Individual budgets: Lessons from early users' experiences. *British Journal of Social Work*, *39,* 918-935

[19] Ibid.

[20] Clift, K. (2014). Access to the National Disability Insurance Scheme for people with intellectual disabilities who are involved in the criminal justice system. *Research and Practice in Intellectual and Developmental Disabilities*, *1,* 24-33.

[21] O'Connor, M. (2014). The National Disability Insurance Scheme for people with mild intellectual disability: Potential pitfalls for consideration. *Research and Practice in Intellectual and Developmental Disabilities, 1,* 17-23.

[22] Collings, S., Dew, A., & Dowse, L. (2016). Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. *Journal of Intellectual and Developmental Disability, 41,* 272-276.

environment[23]-[24] which requires collaborative and integrated planning between the universal service system, the NDIA and Disability Services Organisations.

3. Determining reasonable and necessary supports for complex disability

In determining the reasonable and necessary supports under the NDIS, it is critical there is understanding of the multiple factors experienced by people with complex disability. Without addressing these factors, it is unlikely that needs can be met.

For example, funding for Supported Independent Living might increase if the participant has:

> *"complexity factors not considered in the guidelines but for which a higher level of support can be shown to be reasonable and necessary. Indeed, there are many such complexities not yet recognised in NDIA documentation but the onus is on the participant to articulate these complexities and establish them with sound evidence"[25].*

Another example is that the price guide only considers the efficacy of the behaviour support plan and not the impact of the behaviour[26]. In planning for and managing challenging behaviour, attention must be given to the nature of the behaviour, including antecedents and triggers, and severity. Severity of behaviour is usually based on the frequency, intensity and duration, as well as the outcomes of the behaviour which, combined, will influence the supports required. For example, a behaviour that occurs infrequently but is intense when it occurs, such as property destruction or self-injury requiring medical attention, may be more severe and costly than a behaviour that occurs more frequently, such as screaming.

The effort and resources required to develop behaviour support plans and manage these behaviours will vary and may be unrelated to frequency; indeed a person's behaviours may be so well managed that they are displayed infrequently; however, supports are still required in order for that behaviour to remain well managed.

Although this may be the case, the NDIS Supported Living Arrangements support categories are based only on incidents of challenging behaviour, which does not take into account the cost and effort required to keep incidents low. These supports may include assessing the behaviours (e.g., functional assessment or analysis), planning for prevention and management of the behaviours when they are exhibited, and teaching new skills to replace challenging behaviours. These activities alone are resource intensive, require access to

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[23] Early Childhood Intervention Reform Project Revised Literature Review (2010). Department of Education and Early Childhood Development. Viewed 21 March 2017.
http://www.education.vic.gov.au/Documents/childhood/providers/needs/ecislitreviewrevised.pdf
[24] Early childhood intervention - an overview of best practice (2014). ACT Government. Viewed 21 March 2017.
http://www.communityservices.act.gov.au/__data/assets/pdf_file/0007/635695/Early-Intervention-Best-Practice.pdf.
[25] Scope Shared Living Arrangements. (2016). Dyson Consulting Group.
[26] Ibid.

behaviour specialists, and well trained staff (e.g., positive behaviour support training, support, mentoring, and practice leadership).

The skills of a support worker is another factor in what is reasonable and necessary. A person with complex needs may need specific skills and experience in a support worker. For example, skills in managing challenging behaviours, as well managing health conditions or alcohol or drug abuse. Given the difficulties that people with disability (including complex disability) face in accessing the health system[27], it also demonstrates the need for a workforce that has advanced skills in communication and knowledge of other systems or sectors (e.g., hospital system, out-of-home care, criminal justice) and capacity to navigate and cross these[28].

Formal supervision and mentoring of staff is required and is known to enhance workforce competence, however, the NDIS will only fund the cost of providing support to people with disability, not supervision and mentoring of staff who deliver support. Given the complexity of managing some of the issues that people with complex disability face (e.g. someone with a mental illness who has complex communication needs and utilises augmentative and alternative communication), there is also a need for improved access to and coordination of services.

4. Cost drivers to support people with complex disability

There is a need for a greater understanding of the cost drivers for people with complex disability that have additional support requirements due to factors such as concomitant acute, acute on chronic and chronic disease conditions.

The presence of factors considered by NDIA in determining an individual's needs-based funding level being the efficacy of a behavioural support plan, need for sleepover/active night, active management of medical support[29].

92% (257) of Scope Supported Independent Living residents have been identified as having needs, not currently considered as cost drivers by NDIA, including:

- Behaviours of concern
- Chronic/acute/complex health issues
- Co-existing mental illness
- Age
- Clients at home during the day
- Clients that require two people for morning/evening preparations
- Clients that require a two-person lift

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[27] Lennox, N. G., & Kerr, M. P. (1997). Primary health care and people with an intellectual disability: The evidence base. *Journal of Intellectual Disability Research, 41*, 365-372.

[28] Hamilton, L. (2016). The complex support needs planning resource kit: Being a planner with a person with disability and complex support needs. Research and Practice in Intellectual and Developmental Disabilities, 3, 191-199.

[29] Scope Shared Living Arrangements (2016). Dyson Consulting Group.

- Clients that require meal time assistance
- Alternative communication system
- Legal order in place
- Lack of natural supports[30].

Complexity drives cost in the provision of support in terms of intensity, duration, staff ratios e.g. OHS requirements for safe transfers, training and supervision and the regularity of interface with other service systems e.g. acute health, primary health.

Consideration to the additional costs of supporting people with complex support needs, which could be used as cost drivers, include recognition of:

- additional staff required due to additional hours of support required
- additional staff required due to higher support ratios required
- the higher cost of staff with the skills required to support people with complex needs
- the cost of providing the required systems and safeguards
- the cost of providing crises support
- the cost of facilities and transport required to support people with complex needs in group activities.

There is a need for NDIS pricing to make an additional allowance for the cost of supporting people with complex disability. This allowance could be used to increase support on an as needed basis, including crisis support that would be consistent with organisations' duty of care obligation.

5. Summary

> "Until the concept of disability disappears and is replaced by a society that is structured to support everyone's life relatedness and contribution—until that day my life and opportunities and the lives of every other person who carries the label 'disabled' depends on the goodwill of people in the human service system. Goodwill is no substitute for freedom"[31].

This paper demonstrates the need for greater recognition of the range of factors that need to be taken into account when determining policy and practice for complex disability, particularly in relation to engaging people to enter the Scheme, understanding the reasonable and necessary supports and the cost drivers.

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[30] Ibid.
[31] Shut Out: The Experience of People with Disabilities and their Families in Australia. (2009). Commonwealth of Australia.

In summary, the key matters raised in this paper in relation to supporting people with complex disability are that there is a need for:

- agreement and education on the parameters for defining complex disability
- integrated planning between the universal service system, NDIA and Disability Services Organisations
- a highly qualified, skilled and supported disability services workforce
- an expansion of cost drivers identified by the NDIA to recognise the range of supports and their interdependencies for complex disability.

6. Case Studies

The following case studies are examples of Scope's customers with complex disability taken from the East and West Divisions.

Case Study 1: Person with multiple disabilities and a range of support needs

42 year old man living in Supported Independent Living accommodation with the following disabilities and health conditions:

- Severe multifaceted neurodevelopmental disorder
- Mild intellectual disability
- Autism
- Epilepsy
- Anxiety and obsessive compulsive disorder
- Major depressive disorder
- Tourette's Syndrome with involuntary movements
- Profound deficits in volitional motor activity
- Sustained severe injuries due to involuntary movement of his head including bilateral retinal detachment resulting in total blindness
- Physical deconditioning due to self starvation and dehydration resulting in losing the ability to walk and stand.
- Sleep disturbance due to blindness (does not live according to normal or predictable circadian rhythms).

His parents are elderly and frail and he has multiple specialists involved in his care including a psychiatrist, a gastroenterologist, a neurologist, a physiotherapist and an occupational therapist.

GCR has been assessed as requiring two staff support for all hoist transfers, seizure management, behaviour support and meal assistance.

There are windows of opportunity to provide mealtime assistance to GCR at any time of the day or night – his ability to eat is not under voluntary control. GCR's Mealtime Management Plan completed by Scope's Speech Pathologist outlines that he is at risk of choking and pneumonia and is to be assisted by two staff.

GCR's Epilepsy Plan documents that he has both absent and tonic clonic seizures and these are triggered by lack of sleep, emotional distress, yelling or screaming, rambling and confusion.

GCR must be under frequent observation for his seizure activity requiring two people to support him during seizure activity. Hospitalisation is a significant stressor for him due to his blindness, anxiety and depression. The sensory overload, cognitive demands and lack of familiar staff and routines while in hospital have a significant detrimental effect on his mental, physical health and wellbeing.

GCR is incontinent and has had significant reviews and had two surgeries to

address a twisted bowel. His continence aids need to be changed immediately to prevent escalation of behaviours of concern including restlessness, distress and self harm. An increase in self harm, vocalisations and aggressive behaviour can also trigger his bowel issues and seizure activity.

GCR's Behaviour Support Plan outlines his behaviours of concerns as self harm; punching or slapping his head, face or stomach, hitting the left side of his head repeatedly which can draw blood and cause swelling and bruising. He can display harm to others by spitting, scratching, punching and hitting. He will also roll or throw himself out of bed and, intentionally or non intentionally, hit his head on objects in the bedroom. These behaviours are described as potentially occurring for hours and occasionally all night. They can also occur daily and result in an escalation of intensity lasting for long periods of time.

GCR does not have a normal sleep/wake cycle, this has been disrupted by his blindness and trials of Melatonin have been ineffective. He has a grossly disrupted sleep pattern and often misses out on sleep, a situation which his specialist described as 'medically dangerous and will increase his seizure activity'.

GCR requires two person assists at all times. There is no predictable pattern to his day and night time activities. GCR use to enjoy being in the family pool as a child and adolescent when he lived at home. Staff believed that GCR would possibly respond well to being in water. It took five people to assist GCR into the pool and to ensure his safety. After his initial anxiety, GCR relaxed to the extent that he only needed the physical support of one person and fell asleep in the water for around 30 minutes.

Some of the issues that contribute to GCR's complexity are:

- Multiple disabilities including neurological, medical, psychological and allied health support. Requires Scope to have a person responsible for him who understands the intersections between each area and can facilitate significant administrative coordination between the specialists.
- Multiple specialists involved – time spent organising appointments, tests and follow ups not funded by NDIA because this is deemed medical. Medical system does not fund case coordination.
- Elderly parents – there is a predictable need to manage their eventual deaths and then his legal requirements must be sorted out – NDIA does not fund legal advocacy.
- An unpredictable pattern to his day and night time behaviours – the staffing ratios required do not fit the NDIA framework.
- Serious potential risk to his physical wellbeing if not managed closely – no provision for staff training under the NDIA for specialist training.
- Potential serious risk to staff when GCR lashes out.

Case Study 2: Young person with complex needs

1 year old girl with developmental delays, breathing difficulties (has a tracheostomy which requires frequent suctioning and full breathing support overnight), swallowing difficulties and tongue mal-formation. She spent the first 6 months of life at the Royal Children's Hospital (RCH).

When the Early Childhood Interventions Services (ECIS) started, the family often did not turn up to appointments at the RCH and was not engaged with Maternal and Child Health Services. The family were not following hospital recommendations about appropriate food/fluid for the child's safety. The child, seen by ECIS, is the youngest of 7 children. Both of the parents are originally from Somalia and the father often "goes away" for long periods (months at a time). One of the siblings is of pre-school age and all the others are at the local school. The mother reported that she did not know who to ask so she just ignores appointments or letters if she can not attend an appointment.

Since ECIS input (12 months); RCH Complex Care Service is linked with a Key Worker who supports mum to understand appointments and to reschedule if she is unable to attend. The Key Worker often attends with mum so she can help to ask the questions she has, and help understand the recommendations being made. The child is linked with a Maternal and Child Health Nurse and receives an enhanced service (which means they now have home visits rather than needing to attend the clinic). Mum is linked in with the Salvation Army who are helping out with providing clothing, school equipment and food for all the family. Mum is following recommendations for food/drink for the child; the previous recommendations given by the hospital did not take into account how the family eat (sitting on the floor sharing food in the middle) and the home environment.   The ECIS Key Worker changed this after sharing a meal with the family. The child has now improved so much that she no longer needs modified food. The Key Worker also supported the child to trial a speaking valve, so she is able to vocalise and say words using her tracheostomy.

Most recently, the mother informed the ECIS Key Worker that the landlord had given the family 90 days notice to move out as he was planning to sell the property. The father was away and it was unclear when he was going to return. The mum had already contacted The Salvation Army support service who was allocating a care worker to find the family a new property and help out with costs such as moving costs. It is a shame that ECIS does not actually measure this but it is a massive achievement that the mum is now familiar with services and has the confidence to contact the right people to help her when she needs help, without the ECIS Key Worker.

Case Study 3: Person with complex communication needs and end of life

LS, a 64 year old women with Cerebral Palsy, had no family members active in her life. She required full personal care and used a wheelchair to be mobile. She was assessed as having no intentional communication. LS enjoyed sensory activities such as running a ribbon or tape measure through her hands. LS had significant swallowing difficulties and was seriously underweight. She needed to have a Peg inserted but the operation was deemed high risk given her very low weight. LS was hospitalised several times with aspiration pneumonia in the period preceding her death. She was admitted to hospital with aspiration pneumonia and after a few days, the hospital made the decision that she should be transferred to a palliative care service. She died there some seven days later. Scope staff maintained a bed side vigil so that LS could be comforted by familiar people.

Managing end of life processes is difficult when there is no advance directive or no capacity for the person to provide an advance directive. It does not appear that the hospital considered there to be a need for an independent person to be involved in making the decision to move LS to palliative care. In this instance, staff volunteered their time to be with LS but this is not guaranteed in all instances (and is not funded under the NDIS).