



Submission to the Department of Social Services June 2016

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

A response to the Government inquiry into designing the new integrated carer support service

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About the Department of Developmental Disability Neuropsychiatry

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Australia supports the mental health needs of individuals with an intellectual disability (ID) through the education and training of health and disability professionals and by conducting research with a particular focus on the mental health of people with ID. 3DN's vision is to work with people with ID, their carers and families, to achieve the highest attainable standard of mental health and wellbeing. 3DN is led by UNSW's inaugural Chair of Intellectual Disability Mental Health, Professor Julian Trollor, who is supported by a dedicated team of researchers, project and administrative staff. Professor Trollor has over 20 years of clinical experience in the management of people with ID and complex health and mental health problems. He has had extensive experience with a range of disability service providers and professionals, and has led or contributed to numerous legislative, policy and service reviews in the disability arena. More information about 3DN and the work of the Chair IDMH can be found on our website: <http://3dn.unsw.edu.au/>

Background

We wish to draw attention to those carers who care for a relative or friend with ID and complex support needs to ensure that the final service plans meet their needs. By "complex support needs" we refer to additional health or mental health needs, age-related problems, challenging behaviours, or additional physical or sensory disabilities.

People with ID represent about 1.8% of the Australian population, or approximately 400,000 individuals (1). People with ID experience very poor physical health and mental health compared to the general population. They often have complex support needs, which can arise because of complexity at the person level, complexity at the service level or systems levels. The prevalence of mental disorders is at least two to three times higher in people with ID compared to the general population (2). Many people with ID experience a high degree of complexity and an atypical profile and presentation of mental disorders (3), thus requiring a high level of psychiatric expertise, and coordinated approaches between services.

Carers of people with ID and complex support needs are a unique group for several reasons. Firstly, their caring role often involves a life-long journey of providing support, and as such, can involve numerous transitions due to changes in the life of the person for whom they care. These may include transitioning from school to post school options, from day programs and work to retirement, as well as the move to residential care, or the death of their relative with ID. Other major changes in the caring role can occur due to substantial changes in the care needs of the person for whom they care, such as age-related deterioration in the person with ID's health, or the onset or escalation of challenging behaviours. Another major change in the caring role may occur when the primary responsibility for care shifts to another family member, commonly from a parent to a sibling of the person with ID. These changes can be very stressful for all involved and can be a source of tension within the family (4).

Secondly, individuals with ID and complex support needs have often been identified by services and policies as a population that is more likely to fall through the 'gaps' in the current service system (5-7). This population is more likely to be disadvantaged by chronic, severe or multiple health problems across the lifespan, and a relatively high number present with challenging behaviour (8-10). As a result, people with ID frequently require cross-sectoral support, and some need continuous care. The day to day support and management of services from different sectors has thus far mostly fallen to the carers. It has been suggested that the incoming National Disability Insurance Scheme could increase the need for people with disability and carers to be involved in navigating pathways towards the care they require (11). A person with ID will likely require substantial support in dealing with the administrative burden this entails, and therefore this group of carers is likely to experience additional fatigue related to providing such support.

Recommendations

We would like to express our acknowledgement and support for the prevention driven service concept, the recognition of the uniqueness of the caring journey and the holistic approach proposed in the Draft Service Concept Paper in the Integrated Carer Support Services.

We would like to propose six key elements to be considered in developing services under the eight design elements:

1. The design elements should incorporate a lifespan approach, with support for planning and navigating transitions. The Draft Service Concept acknowledges the need to support carers at times of transition, and makes particular reference to two major ways caring can change: when the care recipient dies, or moves into residential care. We suggest that other forms of transitions in the caring role must also be considered, particularly those relating to changes in the care recipients' level of function and support needs; the care recipient transitioning to independent housing; and transitioning of care from one family member to another. For carers of people with ID, assistance in planning life transitions could be very beneficial for reducing carers' stress levels (4).

In line with a lifespan approach, there should be flexibility in determining when a carer has ceased to 'care'. For family carers of adults with ID, the stress and emotional turmoil of relinquishing care of their relative may last well beyond the period of transition. Carers of adults with ID often do not end their caring role once their relative enters residential care. A lack of flexibility within the housing options for people with ID means there are frequently ongoing concerns about the suitability of an arrangement. This can result in strained relations between family and service providers (4). Family members frequently continue to provide a large degree of assistance for their relative living in residential care, or living independently. Our department has recently investigated the relationships between the factors relating to older adults with ID and the health and wellbeing of their family carers, finding that some family members had spent over 30 hours of the prior week providing support in areas such as paperwork, medications or providing supervision or emotional support. Those whose relative with ID lived independently, spent an average of over 20 hours in the past week supporting the person with ID, with a range of 3 to 72 hours. This highlights the importance of ensuring that such carers continue to receive support beyond the care recipients' transition to residential care, and that their eligibility for practical assistance and counselling support does not automatically cease but instead is assessed on a case by case basis.

2. Effective web-based psychological and psychosocial interventions should be available. As outlined above carers of people with ID often have a unique set of circumstances that can make it difficult identify others with shared or similar experiences – the intersection of physical & intellectual disability and mental health issues can present a challenging and distinctive experience. Online formats can allow carers to connect with others in similar situations, where they may be separated by geography, cost and time. Web-based interventions and supports offer flexibility of use to people who are often over-stretched and time-poor as a result of the caring role (12). They also represent a cost-effective solution to issues of access to mental health support. Online interventions for depression and anxiety have been well established as efficacious in other populations (13-14), and would be easily adaptable for the specific needs of carers.

3. Support should be accessible at acute health services and Accident and Emergency (A&E) services for carers. People with ID have more frequent hospitalisations than the general population, including regular contact with A&E services. Carers of this population experience significant levels of stress and are more likely to be exposed to traumatic experiences in supporting their loved ones and have limited time and resource for self-care.

4. A preventative approach in assisting carers to support people with challenging behaviour should be integrated to the design elements. The prevalence of challenging behaviour in adults with ID is 10% with a range of 10% to 50% for some types of aggressive behaviour (15). Carers' wellbeing can be significantly impacted by the on-going support provided to people with challenging behaviour (16). A literature review has shown that challenging behaviour, lack of support, poor coping, dire financial concerns and carer distress are the key factors leading to relinquish care (17). However, carers have reported receiving very little family support in managing challenging behaviour (18). Information and Education on challenging behaviour should be available for carers to access.

5. Any intervention package for carers should include information regarding pathways for accessing additional mental health care via the health system. The draft highlights the need to ensure that limited resources are able to serving those with acute needs as well as serving all carers through a preventative focus. Some carers who are in acute need of psychological interventions would qualify for Medicare-funded services through the mental health system, and indeed, where a carer has an existing mental health problem, it is appropriate that they receive mental health services. However, carers may be unaware of their eligibility for such services.

6. Psychological interventions should incorporate an assessment of the way a carer appraises their role and their coping strategies, and where needed, an intervention designed to teach positive coping strategies. The Draft Service Concept gives examples of interventions found to be effective with other groups of carers. Research suggests that coping style can mediate the relationship between objective care demands and carers' subjective experience of burden (19-20). Teaching positive coping strategies could be incorporated within an intervention package, where needed.

We thank the Senate for this opportunity for input into this important issue. Should you wish to discuss the content of this submission please do not hesitate to contact us. We can be contacted by phone on (02) 9931 9160 or by email, j.trollor@unsw.edu.au,

Sincerely,



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Chair, Intellectual Disability Mental Health

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