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Developmental Disability Neuropsychiatry 3DN

Submission to the Select Committee on Autism

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## About Us

The Department of Developmental Disability Neuropsychiatry (3DN) UNSW Sydney is pleased to have the opportunity to make this submission to the Senate Select Committee on Autism (hereafter “the Committee”). 3DN is led by Professor Julian Trollor and is part of the School of Psychiatry within UNSW Medicine. We champion the right of people with an intellectual or developmental disability, including autistic people, to the same level of health and mental health care as the rest of the population. We promote a standard of excellence in clinical practice, research, workforce development, education, and policy in the field of intellectual and developmental disability mental health.

3DN has a dedicated autism research team, which coordinates the Australian Longitudinal Study of Autism in Adulthood (ALSAA; Arnold et al., 2019) and associated studies, and which is funded largely by the Australian Government through the Cooperative Research Centre for Living with Autism (Autism CRC). Our team works closely with researchers at the Olga Tennison Autism Research Centre, LaTrobe University, who lead the sister study, Study of Australian School Leavers with Autism. The 3DN team includes a current PhD candidate who is focused on a substudy on pathways to autism diagnosis in adulthood, with a previous PhD scholar on aging well on the autism spectrum (Hwang et al., 2017). A current smaller related project, also Autism CRC funded, is looking at the conceptualization of autistic burnout. Our team has published extensively on autism in adulthood, including on health needs (Foley & Trollor, 2015), barriers to healthcare (Arnold et al., 2020) and healthcare usage (Foley et al., 2017), medication usage (Birch et al., 2018), caregiver mental health (Sonido et al., 2020), anxiety (Hwang et al., 2020), depression (Arnold, et al., 2020) and suicide ideation (Hedley et al., 2018), premature mortality (Hwang et al., 2019), loneliness (Ee et al., 2019), emotion regulation (Cai et al., 2018), sleep (Jovevska et al., 2020), leisure activities (Stacey et al., 2019), the impact of receiving an autism diagnosis in adulthood (Arnold et al., 2020), resilience (Hwang et al., 2020) and quality of life (Lawson et al., 2020). We have also been recognized as an Autism CRC co-production partner, and wherever possible, utilize inclusive research practices, and work directly with autistic adults as co-researchers.

For the assistance of the Committee, 3DN is pleased to provide the contained summary of national and international literature relevant to the Committee’s Terms of Reference (ToR). We have focused on literature relating to health needs of autistic people and the health service system, given the mission of the department. We have also focused to some degree on autism in adulthood, given our research focus. We note the majority of autism research has focused on children and adolescence (Howlin & Moss, 2012; Jang et al., 2014; Nicolaidis, 2019). We outline research highlighting comparatively worse life outcomes for autistic people in Australia and the need for improved services and supports. In places we have drawn directly from Prof Trollor’s recently published Statement of Evidence to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Trollor, 2020). We also provide commentary based on our clinical and research background. Importantly, our team working on this submission includes Julianne Higgins, who is a late diagnosed autistic adult peer researcher. Collectively we agree there is a need for a National Autism Strategy, which should include a specific focus on health and community health services for autistic people.



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### *Note on Terminology*

*The language preferences of people on the autism spectrum vary, but many adults prefer identity first language (Autism CRC, 2017; Kenny et al., 2016). In response to this, the use of various terms such as "autistic person" or "autistic people", or where more appropriate "on the autism spectrum" are used throughout this statement, except in specific reference to autism diagnosis.*

## **The Prevalence of Autism in Australia (regards ToR b)**

Autism Spectrum Disorder (ASD) is defined as a developmental disorder characterised by impairments in social communication, and restricted or repetitive behaviours, interests, or activities. This heterogeneous and complex disorder impacts on daily functioning ranging from mild to profound (Williams et al., 2014). Over 60% of the people on the autism spectrum have a disability involving profound or severe restrictions in core activities of daily living (Australian Bureau of Statistics, 2016). A combination of developmental assessments and behavioural observations are used during the diagnostic process (Whitehouse et al., 2018).

**We wish for the Committee to have an understanding of intellectual disability and its intersection with autism.** Intellectual disability is a form of developmental disability characterised by impaired mental abilities and reduced ability to manage common demands of day-to-day life (adaptive functioning). The Australian Institute of Health and Welfare (AIHW) estimate an Australian population prevalence of 1.86% for intellectual disability (Wen, 1997). A person with intellectual disability may have difficulty with thinking skills that impact planning, problem solving, abstract thinking and learning. They may also experience difficulties with communication, social skills, and independently managing daily activities. While autism and intellectual disability are separate developmental conditions, approximately 1.08 people in every thousand are estimated to have both intellectual disability and autism (Dunn et al., 2019). This dual diagnosis had been linked to poorer health status and more complex health care needs across the lifespan (Dunn et al., 2019).

**We wish for the Committee to also have an understanding of developmental disability and differentiation (Bigby & Clegg, 2018), and where systematic changes are needed specifically for autistic people, or where change could be of benefit to the larger group of people with developmental disability, or the broader Australian population.** American data suggests in children aged 3-17 developmental disability has a prevalence of 6.99% (Zablotsky et al., 2017). Both autism and intellectual disability fall under the broader categorisation of developmental disabilities, and many systematic changes required in our health and community support systems could be applied to the benefit of this larger population grouping. If principles of Universal Design (Story, 2006) are followed in the design and redesign of service delivery, then overall improvements implemented for autistic people are likely to benefit many service users from the broader Australian population.

According to data from 2015, approximately 1 in 150 Australians, or 0.7% of the population are estimated to be on the autism spectrum (AIHW, 2017). Over the past 70 years, the reported worldwide prevalence of autism has increased dramatically from 4 in 10,000 people to 1 in 100 people (Ward et al., 2016). Australian statistics reflect this rise, with a 79% increase in the number of children diagnosed with autism since 2009 (Autism in Australia, 2009). It is likely that improved clinician awareness, screening practices and expanded diagnostic criteria are the chief drivers behind these significant shifts in prevalence (Hansen et al., 2015; King & Bearman, 2009; Ward et al., 2016). Given childhood rates of 1 in 54 recently reported in American studies (Maenner, 2020), and the fact that autism is a lifelong condition, **we highlight to the committee it is likely that Australian data are underestimating the true population prevalence of autism.**

International systematic reviews report autism prevalence among people with intellectual disability to fall between 8% and 30% in adult populations (Emerson & Baines, 2010), and between 4.5% and 25.1% in younger populations (Oeseburg et al., 2011). Factors such as severity of intellectual disability, sample selection and diagnostic criteria used in studies all contribute to this variance (Dunn et al., 2019). Prevalence of intellectual disability among autistic people falls between 15% and 84% (Emerson & Baines, 2010). Co-occurring prevalence rates have declined with expanded autism diagnostic criteria and the identification of more autistic people with less intense or constant support needs (Dunn et al., 2019).

## **Current approaches and barriers to consistent, timely and best practice autism diagnosis (regards ToR a)**

We refer the Committee to the significant body of work undertaken to develop the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia (“the National Guideline”) on autism diagnosis (Whitehouse et al., 2018). Professor Trollor was the representative for the Royal Australian and New Zealand College of Psychiatrists for the committee overseeing its development.

Our published work (Arnold et al., 2020; Huang et al., 2020) highlights, in regard to diagnosis of autism in adulthood:

- The high and prohibitive expense of autism diagnosis
- The lack of supports or services for autistic adults at diagnosis
- The significant time delay between suspicion of autism to diagnosis
- The lack of support or services for autistic adults in general
- The frequent lack of expertise in treating health and allied health professionals
- That some adults who suspect they are autistic do not continue to seek a formal diagnosis, due to the related expense and lack of services available post-diagnosis
- The importance of trained clinicians that approach autism diagnosis, and the communication of diagnosis with sensitivity, and focus on strengths and difference relating to autism, rather than deficits.

We are currently analysing data where we have surveyed autistic adults in regard to the ideal supports and services needs following diagnosis, and in the process of publishing data related to pathways to diagnosis in adulthood in Australia. We would be pleased to provide the Committee with further data and detail if desired. **We recommend 1) that post-diagnosis services and support groups are needed, particularly for**

autistic adults, 2) action to reduce the costs of diagnosis, and 3) co-developed training for diagnosing clinicians with a focus on neurodiversity and updated information of the heterogenic presentations of autism is needed.

## **Misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services. (regards ToR c)**

It is commonly reported that the prevalence of autism in boys is 4 times higher than in girls (e.g. Maenner, 2020), though a recent review suggests the ratio is closer to 3:1 (Loomes et al., 2017), with other studies suggesting it could be even lower than this (see Arnold et al., 2019). Potential reasons for this ratio discrepancy have found:

- ASD diagnosis tends to be centred on male-dominated presentation of symptoms, thus impacting effective diagnosis of autistic girls (Hiller et al., 2016).
- Detection of autistic symptomatology may be more challenging in girls possibly due to the influence of caregiver's perception of gender specific "acceptable" behaviours (Dworzynski et al., 2012; Hiller et al., 2016).
- Socio-cultural differences in gender-based expectations can also lead to differences in interpretation of presenting symptomatology (Geelhand et al., 2019).

**We recommended co-developed training for diagnosing clinicians with a focus on neurodiversity, and updated information of the heterogenic presentations including those in girls and women.**

## **International best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity. (regards ToR d)**

With respect to diagnosis we again refer the Committee to the work on the National Guideline that included a review of international best practice. We note the National Guidelines makes reference to an assessment of functioning and support needs, where there is currently no tool available that is fit for purpose. Although we have collaborated in some work towards the development of such a tool with colleagues affiliated with the Autism CRC, **we recommend targeted research funding is needed to fully develop an assessment of functioning and support needs specific to autism.** This tool would be needed in order to realise the implementation of the National Guidelines. The development of such a tool would likely also be of great benefit to the National Disability Insurance Scheme (NDIS).

With respect to support services we again highlight findings from our research published and underway that identifies a paucity of services for autistic adults in general, and particularly for those diagnosed in adulthood. We also highlight the barriers and lack of appropriately trained clinicians in the field of health and mental health care, which we address in greater detail below. **We recommend that post-diagnosis services and support groups are needed, particularly for autistic adults. We recommend actions to reduce the costs of diagnosis are needed.**

## **The demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages; (regards ToR e)**

### **The Complex Health and Mental Health Needs of Autistic People**

A combination of physical and psychiatric co-morbidities, adaptive functioning challenges and contextual stressors such as poverty, unaccommodating environments and contact with the criminal justice system, contribute to the complex health care needs of individuals on the autism spectrum. To provide this vulnerable population with the same standard of health care as is afforded to the general population, significant adaptations to standard practice are required.

These include: a health workforce with sufficient knowledge and training to tailor practice to patients' complex needs and communication requirements; accessible health care information and accessible health care services; specialist multidisciplinary health teams to support cases with additional complexities; strong cross sector collaboration to ensure a coordinated approach in the face of multi-morbidities; and well defined strategies and pathways to co-ordinate effective health care at the intersection of disability, mental and physical health domains.

Physical and mental health co-morbidities (Arnold et al., 2019), core adaptive functioning impairments and other vulnerabilities commonly occur in autistic populations (Henninger & Taylor, 2013). There are significant implications of these complex presentations, both in terms of health care needs and service delivery requirements.

In addition to their primary developmental condition, autistic people have a high number of co-occurring physical and psychiatric morbidities (Bishop-Fitzpatrick & Kind, 2017; Cashin et al., 2018). Higher rates of co-morbidities have been reported in both child and adult autistic populations (Jones et al., 2016; Kohane et al., 2012). While quantitative Australian data is limited, a United States (US) study in 2010 reported a 94% rate of comorbid health conditions among autistic children compared to only 17% among those without autism (Curtin et al., 2010).

Very high rates of mental ill health have been reported (Kohane et al., 2012; Mannion & Leader, 2013). Depression and anxiety disorders are the most common conditions experienced. Whilst most research has focused on children and adolescents (Gillberg & Billstedt, 2000; Simonoff et al., 2008), very high rates of mental ill health are also observed in autistic adults internationally (Croen et al., 2015; Lever & Geurts, 2016) and in Australian adults on the autism spectrum (Cvejic et al., 2018; Hedley et al., 2018; Uljarević et al., 2019). A striking feature is the very high rates of suicidal ideation (Hedley et al., 2018) experienced by this group. While Australian data relating to suicide attempts is limited, a large 2015 US study comparing health of autistic adults with a non-autistic control group found a 5-fold risk of suicide attempts in the autistic group (Croen et al., 2015). **We recommend that people on the autism spectrum are a population**



**group with significant vulnerability to mental ill health for whom specific responses and environmental accommodations should be provided.**

Compared to the general population, autistic people experience higher rates of a range of physical health co-morbidities (Cashin et al., 2018; Cooper et al., 2015; Croen et al., 2015; Krahn et al., 2006). These include the following:

### Sensory differences and sensitivities

Sensory differences are overrepresented among autistic people (Thye et al., 2018). While Australian data is lacking, a number of sensory conditions have been described in autistic populations internationally, including both hyper and hypo sensitivity to sensory stimuli (Thye et al., 2018) and visual processing differences (Croen et al., 2015; Simmons et al., 2009) including an increased prevalence of strabismus (a condition which results in a squint, and if uncorrected, impairment of vision in the affected eye) (Butchart et al., 2017). Atypical auditory processing (Croen et al., 2015; O'Connor, 2012) and differences in olfaction and gustation responses have also been described (Tavassoli & Baron-Cohen, 2012). Autistic populations therefore experience a range of sensory challenges, exacerbated by unaccommodating environments, which need to be taken into account in health care. For example, care providers need to screen for and provide appropriate supports to autistic people who also have sensory differences and sensory sensitivities. This is vital as under-detection and under-treatment of visual impairments has been linked to decreased quality of life and receptiveness to new information and increased levels of stress and potential behaviours of concern (Butchart et al., 2017). Since atypical sensory processing also impact how patients engage with a range of clinical assessments, clinicians require specific expertise to tailor their assessments accordingly (Butchart et al., 2017).

Further, sensory sensitivities can be a barrier to accessing healthcare (Dern & Sappok, 2014; Raymaker et al., 2017). **We recommend targeted funding to develop and implement a program of research to improve accessibility of Australian health services for autistic people.** Initiatives such as the Coles quiet hour need to be considered and contextualised to health service delivery.

### Epilepsy

Epilepsy is overrepresented in autistic populations. While Australian data is lacking, a correlation between epilepsy and autism has been noted in the international literature (Bolton et al., 2011; Croen et al., 2015; Kohane et al., 2012; Mannion & Leader, 2013; Spence & Schneider, 2009). A recent systematic review that included 74 topical studies (n=283,549) reported a 12.1% median overall period prevalence of epilepsy among the autistic cohorts (Lukmanji et al., 2019). Epilepsy has been associated with an increased risk of falls, cuts, burns, broken bones, head trauma and respiratory issues (Shafer, 2014). People who have been diagnosed with epilepsy have an overall risk of dying that is 1.6 to 3 times higher than comparable populations without epilepsy (Shafer, 2014). Given the demonstrated higher prevalence of epilepsy among autistic people, **we recommend specific responses should be provided by our health system to mitigate epilepsy related risks in these populations.**

## Problematic feeding behaviours

Problematic feeding behaviours such as gorging and eating non-food items (pica) are overrepresented among autistic people (Sharp et al., 2013). Pica prevalence has been noted to increase with disability severity and in populations with co-occurring autism (Matson et al., 2011). Feeding issues are also more prevalent in autistic populations compared to age matched peers (Spek et al., 2020; Vissoker et al., 2019). Driven by a combination of behavioural rigidities, social idiosyncrasies and sensory processing difficulties, problematic feeding behaviours among autistic children include increased food selectivity (Zhu & Dalby-Payne, 2019), higher rates of pica (Kral et al., 2013), and food refusal (Bennetto et al., 2012). Risk of nutritional deficiencies and poor diet quality is therefore higher for autistic people due to issues relating to food selectivity (Kral et al., 2013). A high prevalence of dental caries (tooth decay) and periodontal disease has also been noted in paediatric autistic populations (da Silva et al., 2017). Feeding difficulties and high rates of oral ill-health increase respiratory and other risks for autistic people. **We recommend tailored oral health policies, routine implementation of swallowing assessments and mealtime management plans for at risk individuals are examples of strategies that need to be embedded within health care policy to address this vulnerability** (da Silva et al., 2017).

## Respiratory and gastrointestinal diseases

International data has identified higher rates of a variety of gastro-intestinal disturbances among autistic cohorts compared to controls (Buie et al., 2010; Nikolov et al., 2009; Tyler et al., 2011). Significantly higher rates of bowel disease, for example, have been reported in autistic people aged under 35 years compared to aged matched non-autistic people (Kohane et al., 2012). A recent international review that included 144 topical studies reported the following median prevalence rates for gastrointestinal disturbances among autistic cohorts: constipation (22%); diarrhea (13.0%); any or more than one gastrointestinal symptom (46.8%) (Holingue et al., 2018). **We recommend the higher vulnerability to gastrointestinal and respiratory issues among autistic cohorts are areas of concern for which specific tailored health care responses should be developed to mitigate risk.**

## Mobility restrictions

Autistic people experience a range of movement related challenges that are more than those experienced by the general population. Australian data has highlighted that in populations with co-occurring disability and autism, 52% are reported to have profound or severe limitations in mobility (Australian Institute of Health and Welfare, 2017). Delays in motor development and a number of other motor abnormalities have also been reported to be overrepresented in autistic populations (Hocking & Caeyenberghs, 2017). A 2010 international meta-analysis of 83 studies, for example, found that autistic cohorts had substantial motor coordination difficulties compared to controls (Fournier et al., 2010). This included difficulties with motor planning, sensorimotor integration, and motor execution. Movement difficulties and mobility related challenges are thus overrepresented in autistic cohorts. **We recommend specific health care policy and practice responses are required to address these vulnerabilities relating to mobility.**



## Frailty and premature aging

Frailty is characterised by diminished strength and physiologic function that increases a person's vulnerability for dependency and/or death. To date little research has focused on the impacts of frailty and aging for autistic people (Wise, 2019). While Australian data is lacking, early onset Parkinsonism has been noted in international studies to be higher among autistic cohorts than in comparable general population groups (Croen et al., 2015; Starkstein et al., 2015). Several studies have also reported comparatively greater rates of age-related decline for autistic people in measures such as sustained attention, working memory, fluency (Geurts & Vissers, 2012) and cognitive flexibility (Powell et al., 2017). Accelerated brain cell loss has also been described in a longitudinal study of autistic people compared to controls (Zielinski et al., 2014). However, there is both a lack of sufficient studies and consistency of findings (Roestorf et al., 2019; Wise, 2019) to make a conclusive statement about the full interaction of aging and autism at present. Populations with co-occurring intellectual disability and autism also appear to have an increased vulnerability to premature aging. While Australian data is lacking, an ongoing prospective multicentric study in France found that the comorbidity burden of the cohort with co-occurring intellectual disability and autism (mean age 42.9 years) was comparable with that of a much older general hospital geriatric population (mean age 79 years) (Miot et al., 2019). Given the complex health care profile of aging populations with intellectual disability and/or autism, that includes a high co-morbidity burden (Miot et al., 2019), **we recommend specialised training for health care staff and specific health care policies are needed to provide optimum care to these populations** (Reppermund & Trollor, 2016; Wise, 2019; World Health Organization, 2000).

## Other overrepresented health conditions

An overrepresentation of sleep difficulties has been described in populations with autism (Cortesi et al., 2010; Mannion & Leader, 2013). A 2012 US study in people under 35 years old, for example, found that sleep disorders were 10 times more prevalent in the autistic group than among people without autism (Kohane et al., 2012). Recent evidence suggests that autistic individuals continue to experience sleep problems across their lifespan, and these problems are characterized by poorer sleep quality and taking longer to fall asleep (Jovevska et al., 2020). A study examining sleep quality in autistic adolescents and adults have found that it serves as a significant predictor for quality of life associated with physical health (Lawson et al., 2020). A comparative overrepresentation of dyslipidaemia and hypertension has also been described internationally in autistic adult cohorts (Croen et al., 2015). Multimorbidity and complex health care needs across the lifespan are common for individuals on the autism spectrum. The extent of multimorbidity suggests that this population group experiences one of the most significant health disadvantages of any population group in Australia. Meeting these needs requires a health care system which is responsive at each level, including health policy, health services, and individual practitioners.

## Intersection of disability and health care needs

In addition to the multi-morbidities described above, challenges related to the core features of autism also impact on health care needs and service delivery. These challenges include communication differences,



sensory sensitivities and adaptive functioning difficulties. The impact of these factors on health care provision are outlined below.

People on the autism spectrum display significant variability in functional language ability. For some autistic individuals, communication difficulties may be limited to pragmatics such as topic selection, use of appropriate conversational style, or metaphor comprehension (Boardman et al., 2014). Autistic people with high support needs and/or including co-occurring intellectual disability on the other hand may not develop effective speech (Shields & Hare, 2001). Over 50% of autistic people with intellectual disability experience severe or profound communication impairments, impacting understanding or being understood by others (Australian Institute of Health and Welfare, 2017).

Lower adaptive functioning coupled with communication challenges means that, compared to the general population, autistic people are more likely to be reliant on external people for support with day-to-day activities such as accessing transport, food, or health care. They are also more likely to receive care from disability services.

These cognitive differences mean that many autistic people may have difficulty with learning new information, or with processing and interpreting written or spoken information. Cognitive, communication based, and adaptive functioning challenges associated with intellectual disability and/or autism, have multiple implications for health care provision. For example, health related knowledge among populations with co-occurring intellectual disability may be lower, and ability to self-initiate health related help seeking and to navigate complex systems, may be impacted.

Written brochures and other health related resources designed for the general population might be inaccessible for many in these cohorts, and ability to participate in generic preventative health measures may be limited as a result.

It has been observed that some autistic people may struggle to identify or communicate their internal experiences of mental distress or physical discomfort to clinicians (Arnold et al., 2020). Diagnostic overshadowing therefore occurs more frequently in such populations, especially in the absence of effective communication strategies.

To overcome these challenges, we are of the view and **recommend that clinicians require disability specific knowledge and training including in the use of adapted communication and diagnosis of atypical presentations** (Arnold et al., 2020). This training should be developed and delivered in partnership with autistic people. The training should address the multiple elevated health needs of autistic people, though also address concepts of neurodiversity and avoid a deficit-based approach. Care pathways need to be clear and well defined to ensure that the person can participate in health care interactions as fully as possible.

Services need to consider the sensory environment and interactions with patients to achieve more autism-friendliness. Aspects of the process underlying access to healthcare service such as exposure to the waiting room, changes to waiting time, travel to the clinic/hospital, and other environmental factors (lighting) have been found to play a role in causing sensory overload (Dern & Sappok, 2014; Nicolaidis et al., 2015, 2016; Saqr et al., 2018). Therefore the contribution of these sensory sensitivities as a significant barrier towards

healthcare for autistic individuals need to be considered (Mason et al., 2019). As mentioned, we continue to seek funding to develop and implement a program of research to make Australian health services more accessible to autistic people. **We recommend targeted funding to develop and implement a program of research to improve accessibility of Australian health services for autistic people.** Initiatives such as the Coles quiet hour need to be considered and contextualised to Australian health services delivery.

### Specific highly vulnerable populations

The health care needs of populations with autism and additional vulnerabilities such as poverty and those with contact with the criminal justice system are especially complex. Among a US paediatric population with autism, neighbourhood affluence was also linked to greater access to early intensive behavioural intervention (Yingling et al., 2019). Specific strategies and additional supports are required to ensure health care access for those with autism living in poverty. While data is limited for autistic populations, there is some evidence that this group may also be over-represented in prison populations (Cashin & Newman, 2009).

## Recommendations to improve healthcare for autistic people

In Professor Trollor's Statement of evidence to the Disability Royal Commission, he highlighted key building blocks of a comprehensive health service system and these are useful to highlight key actions in healthcare for autistic people to The Committee. The World Health Organization (WHO) describes six building blocks of health systems that have been used to frame strengthening of health services worldwide (World Health Organization, 2007). These building blocks are:

1. Service delivery
2. Health workforce
3. Health information
4. Medical products, vaccines and technologies
5. Financing
6. Leadership and governance.

This framework provides a simple structure under which to organize recommendations for improvement of health services for people on the autism spectrum with and without intellectual disability.

### 1. Service delivery

#### *Reasonable adjustments*

Best practice internationally involves the implementation of 'reasonable adjustments' to ensure that health professionals and services can meet the needs of people with disabilities. These are a legislated requirement in some jurisdictions including the National Health Service in the UK, under the Equality Act 2010 (UK) (National Health Service (NHS)). In an Australian context, key 'adjustments' have been identified

to make mental health services accessible for people with intellectual disability. These have been articulated in Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers ("The Guide") (Department of Developmental Disability Neuropsychiatry (3DN), 2014). Arguably, these adjustments are equally applicable to autistic people and the whole of health care. They include the adaptation of clinical approaches involving making reasonable adjustments related to the person's disability within clinical interactions, adapting and ensuring effective communication, involving the person in decision making, and working with family and carers according to the preferences of the individual. These adjustments are universally required in clinical interactions. **We recommend reasonable adjustments should be a mandated requirement for health practitioners and services.**

### *Provision of health information*

Provision of health information is vital. A comprehensive recommendation is available on this issue (Department of Developmental Disability Neuropsychiatry (3DN), 2018). Consumer health information and health promotion materials (including online materials) are not routinely made available in formats that are accessible to people on the autism spectrum. This is an important step in enabling people with disability to understand and manage their health needs. Health services do not routinely have accessible information available for people who are unable to read and understand conventional health information. **We recommend a minimum service standard should be set which ensures all health information, and all mainstream health services information, including commonly utilized forms and patient information, should be available in an accessible format.** This should be accompanied by training for health staff so that they know how to use them.

### *Development of services and service models*

People on the autism spectrum, with or without intellectual disability, have a right to timely access to health services at every stage of life. As noted by a research participant in the UK "People like me don't get support", with an urgent need for the develop of clinical pathways needed (Camm-Crosbie et al., 2019). This situation also exists in Australia. **We recommend a requirement for all mainstream health and mental health services to develop clinical care pathways through each of their core service components.** Information about these care pathways should be available to external health providers, health care consumers and carers. This would complement 'reasonable adjustments' above (Department of Developmental Disability Neuropsychiatry (3DN), 2014).

It is critical that models of integrated care are developed and implemented across each state and territory that specifically target the health needs of people on the autism spectrum. An integrated care working group could be established with high level support. Opportunities could be sought to integrate the needs of autistic people into all existing integrated care initiatives.

Access to specialist health services for people with developmental differences such as intellectual disability or autism in Australia is currently very limited and varies substantially across jurisdictions. These are most well developed in NSW, where a few pilot programs have been implemented. Where they do exist, specialist services form a very valuable component of comprehensive health services for people on the autism spectrum with or without intellectual disability. **We recommend all States and Territories should**

**develop and implement a specialised model of care which includes mental health and whole of health care across the life span, with these services inclusive of the health needs of those on the autism spectrum.**

For very complex individuals, particularly those autistic people with intellectual disability, a formalised service is required in each jurisdiction to provide a one stop comprehensive evaluation of health care needs including oral health care and, if necessary, imaging, and other investigations and procedures under anaesthetic. These services would ensure timely and comprehensive assessment in situations of significant complexity. To address the high rate of potentially avoidable morbidity and hospitalisations, **we recommend the specific inclusion of the needs of people on the autism spectrum is required in all primary care and preventative health initiatives.**

## 2. Health workforce

### *Training for all future doctors, nurses and allied health*

Australia's higher education sector plays a key role in preparing medical and nursing graduates to meet the diverse health care needs of our population. Training provides an opportunity to shape attitudes, teach skills and provide direct experiential learning with autistic people. Unfortunately, from our experience and as described in an open letter to King's College London (Vivian, 2019), university education can often provide a deficit-based education regarding autism and potentially further exacerbate clinician misunderstandings. International and Australian research has noted this lack of understanding of autism and need for co-delivered training of future health practitioners (Arnold et al., 2020; Maddox et al., 2020; Urbanowicz et al., 2020; Vogan et al., 2017). **We recommend mandated training for all medical, psychological and nursing students that is co-developed by autistic adults. We recommend, similar to work that has been conducted regarding intellectual disability, a national audit of university education for doctors, nurses and psychologists, identifying the extent of coverage of the specific needs of autistic people, and whether autism is presented as a difference or deficit.** This should be accompanied by the co-development, with autistic adults, of neurodiversity education resource packs made available to university educators, tailored to each clinical discipline. This work could go alongside efforts to improve university education on intellectual disability.

### *Mandatory training for the health workforce*

A broad range of clinical and non-clinical professionals interact with people on the autism spectrum during access to acute and non-acute health care. To mitigate the lack of training, skills and confidence, **we recommended that all staff in public facilities undertake mandatory minimum basic training to ensure they adopt appropriate attitudes and are able to adjust their practice to meet the needs of people with intellectual or developmental disability, including autism.** This could be incorporated for example as a component of existing mandatory training in public and community health system settings for all administrative and clinical staff. The passing of legislation to ensure mandatory training in these areas is in progress in the UK (UK Parliament, 2020). Staff in some clinical departments require greater skills and training. Clinicians in Emergency Departments and acute inpatient settings frequently encounter autistic people, including those with complex needs. **We recommend that all clinical staff undertake specific training to a higher standard. Training could be tiered in complexity depending on role (basic,**

intermediate, expert). Such training should ideally be based on an overarching national competency framework, which could be developed for health professionals in public settings. A useful model is the competency Manual and Toolkit we developed at 3DN for the New South Wales Mental Health Workforce which is focused on intellectual disability. It could easily be implemented nationally across mental health settings. The methods we used to develop it could be a useful starting point for the development of a whole of health competency framework. Further, 3DN's e-Learning, such as the comprehensive courses developed for health professionals, disability professionals and carers, (Department of Developmental Disability Neuropsychiatry (3DN), 2020) although focused on intellectual disability, could also be a useful model for the further development of training.

#### *Enhanced training and career pathways for existing medical/specialists*

Enhanced training for specific medical specialty groups is required so that people on the autism spectrum can have their health needs met by their health care specialist. Key target groups should include general practitioners, paediatricians, psychiatrists, rehabilitation physicians and emergency physicians. For each of these groups, **it is recommended that improved training regarding autism and neurodiversity is incorporated into medical specialty training.**

#### *Subspecialty training in key medical specialties*

**We recommend formal subspecialty training capacity should be developed for general practitioners, psychiatrists and specific groups of physicians. This training should focus on developmental disability, including autism and intellectual disability.** Scoping of the need and feasibility of subspecialty training is an essential prior step. At present, there is no definitive subspecialty Faculty within the Royal Australian New Zealand College of Psychiatrists (RANZCP), but the proposal for its development has been supported by the RANZCP at the highest level. 3DN recently conducted a series of scoping studies to examine workforce capacity, need and feasibility of subspecialty training in Psychiatry (Eagleson et al., 2019). This methodology may provide useful guidance for other specialty areas. There has been some experience with this in NSW with a training of 15 new subspecialists in the area of intellectual disability mental health. Initially, this was a program funded by the former Ageing, Disability and Home Care, part of the Department of Family and Community Services, NSW Government. The program is now funded through competitive application for training through the Health Education and Training Institute (HETI). The experiences of some of these trainees are summarised on the 3DN website (Department of Developmental Disability Neuropsychiatry (3DN), 2018).

#### *Career pathway development in key medical specialties*

In addition to subspecialty training, it is vital that career paths are available for medical practitioners who wish to practice as subspecialists in this area. Despite training 15 new subspecialty psychiatrists in NSW over the past 10 years, very few of them have been able to find funded positions within the public health system in NSW.



*Development of a national training centre and resources clearing house*

Resources developed by Autism CRC (Autism CRC, 2020a) are dependent on the continuing funding of that entity. **We recommend the development of a national training centre and resource clearing house would equip the workforce by developing, collating and disseminating resources for health professionals to support improved practice for people with intellectual or developmental disabilities, including those on the autism spectrum.** A national training and resources clearing house could be virtual, with different components. For example, mental health, acute care, paediatric care, etc. being the responsibility of specific expert groups.

**3. Health information**

Critical to improving health outcomes for people on the autism spectrum is accountability by services and government. To date, exposure of health outcomes has largely been left to the research community. However, there are multiple barriers, very large costs, and significant time delay in the creation of the necessary data linkage infrastructure when undertaking such research. In keeping with national practices for groups with substantial health disadvantage such as Aboriginal and Torres Strait Islander people, **it is recommended that population health outcomes for people with developmental disabilities and those on the autism spectrum, including health status, health service utilization and health outcomes are routinely analysed and reported.** We refer the committee to detailed recommendations that have been made under Recommendations 1, 2 and 3, Element 7 of The Communique in relation to mental health data for people with intellectual disability, and that these recommendations could also be contextualised to autistic people (Department of Developmental Disability Neuropsychiatry (3DN), 2018).

The Australian Data and Digital Council recently announced support for the development of a "National Disability Data Asset." (Australian Government, Department of the Prime Minister and Cabinet, Australian Data and Digital Council, 2019) At this stage it is unclear whether this data asset would lend itself to routine reporting regarding health and well-being outcomes to the community and to government. Furthermore, it remains uncertain whether such a resource would be accessible to researchers.

As a whole of population capture is required to properly examine outcomes, it would be critical for this resource not to focus only on people with disability who access disability or other funded services, as this would capture a non-representative sample of people with specific disabilities, particularly as many autistic adults without intellectual disability are currently not eligible for NDIS. 3DN's work with data linkage suggests that it is feasible and important to develop a system which enables whole of population capture for people with different types of disability, as this enables the most comprehensive understanding of the health and well-being of these populations and their subgroups.

**4. Medical products and technologies**

The use of new technologies is underexploited for people with developmental disabilities and advances are usually delayed in reaching such groups. Emerging artificial intelligence systems could be used to assist in accessing medical services in a timely manner; in medical decision making for people with disabilities and

their carers; and in adherence to treatment. E-health initiatives are in the early phase of development for people with intellectual disability and could be very valuable for people on the autism spectrum. The Black Dog Institute and collaborators have recently developed an online treatment for depression and anxiety for people with intellectual disability. This resource will be evaluated in a clinical trial (Black Dog Institute, 2020). Overseas there has been development of online resources for anxiety treatment for autistic people (Autistica, 2018). **We recommend specific inclusion of people with intellectual disability and people on the autism spectrum as priority groups in competitive funding programs for the development and testing of technologies in health care.**

## 5. Financing

### *Revision of the Medicare Benefits Schedule*

The current Medicare Benefits Schedule (MBS) structure does not enable general practitioners and psychiatrists to support the health needs of people on the autism spectrum with more complex health needs. **We recommend MBS item numbers should be revised in consultation with representatives from these populations to ensure financial viability for health care providers working to meet the needs of people with complex needs, including people with autism and co-occurring health and mental health issues.**

## 6. Leadership and governance

### *Health and disability policy*

The specific needs of people on the autism spectrum are rarely incorporated in national, state or territory health and mental health policy documents, including in overarching health and mental health plans. Given their more frequent and complex health needs, as well as our Australian data that has demonstrated their higher mortality rates associate with mental and physical health (Hwang, et al., 2020), **we recommend these population groups should be specifically named and accommodated within all health policy frameworks, with input from people with lived experience, carers and advocates.** Health and its intersection with disability service provision should also be considered in all high-level policy and standards for disability services provision; for example in the National Standards for Disability Services.

### *Leadership in the disability services sector*

The disability services sector and disability professionals represent critical players in access to health care and continuity of health care for people with disability who receive disability services. It is, therefore, important that professionals working in the disability system are equipped with basic competences in disability health care so that they are supported to do a good job. This could be improved, for example, by including health in the National Standards for Disability Services (Australian Government, 2020) and by ensuring future practice standards and similar frameworks developed by the NDIS Quality and Safeguards Commission specifically outline health-related aspects in such a way that the responsibility of disability and health services in this area is clear and that interagency initiatives are enhanced.

## Further specific action to monitor and prevent deaths

In a recent study we demonstrated that there is a higher risk of mortality in the autistic population that have co-occurring physical and mental health conditions (Hwang et al., 2019). The leading cause of death in the autistic population was attributed to injury and poisoning (including accidents, suicide and self-harm) and “nervous system and sense disorders” (such as epilepsy). Specific recommendations pertaining to the importance of management of comorbid physical and mental health conditions for autistic individuals have been outlined in this study (Hwang et al., 2019). On-going comprehensive state and national mortality data is needed to provide insight into population specific patterns that will then form the basis of targeted preventative and public health initiatives (Lauer & McCallion, 2015). Analysis and reporting of mortality data will detect gaps in care and care pathways, and direct future health care and social service spending, and research initiatives towards areas of high need (Rogers & Crimmins, 2011). Trends in mortality data over-time are also crucial in tracking the impact of policy shifts and other changes in the health and social care landscape on the health of vulnerable populations (Lauer & McCallion, 2015). The NDIS Quality and Safeguards Commission provides an opportunity to develop Australia's first national arrangement for reporting deaths of people with disability. However, for a death to become a reportable one, it must have occurred or been alleged to occur in connection with the provision of supports or services by a registered NDIS provider, and involve an act or omission defined in section 73Z(4) of the *National Disability Insurance Scheme Act 2013* (Cth). Defining reportable deaths in this manner poses significant limitations in the collation and analysis and understanding of deaths in people with disabilities. The deaths of many Australians with disabilities, including those with disability who do not meet criteria for NDIS funding, those receiving supports from providers who are not registered, those whose deaths are not deemed to have occurred in association with the provision of disability supports, and deaths in specific compartments such as those with disabilities dying in residential aged care facilities (Salomon & Trollor, 2019) will not be examined under this arrangement.

Unless the approach is modified, this system will not represent a comprehensive way of reporting, analysing and understanding deaths of people on the autism spectrum from a population health and systems perspective. Without modification, this approach will perpetuate inadequate mortality monitoring practices.

**We recommend that a national platform is required to comprehensively track mortality data for autistic populations over time.** This should include death data, not only for NDIS recipients, but also for people with diagnosed disabilities who do not qualify for NDIS services, as well those who reside in aged care facilities or custodial settings.

Consideration should also be given to developing specific codes within the National Coronial Information System database to better identify people with disabilities.

**We recommend specific strategies should be put in place to reduce the high rates of mortality from potentially avoidable causes that have been described in Australian autistic population.**

## **The interaction between services provided by the Commonwealth, state and local governments, including health and mental health, education, employment, justice, and housing (regards ToR f)**

Autistic people experience a mismatch between their health care needs and the health care services they currently receive. Gaps are systemic and pervasive in nature and span inadequate engagement in preventative health care services, missed diagnosis (Huang et al., 2020) and poor end-of-life care and disease and risk management (Foley & Trollor, 2015; Hwang et al., 2017), and non-evidence based prescribing practices (Cvejic et al., 2018). Poor health trajectories and increased mortality among autistic Australians, particularly from causes that are potentially avoidable or amenable to intervention, emphasise core failures within our current health care system to meet the needs of this vulnerable population. Urgent action on these issues is required in order that Australia meet its obligations under the UNCRPD (United Nations General Assembly, 2007).

The current health care landscape in Australia is one of lack of preparedness for the needs of autistic people. This lack of preparedness manifests on every level (practitioner, services, policy); in each health care compartment (primary, specialist and acute care settings); and in services across the life span (from childhood to later life). Such systemic lack of preparedness is a major contributor to the stark mental and physical health disadvantage experienced by people with developmental disabilities compared to the general Australian population.

The right of Australians with disabilities to "enjoyment of the highest attainable standard of health without discrimination on the basis of disability" is clearly laid out in Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, United Nations General Assembly, 2007). This convention, which has been signed and ratified by Australia, stipulates Australia's obligation to tailor health care services to ensure people with disability receive the same "range, quality, and standard" of health care as the general population. Realising this goal for autistic people requires clinicians, health systems and policies that understand and respond adaptively to the complex and multifaceted impacts of these developmental differences.

## **The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people; (regards ToR g)**

Although not an area of research focus, we understand there is strong evidence of cost-benefit of early intervention in the younger years, as well as impact on families of delayed diagnosis in childhood years (Horlin et al., 2014).

Despite the majority of research having focused on childhood, there are costs associated with autism across the lifespan (Ganz, 2007). There is both a societal and economic argument for vocational rehabilitation services for autistic adults (Jacob et al., 2015). Our unpublished work on pathways to diagnosis in adulthood has highlighted a common theme of misdiagnosis of mental health conditions prior to the late diagnosis of autism. Although we are unaware of cost-benefit analysis in this area, there would again be both social and economic benefit of provision of targeted services and support groups to autistic adults who do not meet eligibility to access services through the NDIS. In addition to the rights based argument for improving the provision of healthcare to autistic people, there is likely an economic argument if studies measured the economic impact of misdiagnosis and lack of preventative healthcare.

**We recommend targeted research funding to identify the cost-benefit of improved diagnosis and service provision for autistic adults.**

## **The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people (regards ToR h)**

Although we have gathered data on NDIS access and usage within Time 2 of the ALSAA study, we unfortunately have not yet analysed this data in detail. From interaction with our participants, however, it is clear there are many autistic adults with significant needs and difficulties in mental health and daily living who have been deemed ineligible or have been unable to access support through the NDIS. Our experience suggests there is a gap in service provision and access for those adults who still have significant impairment in their functioning including their ability to maintain employment and relationships, with substantial impacts on their quality of life and that of their carers (Sonido et al., 2020), but whom are deemed ineligible for the NDIS. We note that the majority of autistic NDIS participants are currently younger than 25 years old, yet autism is a lifelong condition. Indeed, it appears Australia has replicated what internationally has been colloquially termed the “service cliff”, where once an autistic person reaches adulthood, the services available to them disappear (Laxman et al., 2019). **We recommend the development and funding of services and support groups for autistic adults who are not eligible for NDIS funding, or the expansion of NDIS criteria to be inclusive of autistic adults with lower support needs.**

## **The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy; (regards ToR h)**

**We recommend that any development of a National Autism Strategy includes a specific focus on healthcare, and the intersection between health and disability care. We recommend that any development of a National Autism Strategy includes a specific focus on healthcare, and the intersection between health and disability care.** We believe there is overwhelming evidence that more attention is needed to the health needs of autistic people. As previously outlined, available data suggests that people

on the autism spectrum, with or without intellectual disability, experience one of the greatest health disadvantages of any population group in Australia. There is a very large gap between health status and the current capacity of health care professionals and systems to respond to the needs of these populations.

**We recommend a national population health strategy is required which uses a co-design approach to develop and implement a specific strategy for autistic people.** Strategies should also consider the overlap and combine efforts with initiatives designed to improve the quality of life of people with intellectual disability.

## The adequacy of funding for research into autism; (regards ToR j)

Despite concerning findings internationally, a limited amount of research is being conducted in Australia related to the health of people on the autism spectrum. Rigorous, inclusive, and collaborative research related to population health needs, health economics, designing and evaluating health services, preventative health, and health outcomes is urgently required in this area. The maturity of research in these areas lags behind mainstream research and is often undervalued, making it difficult to compete for competitive funding from major organizations such as the National Health and Medical Research Council (NHMRC).

The Autism CRC (Autism CRC, 2020b) has increased capacity related to autism, but this has short-term funding only. The Autism CRC has completed its final research investment rounds, and its ability to fund research ends entirely in the 20-21FY to our understanding. Centre's and academics working in intellectual disability research and capacity building often also contribute to autism research, though have temporary funding only, most often from State governments. Recurrent funding for them is often difficult to obtain. In part, this is because their funding is a shared responsibility between disability and health services, but there is no overarching framework for such sharing of this responsibility between government departments. NHMRC and the Australian government Department of Health should consider the best ways to support and sustain research in this area. For example, the role and utility of the Medical Research Future Fund could be explored. **We recommend the needs of people with intellectual disability and people on the autism spectrum should be considered as potential priority areas within specific grant schemes. We have also recommended several areas where targeted research funding is needed.** A priority should be given to research investment which provides better understanding of individuals with complex needs. This could include, for example: research that develops, trials, and evaluates models of improving the health-related support of individuals with complex needs; and research examining the intersection of the criminal justice system, disability, and mental health. We reiterate that targeted calls for research are needed in areas of accessibility of health services, the development of an assessment of functioning and support needs tool, and cost-benefit analysis of improved diagnosis and services for autistic adults.



## **The social inclusion and participation of autistic people within the economy and community; (regards ToR k)**

As noted above there is evidence supporting a social and economic argument for the provision of vocational rehabilitation services to autistic adults.

Overall autistic people have reduced participation in social and community-based activities. Research indicates that autistic individuals are often bullied and reportedly experience increased feelings of loneliness and social anxiety (Ee et al., 2019; Kuusikko et al., 2008; Locke et al., 2010; Sreckovic et al., 2014). There is evidence that supports the mediating influence of environmental factors such as social support and availability of services in young individuals with disability (Anaby et al., 2014). However, there is limited research that investigates the role of external factors in the societal inclusion and participation of autistic individuals. We are currently publishing data showing reduced community mobility (e.g. access to public transport) for Australian autistic adults. There is likely a range of factors including availability of support, accessibility, transport and community attitudes all impacting community participation (Stacey et al., 2019). We suggest that efforts to promote concepts of neurodiversity, destigmatise and increase understanding of the autism spectrum could be of benefit. Efforts to improve social support must be informed by the specific needs of autistic individuals (Ee et al., 2019).

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