



17th July 2020

Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2601

Via email: autism.sen@aph.gov.au

Dear Members of the Senate Select Committee on Autism,

Re: Submission to the Select Committee on Autism

The Queensland Centre for Intellectual and Developmental Disability at The University of Queensland and the Social Global Studies Centre at RMIT University welcome the opportunity to make a submission to the Select Committee on Autism.

For more than a century, The University of Queensland (UQ) has maintained a global reputation for delivering knowledge leadership for a better world. The most prestigious and widely recognised rankings of world universities consistently place UQ among the world's top universities. UQ has won more national teaching awards than any other Australian university. This commitment to quality teaching empowers our 52,000 current students, who study across UQ's three campuses, to create positive change for society. Our research has global impact, delivered by an interdisciplinary research community of more than 1500 researchers at our six faculties, eight research institutes and more than 100 research centres.

The Queensland Centre for Intellectual and Developmental Disability (QCIDD), located within the Mater Research Institute-UQ conducts research to improve the health and wellbeing of people with intellectual and developmental disability including Autistic people¹. QCIDD receives funding from the Cooperative Research Centre for Living with Autism (Autism CRC) to conduct translational research on the health and wellbeing of Autistic adults. The Autism CRC is the world's first national cooperative research centre focused on Autism that takes a whole-of-life approach to autism focusing on diagnosis, education and adult life. As part of QCIDD's program of research with the Autism CRC, an advisory group of Autistic adults meet regularly to provide input and give guidance to the research.

¹ We use identity-first language (i.e., Autistic adult) throughout our submission as is preferred by many Autistic adults and their allies.



RMIT is a multi-sector university of technology, design and enterprise with more than 94,000 students and 11,000 staff globally. The University's mission is to help shape the world through research, innovation, quality teaching and engagement, and to create transformative experiences for students, getting them ready for life and work. The Social and Global Studies Centre (SGSC), in the School of Global, Urban and Social Studies, was launched in 2018 with the mission to deliver transformative research for social justice. Our research develops new knowledge and critical interventions to transform policy, practice, culture and lives, locally, nationally and internationally. It is underpinned by a commitment to respond to the Global Challenges agenda and is aligned with five 2030 SDGs: good health and well-being; gender equity; reduced inequalities; peace, justice and strong institutions; quality education.

We have addressed the following Terms of Reference in our submission:

- a. current approaches and barriers to consistent, timely and best practice autism diagnosis;
- c. misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services;
- e. the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages;
- f. the interaction between services provided by the Commonwealth, state and local governments, including:
 - a. health and mental health,
- j. the adequacy of funding for research into autism.

Autism is increasingly recognised among adults. However, the focus on autism in children has led to health professionals receiving insufficient, if any, training on Autism Spectrum Condition (ASC)² in adulthood, during their degree or continued professional education (1-4). Consequently, many healthcare professionals are not equipped with the skills and knowledge to diagnose and support Autistic adults (4-6). In fact, in our online survey of 78 healthcare professionals from across Australia, we found over 80% wanted further training in autism in adulthood, particularly regarding behaviour and mental health management and communication (7). Our participants were most commonly working as medical practitioners or nurses, and just over half (54%, 42/78) worked in a disability-specific or autism-specific setting (7).

Potentially due to a lack of training and experience in ASC in adulthood some health professionals hold incorrect assumptions about and therefore stigmatise Autistic adults (8).

² The official medical terminology is Autism Spectrum Disorder (ASD); however, we have decided to use Autism Spectrum Condition (ASC) to respect our Autistic team members who prefer this terminology as it communicates a neutral rather than negative and stigmatising perception associated with the term 'disorder'.



One particularly damaging and common misconception in the health sector and community is the belief that autism mainly affects males and that children outgrow their autism by the time they reach adulthood (2, 9-11). Autistic women mask their Autistic behaviours and traits (5, 10, 12). Without knowledge of autistic traits and presentations across the lifespan and between genders, particularly female presentations, healthcare professionals commonly overlook the diagnosis and dismiss patient concerns regarding autism diagnosis (2, 4-6, 13). There is a concerning lack of knowledge on the experiences of trans and non-binary autistic adults and research into this area is urgently needed to help guide health professionals.

Lack of knowledge, training and education in autism in adulthood can also cause healthcare professionals to misdiagnose Autistic individuals - often with mental health conditions, instead of being able to connect health issues that together, make up the much larger diagnosis of ASC (6, 14, 15). Misdiagnosis leads Autistic adults to resent health professionals (14). Consequently, Autistic adults may be fearful of disclosing their diagnosis due to fear of discrimination and because of health professionals' lack of ASC awareness (8, 10). Incorrect assumptions and stigma result in negative healthcare experiences for Autistic adults, erode trust, and deter health seeking when it is needed (8, 16, 17).

Recommendation: Mandate minimum autism training requirements for all health professionals with a strong focus on autism in adulthood and the experiences of Autistic women. Training should be developed and delivered in collaboration with a diverse range and representation of Autistic people who are appropriately remunerated for their time and expertise.

The manner in which autism assessments are organised and conducted creates significant barriers to timely, accessible and accurate diagnosis and support services for Autistic people, particularly adults. The erroneously held belief that a GP referral is needed to be eligible to access an autism assessment in adulthood is a significant barrier to undiagnosed Autistic people's right to assessment and diagnosis (4, 6). This misconception perpetuates GPs' position of power as "gate-keepers" and is reinforced by GPs who neglect to inform patients that such a referral is not required. Stories of Australian GPs refusing autism assessment referrals are common in the Australian autism community.

The Autistic co-author of this submission, Pia Bradshaw, has experienced this firsthand with her long-standing GP. When Pia approached her GP about a possible autism diagnosis, her concerns were dismissed and she was told "she just needed to use her brain more" (despite the GP knowing she had completed Bachelors with Honours and Masters degrees). Her GP was shocked when Pia independently sought out and received a formal ASC diagnosis. The GP responded by telling her that she did not share any characteristics with male children with an autism diagnosis at her clinic and they never would have guessed she was Autistic.



Pia's experience has been validated by the many emails she has received from people who believe they are Autistic, but are not able to access formal autism assessment because their GP will not refer. However, people aged 18+ years may self-refer for an autism assessment. Pia created a YouTube video outlining the challenges and providing advice for seeking an autism assessment in response to the emails she's received (18).

These experiences are indicative of poor knowledge of autism and availability of referral networks amongst GPs, and a shortage of psychiatrists and psychologists with substantive knowledge and experience working with and diagnosing Autistic adults of all genders.

Recommendation: Provision of clear information on diagnosis pathways for adults seeking a formal autism diagnosis.

The Autism CRC has sought to address: (i) the difficulties practitioners face in discerning developmental conditions that may overlap with Autistic behaviours, (ii), practitioner understanding of autism characteristics across the lifespan, and (iii) the widely varying levels of skill and experience of clinicians by developing Australia's first National Guideline for the Assessment and Diagnosis of Autism (19). The Guideline provides a consistent standard for how autism assessments for children, adolescents and adults are conducted in Australia. It was informed by a review of diagnostic practices in Australia which highlighted the varying diagnostic practices across and within Australian states and territories and the detrimental impact from inconsistent provision and availability of public services and support for Autistic people (19). It is up to the discretion of the diagnostic practitioner and clinic as to how many appointments and tests are necessary for them to provide an autism assessment which can increase cost, while others clinics deem one session appropriate to make an assessment, as was the case of the Autistic co-author's experience. The combination of high unemployment amongst Autistic people and excessive autism diagnostic assessments are barriers to autism assessment and diagnosis.

There is insufficient availability of diagnostic services and public supports for autistic adults, and very few staff are themselves Autistic. Waitlists are often 6-12 months. The lack of educated, trained and experienced healthcare professionals that are equipped to provide accurate ASC diagnoses and ongoing support to Autistic adults should raise concerns about ethical practices around diagnostic guidelines and the clinicians that conduct them.

Similarly, the expense of autism assessment is commonly cited act as a barrier. This is especially problematic given the unemployment rate for Autistic people is 31.6%, more than three times the rate for people with disability and almost six times the rate of people without disability (20). Costs range from approximately AU\$450+ or upwards of AU\$1000 (21-23). Higher costs are usually associated with shorter, but still significant wait times. The number of appointments and the use of cognitive tests varies significantly between clinics. A medical



diagnosis should be accessible and affordable irrespective of individual's income bracket or socio-economic status (24).

Recommendation: Financial and system level support to implement the Autism CRC guidelines on diagnosis. Reduce financial barriers to autism assessment by capping assessment costs for individuals and increasing incentives or rebates for health professionals. Increase the capacity of the public health system to conduct adult assessments by upskilling health professionals.

Following diagnosis of autism in adulthood there are limited support services available. We conducted interviews with 13 Australian adults who identified as autistic (9 with a formal autism diagnosis and 4 self-diagnosed) about their experiences of seeking an autism diagnosis as an adult (25). A majority of participants felt post-diagnostic support was important. The way in which our participants wanted to be supported following diagnosis differed, with some wanting to continue sessions with the health professional who diagnosed them and others wanting to form connections with the Autistic community via support groups. However, those who sought support groups stated they were either unable to find them or found them overbooked with prohibitive wait times. Some even stated they were able to access no support services following their diagnosis.

Recommendation: Develop systems to support newly diagnosed people who identify as Autistic. This should be designed and delivered in collaboration with Autistic people who are appropriately remunerated for their time and expertise.

Autistic people experience great health disparities resulting in reduced life expectancy (26). They experience a number of factors at a systems level that effect their ability to access timely and high-quality healthcare.

Amongst medical professionals there is a lack of understanding about common co-occurring physical and mental health conditions (e.g., Autistic people experience higher rates of depression, anxiety, sleep problems) (27, 28). Despite this knowledge, no formal process exists to screen Autistic people or newly diagnosed people for these conditions. Similarly, despite the extremely high co-occurring rates of Attention Deficit Hyperactivity Disorder (ADHD) with autism (29, 30), it is extremely difficult and often near impossible for undiagnosed adults to obtain an ADHD diagnosis in adulthood and access medications essential for functioning in our society. However, efforts to combat growing addiction, abuse and dependency upon prescribed stimulant medication has caused many healthcare professionals to refuse requests to prescribe. Such issues around the regulation of ADHD stimulant medication creates barriers for undiagnosed ADHD and Autistic adults seeking an ADHD assessment and a strong suspicions of disingenuous motives behind seeking an assessment and in turn, access to stimulant medications. Moreover, like with autism,



misinformation, stigma and lack of education and training about ADHD in adulthood exacerbates these problems.

The Autistic co-author of this submission was diagnosed with ADHD at the age of 33, 3 years after her autism diagnosis, and 30+ years after her mother had taken her to two healthcare professionals with concerns of ADHD, dismissed based on a belief that females could not have ADHD. Using her PhD connections she was able to access one of the few psychiatrists in Australia educated on ADHD in adulthood and across genders, and also diagnosed with ADHD themselves. Many, if not most, Autistic adults with ADHD are not able to access diagnosis and subsequently appropriate treatment (31).

Recommendations: Mandate minimum training requirements for all health professionals about co-occurring physical and mental health conditions, particularly about ADHD in adulthood and the experiences of ADHD women that is delivered through an integrated neurodevelopmental pathway. Training should be developed and delivered in collaboration with a diverse range and representation of Autistic people across the autism spectrum who are appropriately remunerated for their time and expertise. Medicare item for health assessments for Autistic adults, similar to Medicare items used for health assessments for people with intellectual disability (i.e., add autism criteria to MBS items 701, 703, 705, 707).

Autistic people also experience diagnostic overshadowing when medical professionals attribute a sign or symptom to the person's autism rather than seeking a medical cause (32). Self-harm is commonly inappropriately attributed to autism (i.e., the individual could be banging their head due to a toothache). People with a formal autism diagnosis face barriers to healthcare access because health professionals incorrectly consider mental health issues an inherent part of autism, when in fact much mental illness in autism is a consequence of an absence of understanding and acceptance (33). Mental health services also commonly fail to address physical health needs of autistic people. In research we conducted in the U.S. about Autistic adults' experiences with emergency departments and in-patient hospital services, we found some Autistic participants were not granted access to devices to meet their physical health needs such as mobility aids when an in-patient in a mental health ward. Many participants did not disclose their autism diagnosis to hospital staff for fear of discrimination (34).

Health professionals also often fail to take a holistic approach, frequently missing patterns or symptoms that may be linked, particularly around mental health conditions such as anxiety and depression. Contributing to this problem is the recent push by Medicare for patients to only discuss one issue or problem at a time with their GP. This mitigates against holistic care, forcing patients and GPs to focus on only one problem. This approach is also dangerous as Autistic people often have trouble telling if their health problem is worth visiting a GP for, often waiting until they have multiple issues to discuss to 'warrant' a visit to their GP.



Recommendation: Mandate minimum training that is delivered by Autistic people who are appropriately remunerated for their time and expertise for doctors about common co-occurring conditions and the need for a holistic approach. Encourage the appropriate utilisation of a Medicare item or items allowing the discussion of multiple health problems in one consultation and discourage promotion of ‘one problem per visit’.

Autistic people experience numerous barriers to health system access. Many are health system factors (35, 36). There is a lack of understanding about how the different levels of the health system work together and how people access different parts of the health system. As mentioned above, this impacts Autistic people’s ability to access diagnostic services and other healthcare services. For example, accessing allied health services can be confusing for reasons including the different pathways (e.g. privately and out-of-pocket, referral for bulk-billed appointments to private service using Medicare criteria for care plans or referral to public services, often with long wait times).

When providers do not communicate in a way that meets the Autistic patient’s needs this creates an additional barrier. Strategies to address this include, providing a quiet waiting room, providing patients with the option to make appointments online, and training for health professionals on how to adjust their communication to meet the needs of their patients. A consistent approach to the physical environment, sensory needs, and communication is needed.

Recommendations: Financial support and minimum requirements mandated at a federal level for these strategies need to be implemented.

Despite increasing recognition of autism in the adult population, there is a paucity of research on the topic of adulthood in the autism literature. A portfolio analysis of the allocation of autism research funding in Australia from 2008-2017 found 47% of autism research funding went towards biological research, with only 22% going towards research into treatments and interventions for autism, and no funding allocated for lifespan issues (37). Autistic adults and the broader autism community in Australia and elsewhere have highlighted mental health, autism diagnosis across the lifespan and access to support services as priority areas for future research (38, 39). The Autism CRC in Australia surveyed 158 members of the Autistic and autism communities and found ‘therapies, issues and management’ to be the most highly endorsed priority area, with ‘anxiety and coping’ the most frequently endorsed topic under this item (38). Autistica in the UK consulted with over 1000 members of the autism community and found their top research priority was ‘Which interventions improve mental health or reduce mental health problems in people with autism? How should mental health interventions be adapted for the needs of people with autism?’ (39). Furthermore, Autistica identified research on the most effective ways to provide social care for Autistic adults and on how autism diagnostic criteria be made more relevant for the adult population as high priorities. The second priority for autism research



identified by respondents to the Autism CRCs survey was 'understanding autism' which included research improving identification of autism, especially in later life and in people with subtle autism characteristics.

Recommendation: Specific funding to be made available for research about autism in adulthood and that research funders, including the Australian government, prioritise research projects to address priority areas identified by members of the Autistic and autism communities.

One way to ensure funded autism research aligns with the priorities and needs of the Autistic and autism communities is to fund projects that partner with these communities at all stages of the research. There are a growing number of autism research teams around the globe using participatory approaches, including community-based participatory (CBPR) methods, to conduct meaningful research. CBPR is a collaborative approach to research that places equal value on contributions from all partners (e.g. autistic adults, academics) throughout the research process and recognises the unique strengths of each partner (40). This approach is recognised as an appropriate method for researching a range of issues, particularly for marginalised groups. Typically, this type of research starts with defining a topic of importance for a community, in this instance the Autistic and autism communities. Members of the community are included at all stages of the project, including the development of research questions and proposals, research materials such as interview guides or survey questions, the analysis of data and the dissemination of findings. Involving members of the community that include Autistic people themselves and supporters such as family members, ensures research questions align with the community's needs, research methods are appropriate for Autistic and supporter participants, data are interpreted correctly and findings are disseminated to the community in the most appropriate ways. There are a growing number of research teams across the globe with expertise in these methods and some teams have created guides for adopting these approaches in autism research (41-43).

Recommendation: Funders to prioritise research projects that use CBPR or other approaches to meaningfully partner with the Autistic and autism communities. Also, we suggest funders include Autistic adults on their review committees to ensure funded projects align with the community's needs and use appropriate methodologies.

To conclude, we wish to acknowledge the journey and advocacy by the Autistic and autism communities. We must all continue to work together to improve services, supports and outcomes, particularly in the area of diagnosis and healthcare, for Autistic adults.



Yours sincerely,

Dr Katie Brooker
Postdoctoral Research
Fellow (QCIDD, The
University of Queensland)

Ms Pia Bradshaw
PhD Student & Autistic self-
advocate (QCIDD, The
University of Queensland)

Dr Anna Urbanowicz
Postdoctoral Research
Fellow (SGSC, RMIT
University)

Dr David Harley
Director (QCIDD, The
University of Queensland)

Ms Hayley Chapman
Autistic self-advocate

Mr Chris Tanner
Autistic self-advocate



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