

The Interface Between Autism Spectrum Disorders and Mental Health: The Ways Forward

Discussion Paper December 2012

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EXECUTIVE SUMMARY

- This paper describes the mental health service and support needs of children and young people in Australia 0-25 years of age who have an autism spectrum disorder (ASD).
- Informed by people who have an ASD and their families, and by a wide range of leading Australian clinicians and researchers, clinical studies and government reports, the report uncovers absent or largely ineffective interfaces between the relevant service sectors and these people who have an ASD.
- It emphasises that a person who has an ASD, like any other Australian, has a basic human right to accessible and person-centred mental health services.
- It finds that a lack of relevant, co-ordinated nation-wide data is a major contributor to the lack of knowledge about the needs of people who have an ASD and mental illness.
- It finds that people who have an ASD experience strikingly high rates of lifetime mental illness, such as major depression and anxiety disorders in the 50-70% range.
- It conservatively estimates that 100,000 people in Australia have an ASD with a mental illness.
- There is in general a "silo" approach to care by the health, disability and education sectors often characterised by narrow eligibility criteria, rather than by collaboratively designed inclusive pathways to care and to services.
- Lack of knowledge and lack of sector collaboration have contributed to Australia's health services, particularly mental health services, not taking an appropriate level of responsibility for the identification, assessment, intervention and care of the mental health needs of people with an ASD.
- These factors also explain to some extent why services often mistakenly view mental health concerns as part of the person's ASD, often resulting in a failure to even recognise mental illness, let alone treat mental health issues.
- The failure of mental health systems to take responsibility for the mental health needs of people with an ASD along with the limited knowledge about the presentation of mental health issues in this population, contribute in turn to a lack of ASD-specific expertise among mental health professionals.
- The school years for many with an ASD are characterised by social isolation, bullying, and failure to meet learning support needs.
- As a consequence the adult years for many are characterised by increasing social isolation, unemployment, and mental health issues.
- Effectively shut out from the services and supports they require, this report describes some of the key issues and recommendations that must be addressed by collaborative processes now, in order to make a positive difference to the lives of people who have an ASD, and to the lives of their families.

RECOMMENDATIONS

General Approaches

In order to better meet the needs of people who have an ASD with mental health concerns, we recommend the following general approaches:

- **Awareness raising** a nationwide campaign to change perceptions regarding the aspirations, mental health and the inclusion support needs of people with an ASD.
- **Funding service capacity** ensure the right of every individual who has an ASD, to appropriate services on an equitable basis.
- **Early intervention** include early recognition of mental health issues and ongoing surveillance with access to professional expertise.
- Collaboration have greater collaboration among government departments, people
 with an ASD and the service provider sectors to address issues such as service
 responsibility, service coordination, service capacity, pathways of care and
 professional expertise.
- **Best care service model** fund the Australian Advisory Board on Autism Spectrum Disorders to research world best practice to design an Australian "best care" service model to meet the age related mental health needs of people who have an ASD.
- **Employment roundtable** ensure consultation and collaboration among employers, governments and the disability sector to develop appropriate job opportunities.

Specific Recommendations:

1. Prevalence of an ASD with Co-Morbid Mental Health Conditions

Recommendation 1.1 – Improved recognition and treatment

Because people with an ASD have a significantly increased risk for co-morbid mental health conditions, we call for improved recognition and treatment of these by services with specialist ASD and mental health knowledge and skills.

Recommendation 1.2 – Mental health surveillance

We call for the ongoing surveillance of the mental health of children and young people, commencing at the age of initial diagnosis of an ASD, in order to identify and treat as early as possible mental health issues such as anxiety and depression.

Recommendation 1.3 – Intervening early - the opportunity of the school years
We recommend that the school years be recognised as a period of critical opportunity to intervene early and continuously to prevent the appalling and costly mental health, educational and associated social and employment outcomes described in various reports. Interagency collaboration is the key (particularly between health, education and disability sectors) to share expertise and to design strategies to achieve this objective.

Recommendation 1.4 – Capacity building

We support the consideration of ideas such as the establishment of tertiary level specialised state mental health service units. Their purpose would be to provide capacity building to improve the early identification of mental health issues, ASD knowledge and to develop and champion interventions which are adapted to the special needs of the ASD population whose clinical needs may not otherwise be met (Lunsky et al 2009).

Recommendation 1.5 – Justice system

We recommend the establishment of local on call Autism Response Teams by relevant government departments (such as the Attorney–General's Department). Such teams may include a family member working with relevant professional support, such as a social worker, speech pathologist or psychologist who has specialist ASD expertise. Autism Response Team objectives would be to provide autism knowledge to ensure that, for example, interviews are fair and equitable, and to ensure overall procedural fairness.

2 Awareness

Recommendation 2.1 – Awareness

We call for an integrated communications campaign (similar to the NDIS Every Australian Counts campaign) to change community perceptions regarding the well-being and particularly the mental health and the inclusion support needs of people with an ASD. Elements of the campaign could include media relations, advertising, social media and direct marketing strategies.

Recommendation 2.2 – National register

We support the establishment of a national voluntary prevalence register to collect data to better understand and to plan services for the unmet mental health needs of this population, and suggest that the proposed National Disability Insurance Scheme (NDIS) could play a key role in establishing such a national data base.

3. Access to Services and Support

Recommendation 3.1 – Funding access to services

We call for improved funding to ensure the right of every individual who has an ASD and mental health needs, regardless of age, to appropriate services.

Recommendation 3.2 – Resourcing our schools

We recommend that schools have access to specialised multidisciplinary services. These build the schools capacity through a mix of direct and "knowledge building" strategies to better meet the needs of children and young people with an ASD and co-occurring mental health issues.

Recommendation 3.3 – Best care service model

We recommend that the AAB, with appropriate funding support, prepare a follow-up paper to describe a "best care service model" to meet the varying age-related mental health needs of people who have an ASD. This would be informed by international guidelines and consider funding requirements for such a model in the Australian context.

4. Professional Expertise

Recommendation 4.1 – Training, case management and tertiary support

We recommend a tiered approach to improving professional expertise, where the outcome of improved support and capacity for workers at the coalface is essential. In general terms:

Tier 1 provides education and support for universal service providers, early detection and service "gatekeeper" professionals such as general practitioners, community nurses and school staff. This requires partnerships between specialised disability, health and other sector professionals as appropriate.

Tier 2 provides multi-disciplinary collaborative case management input, including the possibility of government, NGO, disability and mental health service partnerships.

Tier 3 is the tertiary level of highly specialised service supporting clients, families and those at the coal face working with complex needs; it involves a multi-disciplinary multi agency collaborative process. Such a resource could be established across mental health, disability and education sectors in each state to "drive "collaborative and innovative approaches."

Recommendation 4.2 – Online interagency networks

We support online networks that share knowledge and build expertise about the recognition and treatment of mental health conditions in people who have an ASD, by linking professionals across the education, disability, health and mental health fields. This can be achieved in part by expanding existing online support networks such as the Mental Health Professionals Network which provides ongoing education and support for staff across agencies and disciplines.

Recommendation 4.3 – The importance of the school years

We call for realistic responses involving partnerships with specialised third parties that add to schools' capacity to respond to issues such as unmet learning support needs, social isolation, bullying and mental health.

Recommendation 4.4 – Prevention, surveillance and opportunity

We recommend the importance of a preventative response during the school years. This is a critical time to identify through early and ongoing surveillance mental health issues, and to put in place programmes which better meet the learning support, mental health and social needs of children and young people with an ASD as they develop and mature.

5. Collaboration and Co-ordination

Recommendation 5.1 - Collaboration

We call for health and the disability sectors to work together to design a service system that is knowledgeable about ASD and co-occurring mental health issues with clearly defined pathways of care including mechanisms to opt in the key agencies (such as the education sector) as needed.

Recommendation 5.2 – School years round table

We support a collaborative intergovernmental interdepartmental roundtable (including education, health and disability sectors) to develop strategies targeting the school years, to improve the mental health, social and educational outcomes for students, and subsequently for adults, who have an ASD.

Recommendation 5.3 – Person centred approaches

We endorse the strong push by government and communities for person centred approaches where interventions and supports are designed collaboratively with clients rather than offer a one size fits all, take it or leave it approach.

6. Employment

Recommendation 6.1 – Employment

We recommend an employment roundtable including employer groups to improve understanding and to tackle discrimination and to improve access to employment.

7. Funding

Recommendation 7.1 – Funding for mental health services

We call for a national benchmark funding formulae based on the true proportion of the mental health burden, to assist services particularly mental health services across the nation to respond to unmet demand including for people who have an ASD.

Recommendation 7.2 - NDIS - A broader role

We recommend that the NDIS framework and funding include strategies such as information, service coordination, referral pathways and data collection to assist all people who have an ASD and mental health concerns to access appropriate services and care.

INTRODUCTION

This discussion paper of the Australian Advisory Board on Autism Spectrum Disorders is funded by the Department of Families, Housing, Community Services and Indigenous Affairs. It identifies some of the key issues regarding the level of interface between the disability sector and the health sector, in particular mental health, in regard to service provision for children and young people with an ASD under the age of 25.

The paper highlights key issues and recommendations for further discussion and consideration by communities, governments, the health and disability sectors, other service providers, and specific groups such as employers.

It provides some general recommendations in the form of broad approaches. It also, for each key issue identified, recommends specific strategies including in some instances examples of programs and processes, and further research that is needed. Recommendations include opportunities and strategies to strengthen the service system in order to provide a more appropriate and comprehensive response to the needs of people with an ASD and comorbid health issues.

METHODOLOGY

Information contained in the paper and its recommendations are informed by multiple sources including:

- the voice of people who have an ASD, and that of their families;
- leading Australian clinicians, researchers and other service providers;
- Australian and international reports; and
- clinical research findings.

Key issues raised for discussion are:

- Prevalence of an ASD with Co-Morbid Mental Health Conditions;
- Awareness;
- Access to Services and Support;
- Professional Expertise:
- · Collaboration and Co-ordination;
- Employment; and
- Funding.

OVERVIEW

Autism spectrum disorders

Autism spectrum disorders (ASDs) are lifelong developmental disabilities characterised by marked difficulties in social interaction, impaired communication, restricted and repetitive interests and behaviours and sensory sensitivities. These highly prevalent conditions affect around 1 in 100 Australians.

The word "spectrum" is used because the range and severity of the difficulties people with an ASD experience can vary widely.

ASDs include autistic disorder, Asperger's disorder and pervasive developmental disorder – not otherwise specified. Sometimes the word "autism" is used to refer to all ASDs. From 2013, because of changes to the current Diagnostic and Statistical Manual of Mental Disorders (DSM IV), there will be a single category called Autism Spectrum Disorder.

ASD and mental health

Many researchers, clinicians and service providers are of the view that the mental health needs of children and young people 0-25 years of age who have an ASD have been largely neglected. Evidence suggests that this group of Australians have been overlooked by our mental health services, despite the detrimental impact of mental illness on their health, educational, social, community participation and employment outcomes.

A matter of human rights

Like all other Australians, people with an ASD are entitled to access mental health services with sufficient understanding and professional expertise to accommodate their needs.

It is not acceptable to regard their mental health needs as part of their ASD, or to dismiss their need for services and supports on this basis. Such thinking has led to a service system culture of buck passing and neglect. This in turn explains the lack of commitment, knowledge, innovation and expertise in regard to ASD-specific interventions and supports by our health (particularly mental health), disability and education services.

This occurs in Australia during an era when the United Nations (UN) Convention on the rights of persons with disabilities (CRPD) 2008 affirms that all persons with a disability must enjoy the same fundamental rights and basic freedoms as those without disabilities. The rights based approach represents a paradigm shift in the way that society understands the issues that confront people with a disability. Society expects fair and equitable treatment for all of its citizens.

Service responsibility

In Australia responsibility for services for people who have an ASD is primarily viewed as belonging to the disability sector. However, people, who have an ASD, their families, and mental health service providers themselves, frequently report that services refuse to see people who have an ASD, instead referring them back to the disability sector which in general lacks the professional expertise to diagnose and treat their mental health concerns.

This systemic failure to take responsibility for mental health also means that mental health professionals do not receive the training or experience to diagnosis or treat people who have an ASD.

KEY ISSUES

1. Prevalence of an ASD with Co-Morbid Mental Health Conditions

Clinical research consistently reports very high levels of mental health issues among people who have an ASD; for example Lugnegard et al 2011 found 70% of adults with Asperger's Disorder had experienced at least one episode of major depression, and 50% had suffered from recurrent depressive episodes.

A recent community based study of ASD in the UK found that 71% of the sample could be diagnosed with a psychiatric disorder (Simonoff et al 2008).

Gillott et al. (2007) found high lifetime rates of psychiatric problems in their adult sample; mood disorder 53% and anxiety 50%.

The 2012 Autism Spectrum Australia (Aspect) report *We Belong* study found that more than 70% of mainly young adult respondents identified a clinical mental health condition.

Similarly, a recent survey of 96 parents of young adults with high functioning ASD conducted in Queensland (Neary, 2012) found that 47% of these young people were experiencing clinically significant mental health difficulties as rated by the Mental Health Inventory-5 (Cuijpers et al., 2009), as compared to 7% in the general population.

Regarding children, Vasa et al 2011 reported that over 50% of older children in their study experienced clinical or sub-clinical anxiety. They noticed that for each age group, anxiety was significantly associated with multiple psychiatric co-morbidities.

They point out that this data indicates the need for comprehensive care of children with ASD and anxiety.

Similarly, Wilson et al 2012 found that 76% of adults who were diagnosed with an ASD also met diagnostic criteria for at least one other co-morbid mental health condition with the most common of these being depression, followed by obsessive compulsive disorder, and generalised anxiety disorder.

Such studies challenge the current organisation of the diagnostic classification system. For example, the notion that diagnoses of co-morbid psychiatric conditions such as ADHD should not be made if an individual has an Autism Spectrum Disorder. In fact an ASD typically occurs with multiple other developmental and psychiatric disorders, each requiring assessment and intervention, in the context of the needs of the whole person.

A high level of expertise and awareness of possible co-morbid psychiatric disorders is therefore essential when a person is being assessed for a possible ASD. Similarly immediate access to suitably modified treatment and support is essential.

Given that recent studies indicate that around one in 100 people have an ASD, with diagnosis rates acknowledged to be on the rise (Weintraub, K 2011; AAB 2011), and the prevalence rates for co-morbid mental health conditions, we conservatively estimate that around 100,000 people in Australia have an ASD with a mental health condition.

While the vast majority of people with autism are law abiding and respect the rules of society, a small proportion, probably similar to that in the general population, come to the attention of the criminal justice system, often due to a mental health illness (Mouridsen 2012).

Clinical experience suggests that a substantial number of such contacts occur because the person's behaviour and its intent are misunderstood. In reality, adults with an ASD are more likely to be victims rather than offenders, at all levels of the judicial system. For example,

because of a desire to please, along with communication difficulties, a person who has an ASD may confess to criminal behaviour which they did not commit (National Autistic Society, Working with People with Autism 2011 and 2012). To ensure judicial fairness, all levels of the criminal justice system from police to courts need access to autism support (NAS Guide for Criminal Justice System 2012).

Recommendation 1.1 – Improved recognition and treatment

Because people with an ASD have a significantly increased risk for co-morbid mental health conditions, we call for improved recognition and treatment of these by services with specialist ASD and mental health knowledge and skills.

Recommendation 1.2 – Mental health surveillance

We call for the ongoing surveillance of the mental health of children and young people, commencing at the age of initial diagnosis of an ASD, in order to identify and treat as early as possible mental health issues such as anxiety and depression.

Recommendation 1.3 – Intervening early

We recommend that the school years be recognised as a period of critical opportunity to intervene early and continuously to prevent the appalling and costly mental health, educational and associated social and employment outcomes described in various reports. Interagency collaboration is the key (particularly between health, education and disability sectors) to share expertise and to design strategies to achieve this objective.

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Recommendation 1.5 – Justice system

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2. Awareness

It is clear from reports and from the experiences of individuals that there is an urgent need to raise community awareness about disability and the need for appropriate services, if people with disabilities are to receive the recognition and opportunities in society that is rightfully theirs.

As the Australian Government report *Shut Out: The Experience of People with Disabilities and their Families in Australia* (2009) notes: "...For many years people with disabilities found themselves shut in – hidden away in large institutions. Now many people with disabilities find themselves shut out- shut out of buildings, homes, schools, business, sports and community groups. They find themselves shut out of our way of life...our nation's forgotten people...."

Stronger Together: A New Direction for Disability Services in NSW 2006-2016, comments that individuals with an ASD tend to "fall between the cracks of disability service provision," reflecting a lack of knowledge by services about the needs of this group.

These and international studies such as the 2008 UK National Autistic Society report *I Exist*, identify common priority areas for reform including:

- Services and supports that facilitate, rather than act as barriers to participation;
- Strengthening the ASD experience of the workforce (including education, health and employment sectors);
- Specialist support to enhance educational opportunities, particularly during transition stages;
- Pre-employment and employment support including workforce capacity building;
- Strategies to effect successful participation in the community; and
- Development of a comprehensive evidence base about autism spectrum disorders.

According to research evidence, lack of awareness about ASD and associated mental health issues is even more apparent than it is for disability in general.

I don't feel like the daily struggles of adults with Asperger's are well understood. I fight through (and hide, as best I can) a relentless struggle. I often feel like I just can't keep going.

Miriam, aged 30, NSW

Aspect's report *We Belong* is the first large scale study in this country to describe the life experiences, aspirations and support needs of people who have an ASD. It gives for the first time a voice to a previously overlooked group of Australians and their families.

Both the *I Exist* study, which profiles adults across the autism spectrum, and *We Belong* which focussed on adults with Asperger's Disorder and high functioning autism (autism in the absence of global intellectual disability), highlight the lack of service awareness, expertise and policies essential to provide access to much needed mental health expertise.

I was depressed for a long time. To have had access to a skilled psychologist when I was younger, who understands Asperger's, would have been very helpful.

Anita, aged 54, QLD

Adults with high functioning autism (HFA) are more likely to experience negative outcomes than those with autism and an intellectual impairment, as their higher intellectual ability and normal expressive language development cannot compensate for their profound difficulties in social interaction and communication (Mordre, M et al, 2011).

We Belong found that more than 70% of adult respondents identified as having a mental health condition, with less than half of these respondents stating that they were currently receiving sufficient support to manage their condition.

It seems like if you have a job and live alone, no one thinks you might still need help. In my experience, you cannot access help until you reach rock bottom. It would cost less and help people better if they received support before crashing. If you ask for support before this time they usually say it is not available because the funds are not there. I had to be totally unable to do things for myself before I got support.

Angela, aged 36, SA

All service providers in the study stated that they would like to improve their own awareness and understanding of ASD. They were not able to pursue the professional development they wanted for reasons such as location, cost and organisational priority.

Half of the adults in the *We Belong* study who identified themselves as currently having learning difficulties stated that they had received insufficient or no additional support for their learning needs during their time in school. More than 70% of adults recalled being bullied, having few or no friends, and/or a pervasive sense of not fitting in during their time in education. Similarly three quarters of parents reported that their son or daughter had been bullied in educational settings.

Unmet needs for learning support and in regard to preventing and coping with bullying, put people who have an ASD at greatly increased risk for mental health problems.

A focus of government policy in disability, health and education, ought to be the removal of barriers to full inclusion faced by people who have an ASD and co-occurring mental health issues. These include barriers that prevent eligibility for service, for example for those with an ASD who do not have a global intellectual disability, and barriers to participation in education, such as a lack of specialised learning support.

In short, a priority must be to raise awareness about ASD in general and in particular about the mental health needs of this overlooked group of Australians. A cultural change is required to facilitate community, health (particularly mental health), education and disability sector reform.

Recommendation 2.1 – Awareness

We call for an integrated communications campaign (similar to the NDIS Every Australian Counts campaign) to change community perceptions regarding the well-being and particularly the mental health and the inclusion support needs of people with an ASD. Elements of the campaign could include media relations, advertising, social media and direct marketing strategies.

Recommendation 2.2 – National register

We support the establishment of a national voluntary prevalence register to collect data to better understand and to plan services for the unmet mental health needs of this population, and suggest that the proposed National Disability Insurance Scheme (NDIS) could play a key role in establishing such a national data base.

3. Access to Services and Support

The findings of *We Belong* suggest that mental health services tend to exclude people with intellectual impairment or ASD. This is the result of narrow eligibility policies, limited capacity and an unwillingness to take responsibility for people with disabilities.

60% of respondents in *We Belong* report that they need support to access professional services.

Two thirds of parents report struggling to find appropriate services within an accessible location or distance, particularly those living in regional areas.

Half of parents identified the cost of professional services as a barrier to their son or daughter obtaining the support that he or she needs.

Regarding access to learning supports during the school years, half of respondents overall reported that they received no, or insufficient, support for their learning needs during their time in education. This rose to 74% in regard to families living in regional locations.

We acknowledge the reality that teachers have been operating under escalating pressures for many years and struggle to meet community expectations. Together with families, they need access to realistic levels of training and specialist support to assist their person with an ASD and mental health conditions. They need access to skilled and ongoing expertise as required.

Recommendation 3.1 – Funding access to services

We call for improved funding to ensure the right of every individual who has an ASD and mental health needs, regardless of age, to appropriate services.

Recommendation 3.2 – Resourcing our schools

We recommend that schools have access to specialised multidisciplinary services. These build the schools capacity through a mix of direct and knowledge building strategies to better meet the needs of children and young people with an ASD and co-occurring mental health issues.

Recommendation 3.3 – Best care service model

We recommend that the Australian Advisory Board on ASD, with appropriate funding support, prepare a follow-up paper to describe a "best care service model" to meet the varying age-related mental health needs of people who have an ASD. This would be informed by international guidelines and consider funding requirements for such a model in the Australian context.

4. Professional Expertise

Experienced Australian clinicians and academics consulted for this discussion paper emphasised the need for more training within psychiatry and psychology courses at universities so that clinicians graduate with greater competence, able to provide mental health services to people who have an ASD.

Similarly "service gatekeeper" professionals such as GPs, and disability and education workers, need educational programs on early indicators of mental health difficulties, and information about referral pathways.

Another point emphasised by our clinicians was the importance of training so that professionals can work with the whole family, including siblings, given the key ongoing support roles they have with their person who has an ASD.

Improvements in mental health for people with an ASD are not possible without an appropriately trained workforce across all levels, from universal health through to specialist mental health providers.

However, public mental health services in Australia include a very small number of clinicians who have ASD experience let alone specialist expertise. There are virtually no specific inpatient facilities for people with an ASD and very few ASD specific mental health teams in Australia (Evans et al 2012; Dossetor et al 2012).

Over three quarters of parents surveyed in the *We Belong* project reported that when accessing services on behalf of their son or daughter, they detected a lack of awareness or understanding of autism among service providers.

Similarly three quarters of parents stated that services had failed to provide practical support, and three quarters had found that services were too generic to meet their son or daughter's specific needs.

All of the service providers who were interviewed stated that they would like to improve their own understanding of ASD. Many were not able to pursue the professional development they needed for reasons relating to location, cost, low organisational priority of ASD training, and limited awareness of training opportunities.

Over two thirds (68%) of parents stated that in their experience, educators in Australia are not well informed about autism. Approximately half of the parents in the study were of the view that their son or daughter have not been able to perform to his or her full potential while in education.

A limiting factor for students with an ASD is the capacity of the school including curriculum design and teachers' skills. Ad-hoc or one off professional development does not result in meaningful change.

Specialised teams ought to be an essential part of a tiered structure to support professionals at the coal face to provide high quality direct service, including excellent case management at the local level, and to inform knowledge building at the universal service level.

Programs such as *School-Link* are examples of collaborative multi-disciplinary and multi-agency strategies that can deliver improved mental health outcomes. *School-Link* is a model where the Sydney Children's Hospital partnered with the NSW Departments of Education and Communities, Aging Disability and Home Care, and Family and Community Services, to support the mental health needs of students with a development disability.

Recommendation 4.1 – Training, case management and tertiary support

A tiered approach to improving professional expertise, with the outcome of improved support and capacity for workers at the coalface is essential. In general terms:

Tier 1 provides education and support for universal service providers, early detection and service "gatekeeper' professionals such as general practitioners, community nurses and school staff. This requires partnerships between specialised disability, health and other sector professionals as appropriate.

Tier 2 provides multi-disciplinary collaborative case management input, including the possibility of government, NGO, disability and mental health service partnerships.

Tier 3 is the tertiary level of highly specialised service supporting clients, families and those at the coal face working with complex needs; it involves a multi-disciplinary multi agency collaborative process. Such a resource could be established across mental health, disability and education sectors in each state to "drive "collaborative and innovative approaches.

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This can be achieved in part by expanding existing online support networks such as the Mental Health Professionals Network which provides ongoing education and support for staff across agencies and disciplines.

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We call for realistic responses involving partnerships with specialised third parties that add to schools' capacity to respond to issues such as unmet learning support needs, social isolation, bullying and mental health.

Recommendation 4.4 – Prevention, surveillance and opportunity

We again emphasise the importance of a preventative response during the school years. This is a critical time to identify through early and ongoing surveillance mental health issues, and to put in place programmes which better meet the learning support, mental health and social needs of children and young people with an ASD.

5. Collaboration and Co-ordination

The prevalence and range of co-morbid psychiatric disorders in people with an ASD means that collaboration across all levels and sectors from national policy consensus to professional knowledge sharing, diagnosis and intervention is essential for this target group of people with mental health needs.

The NSW Ombudsman report (2011), *Consultations with Families with Children with Disabilities*, found that while early childhood intervention services provided a good level of service co-ordination and support "....this type of support ended once their child started school".

Similarly 70% of *We Belong* parent respondents reported experiencing poor co-ordination and collaboration between different services.

The majority of service providers interviewed for the latter report indicated that they did not have systematic processes in place for coordinating or collaborating with other organisations serving the adolescent and adult ASD client group.

Information sharing and cross referrals between services tended to take place on an informal or ad-hoc basis. Services may depend on scores on standardised assessment tools, rather than develop flexible service eligibility criteria based on real human needs.

The issue, however, is deeper than a lack of coordination and collaboration. When services lack the understanding and professional expertise required to recognise mental health issues in people with ASD, the first priority is to address this knowledge gap.

Collaboration and co-ordination between the sectors responsible for the well-being of people with an ASD will be more effective, if their understanding of co-morbid mental health issues is improved.

Recommendation 5.1 – Collaboration

We call for health and the disability sectors to work together to design a service system that is knowledgeable about ASD and co-occurring mental health issues, with clearly defined pathways of care including mechanisms to opt in key agencies (such as Education) as needed.

Recommendation 5.2 – School years round table

We support a collaborative intergovernmental interdepartmental roundtable (including education, health and disability sectors) to develop strategies targeting the school years, to improve the mental health, social and educational outcomes for students, and subsequently for adults, who have an ASD.

Recommendation 5.3 – Person centred approaches

We endorse the strong push by government and communities for person centred approaches where interventions and supports are designed collaboratively with clients rather than offer a one size fits all, take it or leave it approach.

6. Employment

Unemployment and under-employment are likely to contribute to the mental health issues of this population. Various reports such as *I Exist* and *We Belong* show that people with an ASD want equitable access to employment opportunities that match their qualifications, strengths and interests.

They want employment services and professional organisations to be knowledgeable about ASDs and willing to implement the supports and strategies that will enable them to perform to their full potential at work.

For many, the social demands of the workplace and associated discrimination and harassment are particular barriers which must be addressed in order for their basic human right to work to be provided, and through this, to feel valued as a participating and contributing member of society.

I have found the current emplacement services to be poor. I tire of dealing with a world that places more emphasis on sociability and likeability that on actual skill. I tire of seeing idiots that are less capable than me get positions, just because they can play the social/political game.

Damon, aged 28, NSW

We Belong found that just 54% of adults with an ASD who were surveyed were employed, compared with a national employment rate of about 95%. Of those employed however, 33% were working on a casual basis; in contrast just 21% of the Australian labour force as a whole is made up of casual workers.

Over half of parents whose grown child is currently in paid employment believe that their son or daughter's job is inappropriate or only partially appropriate to his or her interests, and, more often than not, did not match their qualifications.

Similarly, the parents of 96 young adults with high functioning ASD surveyed in Queensland rated access to employment services as their highest priority (Neary, 2012). More than 50% of these Queensland parents reported that their adult son or daughter was dissatisfied with his or her employment status, while 85% of parents perceived their sons and daughters as capable of higher level employment.

I want paid work that utilises my skills and abilities and that I enjoy and derive satisfaction from. There are services for older people, but none specifically for those with Asperger's Syndrome. What I need most is a 'mentor' – someone to help me keep my thought processes on track.

Adam aged 22, QLD

Regarding support to find work, two thirds of adult respondents would like more support to find a job, either now or in the future.

Service providers themselves emphasised the importance of ongoing support for adults in the workplace, with particular emphasis on social awareness and skills, and on co-worker education.

Employers, working with governments and specialist service providers, need information and resources to improve their understanding regarding the strengths and talents of this group of Australians, and to plan new opportunities that match the abilities and support needs of young adults with an ASD to work environments.

We call for consultation between agencies including employer organisations, governments and NGO's to develop job opportunities that match the abilities and support needs of young adults with an ASD.

We support Australia's first National Mental Health Commission chair Professor Allan Fels when he says that lifting the employment of people with a mental illness ought to be the "benchmark" by which to judge the success of the government's investment in mental health reform.

Recommendation 6.1 - Employment

We recommend an employment roundtable including employer groups to improve understanding and to tackle discrimination and to improve access to employment.

7. Funding

Shut Out comments that "...despite recent commitments to an increase in resources, the system is unable to meet current need and has limited capacity to meet anticipated increases in demand".

Experts consulted for this paper overwhelmingly noted the need for additional funding for mental health in general, and for mental health services with expertise in ASDs in particular because of the level of co-morbid mental illness in this population.

The Australian Government's recently announced commitment to \$2.2 billion over five years to make mental health a national priority is certainly a very welcome initiative, given that government sources estimate that currently mental health accounts for approximately 30% of the health burden, yet receives substantially less than this proportion of the health budget (Dossetor et al 2012).

In particular child mental health is estimated to be 35% of the mental health burden, yet it receives just 7% of available mental health funding.

Despite four national mental health plans over the last 15 year period, mental health still receives the same proportion of the health budget.

In this historical funding context, it is easy to understand why the health sector pushes responsibility for the mental health of people with an ASD back to the disability sector.

Given the Australian Government's commitment to making mental health a national priority, it is critical that we ensure access to mental health services for people who have an ASD.

The Australian Government's 2012-2013 plan to expand the Access to Allied Psychological Services program to target hard-to-reach underserviced groups such as children, Indigenous and disadvantaged communities is welcomed. Investment in better co-ordinated and accessible services, workforce training and capacity-building within this sector is a priority.

Along with the expansion of the Headspace program for teenagers and young adults, these are opportunities to specifically target children and young adults who have an ASD.

Another opportunity comes with the implementation of the NDIS which is being developed to better support people with a disability as well as those with significant mental health issues. Although at an early stage of development, it may be the best opportunity yet to address the needs of this population who have both disability and mental health issues.

With the high prevalence of mental health issues in this particular ASD population, the NDIS needs to consider ways to address Australia's current mental health service inadequacies,

including poor service co-ordination, narrow service eligibility criteria and lack of ASD-specific expertise.

As well, funding to assist services to build specialised ASD expertise is desperately needed in view of both current and anticipated unmet growth in demand, as diagnostic and assessment services become more accessible and more skilled, particularly in early identification.

Recommendation 7.1 – Funding for mental health services

We call for a national benchmark funding formulae based on the true proportion of the mental health burden, to assist services particularly mental health services across the nation to respond to unmet demand including for people who have an ASD.

Recommendation 7.2 - NDIS - A broader role

We recommend that the NDIS framework include strategies such as information, service coordination, referral pathways and data collection to assist all people who have an ASD and mental health concerns to access appropriate services and care.

CONCLUSIONS

Any Australian, regardless of ability or disability can develop a mental illness. People who have an ASD are currently at a very high risk of also having significant mental health issues.

The right to health is indispensable to the opportunity for "a good life". Like other Australians, people with an ASD tell us that this means having successful social relationships, good health and well-being, access to fulfilling employment, and the opportunity to be productive and valued members of the community.

However, this is often denied to people with an ASD whose mental health needs continue to be overlooked because of a lack of awareness and system failures to take responsibility, such as developing accessible services with relevant expertise.

Exclusion from service, lack of service knowledge and capacity, and discrimination in community, education or employment because someone has an ASD and mental illness is not acceptable in modern Australia.

Improved community and government awareness, funding, collaboration, professional expertise and support will benefit all in the community, not least by shifting people off welfare and into productive, fulfilling and more self-reliant lives.

While mental health services are primarily the responsibility of health departments, services could be enhanced through capacity-building in collaboration with specialist ASD services.

To dramatically improve knowledge about ASD and mental illness, the disability, health and education sectors must collaborate, lead and innovate in meaningful ways with people who have an ASD and their families.

An important next step is to review international practices and guidelines to describe for Australia a best care service model which could equitably and effectively respond to mental health needs.

Defined pathways of care and services and supports that are flexible, accessible and knowledgeable are essential to provide opportunities in society and human dignity to this overlooked group of Australians.

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