

Submission to Queensland Parliament  
**Inquiry into social isolation and loneliness in Queensland**

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Loneliness is more than simply being alone. Numerous studies have documented the extent of social and behavioural effects of loneliness (see for example Hawkey & Cacioppo, 2010). Loneliness and social isolation are present across all age groups – young children adolescents, young adults, adults of working age and older people. Loneliness increases morbidity and mortality: it also reduces overall wellbeing, results in less sleep and poorer overall physical and mental health. Being lonely has additional effects such as reducing confidence and social engagement, while concurrently increasing hypervigilance and depression, both of which may lead to very undesirable outcomes.

This submission to the inquiry into social isolation and loneliness in Queensland discusses the impact of a particular condition on the overall wellbeing of the individual with the condition, and also their family and caregivers. The submission then considers ways that wellbeing could be improved for this group of people with an invisible disability. The submission is written by an experienced Occupational Therapist who has close personal experience of the condition being discussed, and the impacts on their lives and their family. For privacy reasons, these people will not be named in this submission.

The submission recommends that a service to support employment for people with this invisible disability be extended. Through her contact with people with the particular condition, the author became aware of very successful outcomes, but she has no affiliation with the employment support service.

### Loneliness among people with invisible disabilities

Many studies have considered the effects of loneliness across different age groups, but the impacts of loneliness and social isolation for people with disabilities are less well documented. In particular, the effects of loneliness on the employment for individuals with a disability are not well recognised. This especially the situation for people whose disability is not visible (Lin & Huang, 2019). A particular group of people who are affected by loneliness are those with autism spectrum disorder (ASD).

Autism is a persistent neurological disorder that does not resolve over time. In 2019, AIHW estimated that Australians have autism<sup>1</sup>. A much higher rate of 1 in 100 people is identified in Europe<sup>2</sup>. An even higher rate is acknowledged in the USA, where 1 in 54 eight-year-old

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<sup>1</sup> The Australian Institute of Health and Welfare, 2017, <https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism>

<sup>2</sup>Autism Europe <https://www.autismeurope.org/about-autism/prevalence-rate-of-autism/>

children are diagnosed with autism<sup>3</sup>. Many of these people on the autism spectrum are ‘high functioning’, a condition often referred to as Aspergers Syndrome.

### Aspergers Syndrome: High functioning autism

Aspergers Syndrome (AS) is a lifelong condition that persists: it never goes away (Sonido et al., 2020). This condition affects social cognition and behaviour. AS affects how people understand the world, and how they behave and interact with others. As a result, it is very common for people with AS to be lonely. This is an important issue since ‘Social isolation and loneliness can be harmful to both mental and physical health.’<sup>4</sup>

AS is not an intellectual disability. People with high functioning autism can talk, read and write, and manage basic life skills such as eating and getting dressed. Indeed, many people with AS are highly educated and successfully complete vocational training and/or degrees. They may live independently, but they always have some difficulty with communication and social interaction.

People with AS find it difficult to understand social norms and rules, grasp social cues, and recognise what others might be thinking. People with AS may speak in an unusual way, such as by using formal language, being too loud, or using a monotone voice. People with AS can be coached to improve their understanding of social behaviour, but this knowledge and understanding does not come to them naturally during childhood.

Many individuals with high functioning autism crave social interaction and friendships (Causton-Theoharis et al., 2009), but they find it difficult to participate successfully in social situations, and they frequently have difficulty making strong friendships. As a result, people with AS frequently report high levels of social isolation (Sundberg, 2018). An Australian study confirmed that people with autism tend to be lonely and socially isolated throughout their lives (Ee et al., 2019). Many other studies have found that loneliness has a very significant, adverse impact on the wellbeing of both young and older adults (Bessaha et al., 2019; Golden et al., 2009; Mazurek, 2014).

### Supports lacking for adults with Aspergers Syndrome

Loneliness escalates as people with AS leave school and higher education and become adults. At this stage of life, people are expected to have sufficient social skills to manage their lives, but this is not usually the case for people with AS (Locke et al., 2010).

A study in Denmark noted that adults with a disability tend to become lonely, depressed, and some develop thoughts of self-harm and suicide (Lasgaard et al., 2016). Many Australian and international AS studies also found loneliness and social isolation leads to increased morbidity among adults (see for example Ee et al., 2019; Hedley et al., 2018; Mazurek, 2014). This lack of wellbeing is a serious problem, especially as adult services for adults with AS are seriously lacking.

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<sup>3</sup> Centres for Disease Control and Prevention (CDC) 2020 Autism Incidence Rate <https://asno.org/advocacy/2020-cdc-autism-incidence-rate/>

<sup>4</sup> Australian Institute for Health and Welfare <https://www.aihw.gov.au/reports/australias-welfare/social-isolation-and-loneliness>

Having AS does not prevent their intention to live a ‘normal’ life, but most people with AS need some assistance to live a ‘normal’ life.

The Australian Institute for Health and Welfare observed that only 1 in 150 Australians with autism are able to access some form of support service. Thus, approximately 75% of people living with autism have no assistance for personal development, life skills training job support, counselling, social integration support, or any other kinds of services that would aid their wellbeing. Most support is provided as early intervention services to children before the commence school, and some is offered during their school years. Much less support is available beyond the school/higher education years.

Leaving school/higher education is a very important stage of life, when young people aim to get a job and form social relationships beyond their family. Gaining suitable employment is a vital transition into adulthood. Yet despite their considerable potential for employment, once they leave school/higher education, very few Australian adults with AS are able to access support services to help their transition into adulthood.

A recent study found “Many young adults with AS live at home, are unemployed or underemployed, or participate in programs that are inappropriate or unhelpful, leaving parents worried about what the future holds for their adult children”<sup>5</sup>. The lack of support for people with AS beyond school age has a profoundly negative effect on the lives of people with autism, and also on the lives of their families and other caregivers who struggle to help over many years.

Most employment agencies fail to understand the potential of people living with this condition, even though ‘individuals with AS bring many strengths to the work place, such as attention to detail, trustworthiness, reliability, and low absenteeism’<sup>6</sup>.

Like their peers, people with AS want to work, but they find the transition from school/higher education to work is a lonely and fraught process. People with AS do not excel at job interviews, and they frequently lack confidence, so employers do not easily identify their potential. Despite high ability levels and having much to offer potential employers, this leaves them in a state of isolation and loneliness. AIHW estimate that 10-15% of Australians with AS work in open employment. A recent report by Specialisterne Australia provides comprehensive information

...only 40.8% of working age autistic Australians are employed, reflecting an unemployment rate of 31.6% (ABS, 2015). This is more than three times the rate for people with disability (10.0%) and almost six times the rate of people without disability (5.3%). Autistic individuals are often over-educated and underemployed for roles, with an over-representation in casual employment (Baldwin et al 2014). Autistic individuals are willing and able to work, with research showing that they can have higher than average abilities in areas such as pattern recognition, memory, analysis or mathematics, and are more productive and more efficient than their non-autistic colleagues (JP Morgan 2016). The high unemployment rate of autistic adults only highlights the significant barriers to employment.<sup>7</sup>

<sup>5</sup> Asperger Autism Network <https://www.aane.org/employment-asperger-syndrome/>

<sup>6</sup> Asperger Autism Network <https://www.aane.org/employment-asperger-syndrome/>

<sup>7</sup> Specialisterne Australia Submission to select committee on autism <https://specialisterne.com.au/specialisterne-reports/>

If they do gain employment, people with AS may not function effectively, especially at the beginning of the job. They may have difficulty interpreting instructions, working in unstructured or noisy situations, organising to complete tasks on time, and multitasking. Without transitional support to help understand and adjust to workplace routines and expectations, it is a struggle to not only get a job, but also to maintain their employment.

Not being employed restricts the potential for a 'normal' life. Work is an essential aspect of modern life that enables individuals to earn money and socialise. 'What do you do' is frequently the first question asked in any social situation. As a consequence of not having a job, people with AS must live on welfare and family charity – this is an unbecoming and demeaning situation for any young person. Not having a job is embarrassing, it leads to an obvious situation of 'being different' which results in further social isolation and loneliness.

People with AS report higher levels of loneliness than neurotypical adults (Lin & Huang, 2019). Some people with AS marry (Finch, 2012; Slater-Walker & Slater-Walker, 2002), but most live for long periods without a partner or other significant person who can offer support. This solitary life can be extremely lonely (Mazurek, 2014), suggesting that people with AS need support to facilitate and maintain social relationships (Lin & Huang, 2019).

People with AS frequently become socially isolated and depressed, with impacts flowing to their parents, families and caregivers. Most parents, families and caregivers are aware of and worry about this loneliness. Parents in particular worry about the future when they will not be around to support their loved one. They are perpetually worried about

- the capacity of the person with AS to live successfully despite their intellectual and other capabilities.
- the consequences of precarious employment and low income in relation to future housing
- their loved one being lonely and socially isolated, and
- the impacts of few friendships and lack of social life on mental health and wellbeing.

### Successful interventions to reduce social isolation and loneliness

A few Australian and international studies have examined the impacts of different interventions to reduce social isolation and loneliness among adults with a disability.

- In the Australian context, an online information service successfully reduced loneliness for adults with affective disturbances (Haslam et al., 2016).
- A recent systematic review of interventions for loneliness among non-elderly adults identified technology could sometimes offer benefits. Some forms of support were successful, such as an online peer mentoring program to build social skills for people with a disability, and an online support forum for a group of caregivers (Bessaha et al., 2019).
- Conventional face to face support services for depressed people were also found to decrease loneliness (Chiu et al., 2017).

## Recommendations to reduce social isolation and loneliness in Queensland

In an attempt to reduce loneliness and social isolation, this Queensland Parliamentary Committee is encouraged to review the extent and structures of support services available to adults with Asperger Syndrome and high functioning autism.

There is a particular need to support the transition from school/ higher education to employment.

Services to support the transition from school/higher education to employment, and to maintain a job are crucial to reduce loneliness and social isolation for adults with AS. Unemployment is demoralising. Unemployment drives social isolation: chronically unemployed people become disheartened, socially isolated, and chronically depressed.

Being employed embeds an adult in a 'normal' life. Having a job provides a capacity to enjoy life. Employment provides the basis for social interactions as well as income for housing, a car, holidays, and some discretionary spending on social and recreational activities. It also allows an individual to buy gifts for others. All of these improve wellbeing and reduce social isolation; but none can be achieved successfully without an income.

There is a great need in Queensland for additional support during the successful transition from school/higher education to employment for adults with AS. Excellent services are provided by Specialisterne<sup>8</sup> in southern states, but there are insufficient services such as this across Queensland.

Specialisterne was first established in Denmark. This agency focuses on the positive attributes that AS people offer. The agency emphasises

...the abilities and strengths of autistic and neurodiverse jobseekers including attention to detail, high accuracy, innovative thinking, loyalty and honesty'...[the aim is] to help to find talented autistic job seekers / candidates looking for a career in that area, for mutually beneficial outcomes. We recognise that autistic individuals offer a range of skills that can be of benefit to any job. We use a unique process to assess potential employees that removes the barriers experienced by autistic adults in the traditional recruitment process. We then work to support the individual and employee in their transition and build the capacity of the employer to support their autistic staff members. We help workplaces to understand the unique strengths of their employee/s on the spectrum and implement strategies across all levels of business and teams including line managers and colleagues to help their autistic colleagues utilise their skills to be successful and valued for their work in an inclusive and supportive workplace.<sup>9</sup>

After completing this Specialisterne program, participants from Queensland and other states have gained employment in the public and private sectors. By offering continued support, participants in these jobs have performed extremely well. Several participants known to the author are delighted to have had support and the opportunity to gain employment in positions and places that suit their abilities and special requirements. They have not only had a stable

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<sup>8</sup> Specialisterne <https://specialisterne.com.au/>

<sup>9</sup> Specialisterne <https://specialisterne.com.au/>

income to ensure they are not homeless; they also have the security to engage in new recreational activities, and build and new additional social connections. In contrast to other employment agencies, this Specialisterne program successfully reduced isolation and depression among participants known to the author in a concrete way. The results indicate participants will have future stability and a more successful and less lonely life.

Recommendation: There is a need to extend this service more widely so adults with AS can be successfully employed. Extending this service supporting ongoing employment will undoubtedly reduce social isolation and loneliness among adults with AS in Queensland.

### Summary

During their transition from school/higher education, and well into their adult lives, people with high functioning autism (AS) need support services and ongoing assistance in three distinct fields:

1. To find and maintain suitable employment
2. To integrate into suitable sport and recreational activities
3. To establish and maintain social relationships.

Providing financial support for services in these three fields will not only benefit the individual with AS, it will also improve the wellbeing of their families and caregivers by reducing constant stress and worry.

In particular, the government is encouraged to investigate extending financial support for Specialisterne services to assist Queenslanders with AS and high functioning autism gain and maintain open employment.



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