Inquiry into Prevalence, causes and impacts of loneliness in New South Wales

Organisation: Autism Spectrum Australia

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In response to the inquiry into the "Prevalence, causes, and impacts of loneliness in New South Wales," the Aspect Research Centre for Autism Practice (ARCAP) at Autism Spectrum Australia would like to present relevant insights from the broader field of autism research, alongside findings from our own research conducted in 2023-24. ARCAP is currently undertaking a multi-stage project focused on investigating loneliness among Autistic adults. This submission includes a summary of our current findings and outlines our future research directions. Specifically, we address inquiries (a), (b), (c), (g), and (i) as they pertain to Autistic individuals.

Autistic individuals represent a crucial stakeholder group when examining the prevalence of loneliness across NSW and Australia due to the growing prevalence of autism. Current estimates suggest that 1 in 31 (Barbaro et al., 2022) to 1 in 36 children (Maenner et al., 2023) are Autistic. Furthermore, increasing numbers of adults are being identified as Autistic due to enhanced awareness, broader diagnostic criteria, and recognition of autism in people previously overlooked (Lai & Baron-Cohen, 2015). This significant portion of the population underscores the importance of considering the impact and prevalence of loneliness for this specific subgroup of our population.

(a) the extent of loneliness and social isolation in NSW and how this is measured and recorded, including opportunities for additional and/or improved data capture

While researchers have begun to uncover the variations in loneliness experiences among Autistic individuals, significant gaps remain in understanding the full extent and nature of these experiences, particularly in NSW. Specifically, the prevalence of loneliness and social isolation among Autistic adults in NSW is not yet comprehensively measured or recorded, leaving a critical void in the data needed to address this issue effectively.

To bridge this gap, ARCAP has initiated a multi-stage project focused on investigating loneliness among Autistic adults in Australia. This project underscores the necessity of collecting reliable and valid data that accurately reflects the experiences of Autistic individuals. Current research has heavily relied on loneliness measures developed for the general population, which have not been validated for Autistic adults (Grace et al., 2022). This reliance on non-validated tools risks skewing the findings and potentially misrepresenting the true extent of loneliness among this population (Grace et al., 2023; Jones et al., 2022; Nicolaidis et al., 2020).

Instruments designed for the general population often present significant accessibility challenges for Autistic adults and individuals with intellectual disabilities (Nicolaidis et al., 2020). Common issues include complex language, inappropriate use of Likert scales, anxiety about providing accurate responses, variability in responses due to differing situational contexts, and an overall failure to capture the unique constructs of loneliness as experienced by Autistic people (Nicolaidis et al., 2020). Additionally, Jones (2022) emphasised the importance of ensuring that these instruments are not only psychometrically sound but also relevant and meaningful to the Autistic community.

Given the emerging evidence that Autistic individuals are at a higher risk of loneliness, it is crucial that any future efforts by NSW to measure and record the extent of loneliness and social isolation incorporate disability status as a key variable. Furthermore, the tools and measures used must be specifically validated for use with Autistic individuals to ensure the accuracy and relevance of the data collected. This approach will not only provide a clearer picture of the issue within NSW but also guide the development of targeted interventions to address the unique challenges faced by Autistic adults. Importantly, the adapted measure of loneliness was validated for use with Autistic *and* non-Autistic people. The changes systematically made will make the questionnaire more accessible for all people, not just Autistic people.

(b) the identification of populations most at risk of loneliness and social isolation

Autistic individuals are among the populations most at risk for loneliness and social isolation. Emerging evidence consistently indicates that Autistic people experience significantly higher and more frequent instances of loneliness compared to their non-autistic counterparts (Grace et al., 2022; Hymas et al., 2022; Quadt et al., 2023; Scheeren et al., 2022). This heightened vulnerability is further corroborated by our recent study (Love et al., under review), which utilised an international sample with a significant representation of Australians. The findings reveal that Autistic individuals report substantially higher levels of loneliness than non-autistic individuals, underscoring the pervasive nature of this issue within the Autistic community.

A key factor contributing to this increased risk is the social challenges that many Autistic individuals face. While many Autistic people have a strong desire for social connection, they often encounter difficulties in forming and maintaining relationships due to differences in social communication and interaction (Ee et al., 2019). These challenges can lead to a cycle of increased social isolation, which exacerbates feelings of loneliness (Grace et al., 2022; Leigh-Hunt et al., 2017; Quadt et al., 2023; Schiltz et al., 2023).

Given these findings, it is crucial to recognise Autistic individuals as a population particularly vulnerable to loneliness and social isolation. This recognition should inform targeted interventions and support systems designed to address the unique social needs of Autistic people, thereby reducing their risk of loneliness and improving their overall well-being.

(c) evidence of the psychological and physiological impacts of loneliness on people, including young people, the elderly, those living with a disability, those living in regional areas and the bereaved

This increased risk is concerning as loneliness is linked to significant mental health concerns and poor wellbeing (Schiltz et al., 2023). For Autistic adults, research has shown that higher levels of self-reported loneliness are related to elevated levels of depression, anxiety (Ee et al., 2019; Mazurek et al., 2013; Quadt et al., 2023; Schiltz et al., 2020), and suicidal ideation (ven Bentum et al., 2024), as well as substance use and a range of physical health conditions (Holt-Lunstad et al.,2010; 2015) such as obesity, increased incidence of cancer, cardiovascular diseases (Holt-Lunstad et al., 2010) and higher mortality (Mazurek et al., 2013). Loneliness is also uniquely associated with social anxiety; in a 2016 longitudinal study, Lim and colleagues found social

anxiety to be the only predictor of future loneliness, a finding that may have implications for Autistic people who often experience social anxiety (Spain et al., 2018).

(g) the identification of existing initiatives by government and non-government organisations to mitigate and reduce loneliness and social isolation

ARCAP is currently conducting an in-depth investigation into loneliness among Autistic adults, a population that is particularly vulnerable to this pervasive issue (Love et al., under review). Despite the significant health risks associated with loneliness, particularly for Autistic individuals, this area remains under-investigated. It is crucial that any initiatives aimed at mitigating loneliness incorporate validated tools specifically designed for Autistic adults to ensure that interventions are both effective and relevant.

As part of our ongoing research, ARCAP has recently completed a study focused on adapting the UCLA Loneliness Scale for use with Autistic adults. This adaptation process was rigorous, involving cognitive interviews and expert reviews, and culminated in the UCLA Loneliness Scale-Modified (UCLA-m). The UCLA-m was then validated using a large, international sample, including a significant number of Australian participants. The results demonstrated that the UCLA-m is a reliable, internally valid, and convergently valid tool that can be used to accurately measure loneliness in Autistic adults.

Our findings revealed that Autistic adults experience significantly higher levels of loneliness, social anxiety, and depression compared to non-autistic adults. This underscores the urgent need for tailored interventions and initiatives that address the unique challenges faced by this population. The evidence gathered from our study provides a strong foundation for future research and intervention efforts, highlighting the necessity of using validated, accessible tools like the UCLA-m in both government and non-government initiatives to effectively mitigate loneliness among Autistic individuals.

Moreover, the adaptations made during the development of the UCLA-m not only enhance its relevance for Autistic adults but also improve its accessibility for a broader range of individuals. This broader applicability suggests that the UCLA-m could be a valuable tool in various initiatives aimed at reducing loneliness across different populations, including those who may also face challenges with traditional measures of loneliness due to language complexity or other accessibility issues.

In light of these findings, we recommend that existing and future initiatives by both government and non-government organisations consider the unique needs of Autistic individuals. By incorporating tools like the UCLA-m and ensuring that interventions are designed with this population in mind, these initiatives can more effectively reduce loneliness and improve the well-being of Autistic adults.

(i) steps the State Government can take to reduce the prevalence and impacts of loneliness in the community

Addressing loneliness, particularly among vulnerable populations such as Autistic individuals, requires a multifaceted approach grounded in robust research and practical interventions. The evidence from our initial study provides a foundation for understanding loneliness in Autistic adults and highlights the importance of using validated tools, such as the UCLA-m, to accurately measure and address loneliness within this community (Love et al., under review).

To effectively reduce the prevalence and impact of loneliness among Autistic individuals in New South Wales, the State Government can take several key steps:

1. **Invest in Targeted Research**: Further research is essential to fully understand the extent and nature of loneliness among Autistic individuals and to identify effective strategies for alleviating it. The State Government should fund research initiatives that not only explore the prevalence of loneliness but also explore the specific factors that contribute to it within the Autistic community.
2. **Implement Validated Tools in Interventions**: The UCLA-m, a tool specifically adapted for Autistic adults, should be incorporated into existing and new programs aimed at reducing loneliness. This tool, supported by evidence from our study, can be used alongside lived experiences to tailor interventions that address the unique needs of Autistic individuals.
3. **Support Collaborative Efforts**: Encouraging collaborations between researchers, practitioners, and the Autistic community is crucial for developing effective interventions. Such collaborations ensure that the voices and experiences of Autistic individuals are central to the design and implementation of programs, making them more relevant and impactful.
4. **Allocate Funding and Resources**: Adequate funding and resources must be allocated to support initiatives that target loneliness in the Autistic community. This includes ensuring that programs are accessible to all Autistic individuals, regardless of their geographic location or socioeconomic status. Resources should also be directed towards training for practitioners to effectively use tools like the UCLA-m in their work.
5. **Promote a Balance Between Social Connection and Alone Time**: Interventions should recognise the importance of balancing social connection with restorative alone time, a factor that is particularly significant for Autistic individuals (Neville et al., 2024). Programs should be designed to help Autistic adults find this balance, enhancing their overall well-being.

By combining rigorous research with immediate, practical applications, the State Government can take meaningful steps to reduce the prevalence and impact of loneliness in the Autistic community, ultimately improving the quality of life for these individuals.

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Attachments:
- Aspect Loneliness Report and UCLA-m items