Engaging with autistic people with an intellectual disability to develop the National Autism Strategy

A report for the Department of Social Services

June 2023

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Introduction

Inclusion Australia has been engaged by the Department of Social Services (DSS) to undertake a research project to provide information on key issues facing autistic people with an intellectual disability, to feed into Phase 2 of development of the National Autism Strategy (NAS): the national consultation process. DSS has expressed particular interest in understanding the gaps that currently exist, and how they might best be ameliorated through the development of the national consultation process. In particular, DSS was interested in who has been left out; how best to engage with those who have been left out; and what are the most important things this group should be asked about in consultations.

Our understanding is there is concurrent work being undertaken in several areas and that this report will contribute to DSS' overall planning:

- DSS is working with other representative organisations to conduct similar research projects with other communities
- DSS is undertaking a mapping exercise to pull together information from relevant public consultations and submissions
- The Autism CRC is also looking at the evidence base for development of the Strategy, including identifying gaps in evidence.

In this paper, we discuss the intersection of autism and intellectual disability and how the National Autism Strategy can find and highlight the voices of autistic people with an intellectual disability. We spoke to several different advisory groups, sector leaders, and families of autistic people with an intellectual disability about what they most needed to give their input into the National Autism Strategy.

The remainder of this paper:

- Sets out several proposed guiding principles to guide the Strategy consultation
- Considers who the Strategy consultation work needs to reach and how to reach them
- Identifies elements of successful facilitation with this community
- Suggests several important topics for the consultation to consider
- Provides ideas for future work.

Background

Being autistic and having an intellectual disability can constitute a type of multiple marginalisation, with people facing intersecting and compounded marginalisation and discrimination. While there are shared barriers, there are also many differences among this group. Each autistic person with an intellectual disability is unique, and numerous factors contribute to their individual characteristics, experiences, and ultimate outcomes.

Some of these factors include:

- Support needs—lower or higher
- Family and trusted, informal (unpaid) supports, as well as paid supports
- Fair access to a differential diagnosis for both disabilities
- Access to healthcare, including preventative healthcare and check-ups
- Access to school and education, and being safe at school
- Communication method and access to preferred ways of communication
- Work opportunities (supported employment vs. open employment)
- Access to services and systems, like the Disability Support Pension (DSP) or the National Disability Insurance Scheme (NDIS)
- Experiences with justice systems, restricted settings, and people with power
- Experiences in emergency and crisis situations, including with first responders and police
- Community attitudes and influences.

There is a lack of data available in Australia about the prevalence of intellectual disability among autistic people, and investing in further research is a key opportunity for the National Autism Strategy and its associated work.

Internationally, there is a growing body of research that points to a significant prevalence within this cohort. For example, one Italian study estimated that 40% of people with an intellectual disability also had autism, while 70% of people with autism also had an intellectual disability.[1] In a review that looked at studies undertaken among population groups in the UK and the US, researchers estimated that between 40% and 60% of autistic people also have an intellectual disability.[2]

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[1] La Malfa, et al. 2004. Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research* 48(3), 262-267. https://doi.org./10.111/j.1365-2788.2003.00567.x

[2] Buescher et al. 2014. Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatr*. Aug;168(8):721-8. doi: 10.1001/jamapediatrics.2014.210. PMID: 24911948.

Guiding principles for engaging with autistic people with an intellectual disability

We have identified the following principles to guide the development of the Phase 2 Strategy consultation process:

- Different people will need to give feedback in different ways
- The intersection of autism and intellectual disability is a multifaceted experience with compounding impacts
- Consultations must be approached in a person-centred, trauma-informed, and outcomes focused way
- Safety concerns must be recognised and addressed.

These are expanded upon below.

Different people will need to give feedback in different ways

Autistic people with an intellectual disability are diverse and have different communication and support needs. This means that some people will be able to give feedback themselves using a traditional survey or traditional consultation with the right documents and support. However, some autistic people with an intellectual disability will not be able to do this. They may rely on parents, families, or other support people to give feedback on their behalf.

It is critical that all autistic people with an intellectual disability are included in the Strategy and that the consultation process offers a variety of options to support this. To recognise this, there are two important elements for the Department to consider in designing its consultation approach.

The consultation process must provide different options and ways for the community to provide input, including mechanisms that support a range of communication methods. Alternatively, when asking about the experiences a person is having in different environments (e.g., health systems or at home), observing them interacting with that environment can be a way to record their feedback.

Additionally, the consultation process must understand and accommodate the critical voice of families and independent advocates in supporting people with complex support needs and sharing their experiences. Families we have spoken to already are concerned that there might not be sufficient opportunity for them to engage and share the experiences of their autistic family members with an intellectual disability. There must be specific opportunities for this to occur or we risk insufficiently capturing the voices and experiences of people with more complex needs.

Finally, consideration should be given to a targeted in-reach approach to connect with autistic people with an intellectual disability who live in closed or restricted settings, including group homes and the justice system. This is further discussed throughout this paper.

The intersection of autism and intellectual disability is a multifaceted experience with compounding impacts

People with a dual diagnosis of autism and intellectual disability may experience the world in a very different way to people with autism or intellectual disability diagnoses alone. Having a dual

diagnosis, where that duality is not recognised or appropriately supported, can have compounding disabling impacts. This often means autistic people with an intellectual disability have higher support needs than people with autism or intellectual disability alone.

When working with autistic people with an intellectual disability, these differences—and the implications of those differences—must be listened to and embraced as part of the person's context.

Autistic people with an intellectual disability may have very different experiences based on the order in which they received their diagnoses, and the supports they have or have not been given for each disability. We have heard that a diagnosis for both disabilities for the same person can be difficult to get, as diagnosticians have been known to choose not to perform additional diagnoses due to "not wanting to add labels" or a sense that "one diagnosis is enough". There is a growing body of evidence of this within the academic literature, too.[3]

We have also heard that support can vary widely depending on the "primary" diagnosis; for example, Supported Decision Making is usually considered part of support and information for people with an intellectual disability, whereas it can be less common for this to be mentioned or included in supports and resources for people with autism as the primary diagnosis.[4] The range of supports a person has access to and is able to use will vary widely for this cohort, and can depend on family resources and access to informal supports, including access to informal safeguards.

Understanding the compound impacts and multifaced experiences of this community is an important foundation for the Department in developing a consultation process that can meet their needs and ensure their voices are included.

Consultations must be approached in a person-centred, trauma-informed, and outcomes-focused way

People with autism and an intellectual disability are likely to be living in restricted environments, like group homes or hospitals, and they are over-represented in interactions with the criminal justice system. For many, those experiences are likely to have been traumatic.

Additionally, we hear from many autistic people with an intellectual disability and their families that they often face barriers like discrimination, insufficient understanding of their needs, and exclusion through their engagement in other services, including disability services, health, and education. This has often happened in multiple ways over many years.

As a result, for many autistic people with an intellectual disability—and especially those within the cohort mentioned above, there is a "deep sense of mistrust" of government systems, particularly the

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[3] Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward brief "Red Flags" for autism screening: the Short Autism Spectrum quotient and the Short Quantitative Checklist for autism in toddlers. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*(2), 202-2012. https://doi.10.1016/j.jaac.2011.11.003; Metcalfe, D., McKenzie, K., McCarty, K., & Murray, G. (2020). Screening tools for autism spectrum disorder, used with people with an intellectual disability: A systematic review. *Research in Autism Spectrum Disorders*, *74*, 101549–. https://doi.org/10.1016/j.rasd.2020.101549

[4] Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T., & Ford, T. (2019). Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Molecular Autism*, *10*(1), 9–9. https://doi.org/10.1186/s13229-019-0260-x

NDIS. Consultations to develop the Strategy must recognise these experiences and the trauma that many people have been through, and seek to engage in a safe, person-centred, and trauma-informed manner.[5]

Safety concerns must be recognised and addressed

People may have concerns about giving their feedback or making complaints to service providers, and whether they will be resolved in an appropriate manner or whether their speaking up will provoke retaliation.

This is not an unfounded fear. Numerous reports and inquiries have found that there is a well-founded fear of retribution for people with disability when speaking up and voicing concerns about support workers and service providers and that this can prevent complaints and reports of poor practice—including of violence, abuse, and neglect—from being made.[6,7,8]

There is also considerable evidence of feedback and complaints being made by people with disability not being acted on or addressed. The NDIS Own Motion into Aspects of Supported Accommodation Final Report (the Own Motion report) shows that there is inadequate transparency and communication about how serious incidents and issues affecting a person are being managed, as well as why those incidents occurred in the first place. Additionally, the Own Motion report also presented evidence pointing to deficiencies in the capability and culture of the workforce—including the extent to which some support workers and management "reflect the values and principles of the providers, and have the interests and quality of life of the people they support at the centre of how they undertake their work"—which create conditions in which people with higher support needs are at greater risk of experiencing negative outcomes due to poor practice, including human rights breaches.[9]

This helps to explain why many people—especially those with high support needs and/or people in supported accommodation like group homes, as mentioned at the beginning of this paper—do not feel listened to or supported to provide feedback and may fear the reaction, inaction, or potential retaliation from a service provider.

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[5] See, for example, guidance by the Blue Knot Foundation: https://professionals.blueknot.org.au/.

[6] Victorian Ombudsman. (2015). *Reporting and investigation of allegations of abuse in the disability sector: Phase 1 – the effectiveness of statutory oversight*, Melbourne, p. 18.

[7] Australian Senate Community Affairs References Committee. (2015). *Final Report: Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*. Retrieved from: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Violence_abuse_n eglect/Report.

[8] Gray, A., Forell, S., & Clarke, S. (2009). Cognitive impairment, legal need and access to justice. Justice Issues Paper 10. Law and Justice Foundation of New South Wales. Retrieved from: http://www.lawfoundation.net.au/report/justiceissues10.

[9] NDIS Quality and Safeguards Commission. (2023). *Inquiry Report: Own Motion Inquiry into Aspects of Supported Accommodation*. Page 52. Retrieved from: https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/inquiries-and-reviews/own-motion-inquiry-aspects

To address this, ensure that service providers and systems are not involved directly in consultations and liaise directly with people giving feedback. Allow for anonymous feedback if possible. Use supported decision-making principles in the delivery of the consultations.

Who does the National Autism Strategy consultation process need to reach?

As with all other groups, autistic people with an intellectual disability are the experts in their own experiences. Autistic people with an intellectual disability often have families, support people, organisations and support professionals involved in their lives. This means there are a range of different perspectives that may be sought, including:

- Autistic people with an intellectual disability
- Parents and families, including partners or spouses and/or other trusted supports
- Friends and housemates
- Support professionals, including support workers or therapists (of the person's choice)
- Individual advocates and advocacy organisations
- Specialists who specifically work with autistic people with an intellectual disability and can discuss clinical factors and outcomes (e.g., speech pathologists who work with people who are nonspeaking).

Because autistic people with an intellectual disability are likely to have many different people in their lives in support roles, both formal and informal, it is important to be clear on who should and should not be a source of information, and to collect information using informed consent and supported decision-making approaches.

Service providers, particularly those who provide NDIS supports like Supported Independent Living, should not be the first port of call for providing information with or about autistic people with an intellectual disability about their lived experiences. While disability support providers can play a valuable role in connecting the people it needs to hear from to the National Autism Strategy consultation process, autistic people with an intellectual disability, alongside their families and informal supporters, should always be the first source of knowledge and guidance on who else to ask.

Some autistic people with an intellectual disability or families may want to include a trusted specialist practitioner (e.g., a speech pathologist, allied health practitioner or therapist) or a support worker to give input. This should be respected if it is what the person wants, there is good evidence of consent, and the professional has capacity to do so.

Individual advocates and advocacy organisations may have general knowledge and experience to share about the experiences of autistic people with an intellectual disability. This does not replace the need for individual consultations but can help paint a clearer picture of a range of experiences and the need for change.

How can the Strategy consultation process reach autistic people with an intellectual disability?

We recommend a multi-tier approach to ensure everyone has the opportunity to contribute to the development of the National Autism Strategy and is fairly represented in the Strategy output.

We propose the following way of working:

Tier 1: Data gathering from a wide range of people
- Online surveys
- Webinars and information sessions
- Information and resources on how to contribute to the Strategy development
- Allowing people to make submissions in whatever way works for them (text, audio, video, image, art)
- Promotion via Disability Representative Organisations, advocacy organisations, and service providers.

Tier 2: Consultations that work for most people (online or in person consultations)
- Group consultations via Zoom or online
- Group consultations in person.

Tier 3: Individualised consultations for people whose voices might not be otherwise heard
- Seeking expressions of interest for individualised consultations
- Meeting directly with autistic people with an intellectual disability, and/or their families or support people, in the place of their choice
- In-reach options, for example, visiting or connecting with autistic people with an intellectual disability living in restricted environments, like group homes, hospitals, or prisons
- Finding and engaging relevant communities of practice, self-advocacy groups, and other lived experience groups or committees.

We are aware this model of consultation has considerable resource requirements and we do not expect every person who wants an individualised consult to necessarily be able to access one. However, we suggest that allocating a portion of the consultation budget to finding and consulting with people who may not otherwise be heard will result in a better informed and more inclusive Strategy.

Priority cohorts

Within the autistic and intellectual disability community, there is great diversity. It is important to remember that an individual autistic person with an intellectual disability is not going to necessarily represent their whole community. We have identified cohorts who we believe are least likely to be heard and represented through traditional consultation methods and offer solutions to capture and engage with these people.

People with high support needs or complex disability

Many people who have high support needs or complex disability, as well as their parents, families, and other support people, often miss out on representation in consultations and subsequent outputs.

Suggested approach

Allow interested people to submit expressions of interest for an individualised consultation. Ask them what they need to give feedback. Individualised consultations should have the option of visiting a person in their home to gather feedback if this is what would work best.

People who have contact with restricted settings like hospitals, the justice system, and aged care

People who have experience with restricted settings and the justice system may be more difficult to access than other autistic people with an intellectual disability, but it is critical that their system experiences are captured. This includes system touchpoints such as early interactions with police or the justice system, short term hospital stays or medical experiences, and respite or short-term accommodation services.

Suggested approach

Connect directly with autistic people with an intellectual disability who live in closed settings via advocacy and legal organisations. Many advocacy organisations funded under the National Disability Advocacy Program[10] work directly with people in group homes and in the justice system. The national peak body for disability advocacy services, Disability Advocacy Network Australia (DANA), is a useful place to start. Clearly brief organisations on the scope of consultation so they can find the right people to talk to.

Several advocacy organisations that are members of Inclusion Australia have specific expertise and programs working with people with an intellectual disability in the justice system, and we could facilitate connections directly. Our members also have substantial experience working with people living in group homes.

Advocacy organisations and legal services, like community legal centres, will also be able to provide input about the trends and experiences they have observed, highlighting the issues within these systems and how autistic people with an intellectual disability can be better supported.

State and territory public advocates and public guardians may also be able to provide input or share information about consultation opportunities with their clients.

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[10] https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap

People living in group homes who may not have access to informal supports

Autistic people with an intellectual disability who live in group homes may not have access to support people or informal supports in the same way as others, particularly if they are older.

Suggested approach

As above re: connecting with advocacy organisations and public advocates / guardians. It would also be valuable to engage with service providers and connect with people using their services.

This could be done through National Disability Services (NDS), the provider peak body, or by directly contacting providers. Providers may have an internal Board, advocacy group, group home resident committee, or advisory committee made up of people they support or their family members or other trusted informal supports. If they do, present at an upcoming meeting about the Strategy and offer opportunities to get involved. For all the above priority cohorts, it is important to be aware that they may have factors affecting their participation in consultations and giving feedback, including health issues, sensory issues and overwhelm, or caring requirements. These can also result in last minute cancellations or reschedules. If rescheduling becomes necessary—even if it is last minute—do not presume the person has nothing to add. Try to work with them to find a way to make sure their voice can be heard.

How to get good information from autistic people with an intellectual disability, their families, and their support people

It is important to remember that a range of approaches will be needed for an effective and representative consultation process. Some people will be able to engage with the Strategy consultations themselves independently, while some may need support, and others may have families or support people give input on their behalf. All these groups have valuable feedback to give and should be engaged separately to ensure everyone can freely share.

Generally, we heard that the family members or other trusted informal supports of autistic people with an intellectual disability are anxious about their feedback being lost to the Strategy due to feedback and consultation options not being accessible or inclusive. For example, because of rigid consultation times and availability, short consultation windows for submissions, and expectations of physical attendance to give feedback—or for some, expectation of digital attendance as well.

There is also a concern that the voices of autistic people with an intellectual disability and/or complex needs will not be adequately captured if families or other trusted informal supports are not included in consultations.

We highly recommend that the Strategy deliberately prioritises hearing from the broadest range of people and experiences possible and has options available that allow people whose voices are not usually heard to engage.

Inclusion Australia and our members have a wide range of materials available to guide the delivery of inclusive consultations.[11] Some highlights are included below.

- Easy Read document options must be included in consultation materials. If Easy Read is prepared to support a consultation, it should be developed and given to participants well ahead of the meeting time—preferably at least a week in advance, if not longer.

- All online documents and forms must be offered in accessible ways, e.g., screen reader compatible and provided as Word docs rather than PDFs.

- Surveys should have clear options to indicate who is completing the survey—the autistic person with an intellectual disability, their family, or other trusted informal or formal support. Some people we spoke to found that completing surveys as a support person did not allow them to accurately describe their family members' diagnoses, making it difficult to capture prevalence of autism and intellectual disability.

- Families need to be included and expected as important sources of feedback. Consider different surveys and consultations for autistic people with an intellectual disability and for families, where each is the primary voice.

- Support workers have an important role to play in giving feedback with their client's consent to do so. However, attending a consultation is unpaid work, and many support workers may not be able to afford to do this for their clients without financial support. If support workers are identified as an important group to speak to, we recommend exploring potential remuneration options for these groups when speaking about priority cohorts.

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[11] See our Towards Inclusive Practice resources: https://www.inclusionaustralia.org.au/towards-inclusive-practice/.

What does the Strategy consultation process need to hear about?

Important topics to talk about

Autistic people with an intellectual disability have different and specific experiences unique to their community. To this end, we offer two lists of potential consultation questions: one of specific common themes identified in our consultation, which may be more commonly experienced by autistic people with an intellectual disability, and some overview questions, which allow consultation participants to self-identify the issues they most need heard and to affirm their place in the Strategy.

Please note that all questions have been aimed at autistic people with an intellectual disability by default. They will need to be translated into Easy Read and other accessible formats. They can be amended for parents, families, and other specific cohorts.

Specific themes and life experiences

These questions are intended to explore common themes experienced by autistic people with an intellectual disability to build an effective dataset. We have also included a 'key outcome' for each topic theme to help guide both conversation and the Strategy's overall goals for this cohort.

Communication

- What form of communication do you primarily use?
- Have you been well supported to find an effective way of communicating?
- If you did not have access to communication support when young, were you supported to access communication support when you were older?

Key outcome: Autistic people with an intellectual disability arrive at 18/school leaver age with a reliable, functional way of communicating that is not reliant on family or other informal or formal supports.

Risks and safety

- Does anyone challenge or question your decisions due to risk concerns?
- Are there things that happen to you at home that make you feel unsafe?
- Are there things that happen to you in the community that make you feel unsafe?

Key outcome: Autistic people with an intellectual disability have personal autonomy and their human rights are respected and upheld.

Choice and control

- When planning or decisions are being made about you and your life, are you included in that process?
- Do you need any support to make your own decisions?
- Are you getting the support you need to make decisions?
- What choices have been made for you by other people that you don't agree with?

Key outcome: Autistic people with an intellectual disability make their own decisions and have access to any support they need to do so.

Housing

- Are you happy to live in a house with other people?
- How many people would you like to live with (zero is an answer)? Why did you give us that answer?
- What sort of home would you feel safe in?
- If you could change anything about your housing situation, what would you change?

Key outcome: Autistic people with an intellectual disability have a living situation of their choice and feel safe at home.

Education

- Did you feel safe at school? If the answer is no, why not?
- Did you feel understood at school?
- Do you feel like you learnt a lot at school? e.g., reading and writing
- Did you get to do the things you wanted to do at school?
- Were you included in activities at school?

Key outcome: Autistic people with an intellectual disability should be included in all aspects of school life and should expect to achieve similar learning trajectories and outcomes as other students.

Transition from school and employment

- Did you get to choose what you did after finishing school?
- Did you have a choice to work in a non-disability setting?
- Do you have a choice in the work that you do?
- Were you offered further study after you finished school?

Key outcomes: Autistic people with an intellectual disability can pursue their chosen pathways after leaving school.

Diagnosis and dual diagnosis

- Was it easy to get a diagnosis for autism and intellectual disability?
- Once you had a diagnosis, was it easy to get support?
- Did your supports focus on just one of your disabilities?

Key outcome: Autistic people with an intellectual disability have adequate access to a differential diagnosis and are subsequently supported through a dual diagnosis lens.

Mental health

There is an increasing body of evidence that demonstrates that people with an intellectual disability—and it follows, autistic people with an intellectual disability—experience disproportionate violence, abuse, and restrictive practice from a young age. As a result, this means autistic people with an intellectual disability are at very high risk of trauma and psychosocial disability. [12]

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[12]Clark, L.L., Hext, G. and Xyrichis, A. (2018), "Beyond restraint: raising awareness of restrictive practices in acute care settings", *International Journal of Nursing Studies*, Vol. 86, doi:10.1016/j.ijnurstu.2018.06.006.; Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. (2021). *Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia.* Centre of

- Have you been offered support for your mental health?
- Have you ever felt very sad for a lot of the time?
- Do you feel anxious or worried a lot of the time?
- Has anyone every explained to you what mental illness is and who to talk to about it?
- Has something scary happened to you that you remember and think about a lot? If yes, have you talked about it with someone?

Key outcome: Autisitic people with intellectual disability have adequate access to education and support regarding their own mental health separate from their disability diagnosis.

System interactions
- How can the Strategy support the community to understand the needs of autistic people with an intellectual disability? e.g., not judging people negatively due to their behaviour.
- Have you had a dysregulated behaviour misinterpreted as intentional that led to you having a negative interaction with someone?

- Do people make assumptions about you or feel threatened because of your dysregulated behaviours?

- Has anyone used power over you because of your behaviours, like being assaulted or arrested?

- If you have had negative experiences, what do you wish the other people had done differently?
- Has your experience with your family member or other trusted informal supports in accessing out of home care services been challenging?
    - If yes, what were those challenges? How could changes be made?
    - If not, what about the experience worked well?

Key outcome: Autistic people with an intellectual disability can access the community safely and are supported by systems and people in power who don't make assumptions about behavioural intent.

Transition from home
People who have transitioned from home

- Did your family member have choice and control over whether they moved out of home, where they moved to and when it happened?
- What would help families and people they support transition smoothly from living at home to living independently in a supported environment?
- Did your family feel supported in this transition from home to living independently?
- What support did you have? How did it help? And what was the outcome?
- What support would you have wanted or needed?

Research Excellent in Disability and Health. Retrieved from: https://disability.royalcommission.gov.au/system/files/2021-11/Research%20Report%20-%20Nature%20and%20extent%20of%20violence%2C%20abuse%2C%20neglect%20and%20exploitation%20against%20people%20with%20disability%20in%20Australia.pdf

People who have not transitioned from home

- Do you feel the current systems could support your family member to transition to living independently with support? If yes, what supports make you feel confident about this change? If no, what needs to change or what is missing?
- Is there anything that is stopping your family member from transitioning to living independently with support?
- Do you have any concerns about your family member transitioning from home into supported accommodation?

Key outcomes: Autistic people with intellectual disability to be supported in the process of transitioning from home to a supported living environment of their choice. Families of these individuals can easily access information and support to ensure a smooth transition that is not crisis driven.

Overview questions

These questions are intended to explore and highlight any intersecting experiences or issues that may not be captured by focussed consultation questions. Further, they also encourage engagement and collaboration with the Strategy as a whole. Referral and other support options would need to be provided.

- What is working well in your life right now? You can talk about anything you need to.

- What is not working in your life right now? You can talk about anything you need to.

- What are the issues that are critical and need to be responded to quickly?

- Are there any risks in your life that might become issues in the future?

- How can we, through the National Autism Strategy, better support autistic people with an intellectual disability?

- How can we involve you in an ongoing way in the co-design projects, outputs, and formulation of the Strategy?

…and one last top tip

Consultation questions are typically specific. They tend to ask direct questions with distinct measurable outcomes. However, for this cohort, many people may not have had an opportunity to have their voice heard before, and they may come with a wealth of experience to share on many topics. Be prepared to hear about any aspect of life that a person might need to talk about. This could include difficult topics such as health problems (e.g., constipation) or serious systemic failures (e.g., abuse and neglect). It could also include difficult emotions such as pain, grief, and anger. This is a valuable opportunity to learn about things that may feel outside the scope of consultation and to truly understand what the most important issues are for autistic people with an intellectual disability. This type of consultation requires a trauma informed approach and good support available. Provide support proactively and do not expect participants to have or provide their own.

Factors for facilitation success

A critical element of a successful community consultation is how the consultation is delivered. There are a range of factors that are involved in this and contribute to getting good feedback and data, including:

- Building a safe and collaborative dynamic where people feel comfortable to give feedback
- Asking relevant questions and exploring responses
- Ensuring alternative accessible consultation methods
- Providing support or referral if needed and leaving people feeling safe afterwards.

We have highlighted some key skills that are important to think about when consulting with autistic people with an intellectual disability. More information about engaging with people with an intellectual disability inclusively is available in our Towards Inclusive Practice resources.[13]

Skilled facilitation and co-facilitation

Skilled facilitation is critical to successful consultation, particularly when working with autistic people with an intellectual disability and their families. A good facilitator:

- In the first instance, seeks advice on what setting would work best for the person to ensure a meaningful engagement and a willingness to be flexible. For example, going for a walk with them
- Shares who they are, what they do, and what they will do with the information they collect
- Takes the time to get to know the people giving information and makes them feel comfortable
- Thinks about the people in the room and finds ways to address power dynamics so people feel safe to talk honestly
- Asks good questions and engages with the answers people give
- Makes sure everyone in the room is included and has a chance to have their say
- Leave people feeling OK with what they have discussed
- Follows up if people experience distress and knows what supports to offer.

While research on best practice for facilitators undertaking consultation work with autistic people with an intellectual disability is still emerging, the usual principles of good facilitation also apply. Facilitators should have specific skills and ideally should have completed facilitation training to enable them to gather data effectively.[14] That is, in a way that is based in human-rights and inclusive practices that enables positive dynamics and trust to be built, as well as a consistent approach across all consultations.

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[13] Available on the Inclusion Australia website: https://www.inclusionaustralia.org.au/towards-inclusive-practice/
[14] Tesfaye, R., et al. (2019). Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities. *Autism*, *23*(8), 1882–1896. https://doi.org/10.1177/1362361319831487

In addition to skilled facilitation, we also recommend employing co-facilitators with lived experience. These can be autistic people with an intellectual disability, families, or other trusted informal supports.

Tools of the trade: documents, prompts, and consistency

For this cohort, it is important to consider the use of prompts as part of the facilitation toolkit. Not everyone will immediately know how to answer a specific question, especially if they are open ended (e.g., "What's working for you in your life?"). Understanding how to guide the conversation if people need help ensures everyone has the best chance to give their answer. You could also provide an example answer so people have an idea of what to say, while being mindful of acquiescence.[15] Allowing as much time as is required by the individual to process the questions and formulating a response will need to be factored in to time allocation for the engagement.

As with working with people with an intellectual disability who do not have autism, accessible documents are important. Have information for autistic people with an intellectual disability, as well as information for families, carers, and support workers, translated into Easy Read. Ask for any other access needs in regard to the document (e.g., languages other than English), and ensure all online documents and forms are accessible (e.g., for screen readers, fillable form fields, provided as Word documents rather than PDFs).

Consistency of data gathering is also important, particularly if there are teams on the ground in different areas or different organisations contracted to do the same work. Make sure training, language and materials are standardised, while allowing for flexibility of engagement for those who need it.

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[15] https://www.inclusionaustralia.org.au/resource/communication-its-not-a-spectator-sport/

Future directions—what comes next?

To write this paper, we spoke to many families and allies of people with an intellectual disability about who to consult with, what should be discussed, and how to make National Autism Strategy consultations accessible and effective. This process allowed us to capture the experiences of autistic people with an intellectual disability who have very complex needs and who are not generally heard through government consultation processes. Our project team also included people with direct and family lived experience.

Together, the people we consulted with provided valuable insight and had specific suggestions for what they thought would be the best actions to take as part of the Strategy process itself. We acknowledge that there will be space for these inputs later in the Strategy consultation timeline, but we feel it is important to capture and document these insights alongside the requested consultation data.

We suggest the following areas for consideration.

Specific investment in a dataset on the prevalence of autism and intellectual disability together

We have highlighted above the critical lack of data on the co-occurrence of autism and intellectual disability. Knowledge gaps affect all aspects of life for autistic people with an intellectual disability: everything from diagnosis to education to life outcomes.

We suggest that, as an action item, the Strategy aims to create a comprehensive data set on co-occurring autism and intellectual disability. This would include prioritisation of this data collection by the National Disability Insurance Agency, with the rollout of the new NDIS PACE ICT system and should align with the work being done on the National Disability Data Asset. There is significant data on life outcomes for people who are autistic or have an intellectual disability – enough to know this is an area that requires critical attention. But there is currently no baseline to effectively assess prevalence of both conditions together, life trajectories and life outcomes.

People with lived experience, as well as their family members and other trusted informal supports, should be actively involved in co-designing such a dataset at every step of the way. It is recommended that autistic people with an intellectual disability, their family members, or other trusted informal supports are deeply embedded in the project as co-designers, co-researchers, and testers in valued and engaging roles.

Representation of autistic people with intellectual disability – including those with complex communication and/or support needs

Families of people with complex needs have told us that so far it feels like the National Autism Strategy work is focused on, and led by, autistic people who do not have intellectual disability or complex communication or support needs. Many of the families we spoke to said they do not feel their experiences are being represented within the Strategy or the Oversight Council. This includes experiences more commonly experienced by autistic people with an intellectual disability such as interactions with the justice system, complex support needs and plans, non-speaking communication supports and styles, and abuse and neglect by service providers.

We acknowledge that there are more committee announcements to come, and this may change; however, if it does not, we recommend making an intentional effort to re-capture and represent this group in the development of the Strategy.

We suggest the following approaches:

- Put specific engagement structures in place within the Phase 2 of the development of the Strategy, to connect with this cohort. This means including consultations and measures that acknowledge the specific experiences and needs of this group, including specific data collection questions and measures that reflect these experiences.

- Consider autistic people with an intellectual disability and parents as paid consultants to fill Oversight Council and Working Group experience and/or representation gaps.

- Consider including subgroups within the existing National Autism Strategy working groups to reflect specific issues faced by autistic people with an intellectual disability. These could include a subgroup on behaviour supports or restrictive practices, justice system interactions, and service provider complaints and escalation. It is our belief that these issues should be specifically included in the Strategy and not segregated into a separate working group. These issues should be treated as relevant to all autistic people, not just those who also have intellectual disability.

Targeted, specialised training for support workers

There is an opportunity for the Strategy to drive workforce capability to better meet the needs of autistic people with an intellectual disability.

We suggest the development of a pack of training resources specifically for working with autistic people with an intellectual disability (though these topics would have relevance to most autistic people, particularly those with complex support needs). This pack should be developed and held at the national level within the Strategy body of work so as not to be influenced by service providers or state registration/licensing requirements. We are not presently aware of these topics being covered by another organisation and feel there is a strong need for additional specialised training.

Suggested topics include:

- **Respectful communication with families and support people:** including trauma informed care, de-escalation of stressful situations, communicating respectfully, and understanding neurodivergent communication styles. Many parents of autistic people have neurodivergent traits, and targeted learning (including key concepts like the double empathy problem) would allow support workers to foster better relationships with families.[16]

- **Working in partnership with families:** including working together in the interest of the autistic person with an intellectual disability, managing the risk of alienation between families and support providers, and improving support worker-family engagement.

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[16] Taylor, S. C., Steeman, S., Gehringer, B. N., Dow, H. C., Langer, A., Rawot, E., Perez, L., Goodman, M., Smernoff, Z., Grewal, M., Eshraghi, O., Pallathra, A. A., Oksas, C., Mendez, M., Gur, R. C., Rader, D. J., Bucan, M., Almasy, L., & Brodkin, E. S. (2021). Heritability of quantitative autism spectrum traits in adults: A family-based study. *Autism Research*, 14(8), 1543–1553. https://doi.org/10.1002/aur.2571

- **Reducing and eliminating systemic trauma:** understanding the factors and situations that lead to systemic trauma, and how to support people who have experienced systemic trauma. This is different to trauma-informed care and focuses on the role of systems in acknowledging and preventing trauma.
- **Behaviour motivations:** including understanding behaviour as a form of communication including why behaviour that may be seen as challenging happens, avoiding the presumption of intent around behaviours, de-escalating to avoid justice system interactions, and challenging implicit bias.

Data and information gaps

We heard a lot about data gaps when we spoke to parents, family members, sector experts and other allies. The National Autism Strategy is an opportunity to address existing significant data gaps and to set the stage for better data and outcomes for autistic people with an intellectual disability.

The following gaps were identified by autistic people with an intellectual disability, families, support people and advocates:

- We have inadequate data on the prevalence of autism and intellectual disability together, including understanding the incidence of different conditions like Down syndrome.

- IQ testing is frequently inaccessible for autistic people with an intellectual disability and prioritises certain skills (like learning facts), which may not be reflective of a person's actual capability.

- We have heard anecdotal evidence of professionals being unwilling to diagnose autism if there is an existing intellectual disability diagnosis – either due to "not wanting to add another label" or a "what's the point" approach. This is further complicated by school funding attached to different diagnoses; some diagnoses attract more funding than others, and parents we spoke to find this concerning.

- Getting an autism diagnosis can be far more complex than some intellectual disability diagnoses, e.g., Down syndrome, which is congenital and usually identified very early. This often requires extra effort, money, and advocacy, all of which can be a barrier to having a clear understanding of an individual's expression of disability.

- Currently there is little understanding of the experiences of autistic people with an intellectual disability within the justice system, including incidence compared to the general population, whether support is freely given while in the justice system, and life outcomes after contact with these systems.
- Many autistic people with an intellectual disability live in group homes. One significant data gap is around how much choice autistic people with an intellectual disability have in their housing situation and whether they would choose differently if given more options.

- The NDIS does not work well for everyone. Many families of autistic people with an intellectual disability experience severe struggles with the system have been left traumatized and have had to work hard to build an individualised support system for their

family member or other trusted informal supports on their own (e.g., a service for one[17]). While these options may be acknowledged by the NDIS and other relevant bodies, there is little guidance available for those exploring ways to manage complex supports. Data on these individualised support systems, the success of these outcomes and guidance for other families in similar situations would be valuable assets.

We recommend that the Strategy prioritises effective data gathering about the intersection of autism and intellectual disability in Australia. This includes rates of dual diagnosis, barriers to dual diagnosis and rate of misdiagnosis or misidentification, access to supports after dual diagnosis, and life outcomes for people with dual diagnosis.

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[17] https://www.inclusionaustralia.org.au/services-for-one-project/

Conclusion

We are very pleased to see DSS is interested in specifically exploring the experiences of autistic people with an intellectual disability in developing the National Autism Strategy. This cohort is not usually well represented in public consultations and community input processes, and data on their specific experiences is lacking as a result.

To consult with autistic people with an intellectual disability effectively, there should be options to allow people who experience more marginalisation to be represented. This includes people with higher support needs, and/or who are non-speaking or have complex communication needs. They may need individualised, flexible approaches, including offline and one-on-one consultations.

We believe that using an inclusive, trauma informed, and outcomes-focused approach will be an important part of the development process for the Strategy. We know that one of the best predictors of good outcomes is having good data, and with the right approach, this work could take a significant step in addressing noted data gaps. We hope that the Strategy's engagements capture all the voices that need to be heard, resulting in an inclusive Strategy for all autistic people – including those who also have an intellectual disability.