



Centre for Program Evaluation
Melbourne Graduate School of Education

Literature Review for Vivid: Better Autism Services for Regional and Rural Victoria

Submitted to Vivid

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ACKNOWLEDGEMENT OF TRADITIONAL OWNERS

The University of Melbourne acknowledges the Aboriginal and Torres Strait Islander traditional owners of the unceded land on which we work and learn. We pay respect to the Elders, past and present, and the place of Indigenous knowledge in the academy.

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- advancement of evaluation theory and methods
- teaching evaluation
- evaluation practice

CPE has a long-history of undertaking projects for government departments, non-government organisations, academic institutions, and community-based agencies across a wide range of policy and program areas with a focus on education, health, social wellbeing, and community development.

Melbourne Disability Institute

The Melbourne Disability Institute (MDI) is an interdisciplinary research institute that was established by the University of Melbourne in 2018 to build a collaborative, interdisciplinary and translational research program to improve the lives of people with disability. Key members of the MDI team have deep knowledge and experience of the current rapid reforms underway in Australia's disability sector. MDI also has relationships with some of the key leaders in disability research and practice nationally and internationally. Furthermore, half of the MDI team have lived experience of disability, enabling a multidimensional understanding of disability. The MDI research program is underpinned by strong conceptual approaches including Human Rights and Active Citizenship, Critical Realism, Capacity Approach and Integrated Knowledge Translation.

MDI's vision is to transform the social and economic wellbeing and the health of people with disability through high-quality research, teaching and training, and knowledge translation.

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List of Abbreviations

Abbreviation	Full text
ADHD	Attention deficit hyperactivity disorder
ASD	Autism spectrum disorder
CALD	Culturally and linguistically diverse
CPE	Centre for Program Evaluation
DHHS	Department of Health & Human Services
MDI	Melbourne Disability Institute
NDIS	National Disability Insurance Scheme
PDD	Pervasive developmental disorders

Plain Language Summary

The Project

We are Vivid (Vivid) is a not-for-profit organisation that provides support to adults with intellectual disabilities. Vivid's clients have autism as their primary disability. Vivid was a successful recipient of the Melbourne Disability Institute (MDI) Community Based Research Program Grants. The aim of these grants is to help community organisations conduct research or evaluation programs that are making a difference in the lives of people with disability and their families/carers. Vivid were partnered with the Centre for Program Evaluation (CPE) to do a review of research about best practices for organisations that support adults with autism. Vivid want to know more about best practices so they can continue to improve their services.

What we did

We reviewed studies that talked about what organisations that support adults with autism need to do to make sure that they receive the best support. We showed our findings to Vivid, and discussed ways for Vivid to continue improving and expanding their services for adults with intellectual disabilities.

What we found

[Meeting the individual needs of adults with autism and supporting them to make decisions about their lives](#)

We found that it is important that organisations provide support that meets individual needs and preferences. Also, they need to provide opportunities for people with autism to choose what activities they want to do, be autonomous and develop new and independent skills.

[Incorporating the voices of the autistic community](#)

To provide the best services, support organisations need to collaborate with people with autism and their families and carers so they can make decisions about activities, programs and ways to evaluate the quality of these supports.

[Improving services and training staff](#)

Finally, it is important that support organisations provide opportunities for their staff to learn and improve skills. It is also important that they evaluate the quality of their services on a regular basis.

Next steps

Vivid will use these findings to continue to improve their services. We recommend that they focus on:

- Creating partnerships with the people that use their services and their families and carers.
- Developing more programs and services tailored to individual needs.
- Evaluating their programs and services regularly.

1. Introduction

1.1. About Vivid

We are Vivid (referred to as Vivid) is a not-for-profit organization based in the Murray area of regional northern Victoria that provides support to adults between 18 and 65 years of age who have an intellectual disability. Services provided by Vivid include day programs, individual support, National Disability Insurance Scheme (NDIS) planning support, and access to transport. Vivid also offers services related to employment, such as transition support for school leavers and supported employment through partnership with local businesses. While Vivid mainly provides services to support people with intellectual disability, 30% of Vivid's clients have autism as their primary disability. As this number is projected to increase, Vivid is seeking to provide more effective support by significantly improving their services for autism.

1.2. Purpose of this Literature Review

The aim of this literature review is to identify Australian and international evidence-based practices to support the improvement of Vivid's services for adults with autism in regional and rural Victoria. This includes providing information on what Vivid can implement as part of their services, informing Vivid's clients about best practices, and supporting clients to make informed choices about the services they receive. Findings from this literature review also extend to supporting connection with prospective clients to ensure that all who are eligible are being reached. This includes members of the Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse clients, and community members who may not be aware of Vivid's services.

The scope of this literature review further includes considerations for Vivid's staff including training and professional development, tailoring and future proofing of sites and services to support autism, and potential use for funding applications to achieve the project's recommendations. Through this project, Vivid aims to ensure services are not only evidence-based and best-practice, but also responsive and sensitive to client needs. This includes supporting all staff to engage with new ideas, embrace change, and continually innovate and improve service offerings.

2. Methodology

An initial search was conducted across the APA PsycInfo, PubMed, ProQuest, Roadrunner Search, Cochrane Library, CINAHL Complete, MEDLINE Complete, and Web of Knowledge databases. Search terms related to autism (autism OR autistic OR Asperger OR Autism spectrum disorder [ASD] OR Pervasive developmental disorders [PDD]) were combined with terms pertaining to community support (NDIS, day programs, disability) and international best practice.

The following websites linked to community support and autism organisations were also manually searched for grey literature: Western Australia Autism Association, Victoria Autism Association, Queensland Autism Association, Aspect Australia, Amaze, Autism Spectrum Australia, Autism Awareness Australia, Australian Autism Alliance, Autism Aspergers Advocacy Australia, Autism SA, and Scope Autism Cooperative Research Centre (Autism CRC).

As a significant proportion of autism-related research focuses on children, additional searching was conducted in Google Scholar using the term "autis* AND adults". Results were manually screened for relevance, and reference lists in included articles were screened for further relevant literature. Some studies included autistic participants; however, the primary focus of the study was related to intellectual disability and as such, these articles were excluded from this review. For this literature review, a total of 38 items were included.

3. Literature Review: Autism Services

3.1. Introduction

The array of both capabilities and challenges displayed by people on the autism spectrum is considerable. People with autism share complexities in the core areas of social communication, restricted and repetitive behaviours, and sensory processing. However, every individual with autism is unique; if you have met one person with autism – you have only met one person with autism (Marco et al., 2011). Because of this, autism is called a 'spectrum disorder' to signify the unique and diverse nature of autism, and no two autistic people are the same. Autistic people may share similar characteristics and core challenges, however individual intellectual profiles (such as executive functioning, language, and perception) markedly contribute to a person's areas of strength and challenge, and can indicate where further supports may be required. Any support services used should be tailored to fit a person's individual needs (Bradshaw et al., 2021).

The autism spectrum is frequently viewed as a linear concept using high- or low-functioning labels, assuming that individuals experience autism either mildly or severely (Alvares et al., 2020). Even though 'high-functioning autism' is not a formal diagnosis (Vahia, 2013), continuous use of the term among health professionals and autism researchers has associated the label with expectations of better functional skills and long-term outcomes, regardless of inconsistent clinical observations (Alvares et al., 2020). Categorising autistic people into degrees and applying high- and low-functioning labels neglects to capture the crucial fact that autism is not static but fluid in nature. As demonstrated in the diagrams below, autism is more accurately represented as a wheel (Burgess, 2019) with variable areas of strength and challenge between each unique individual.

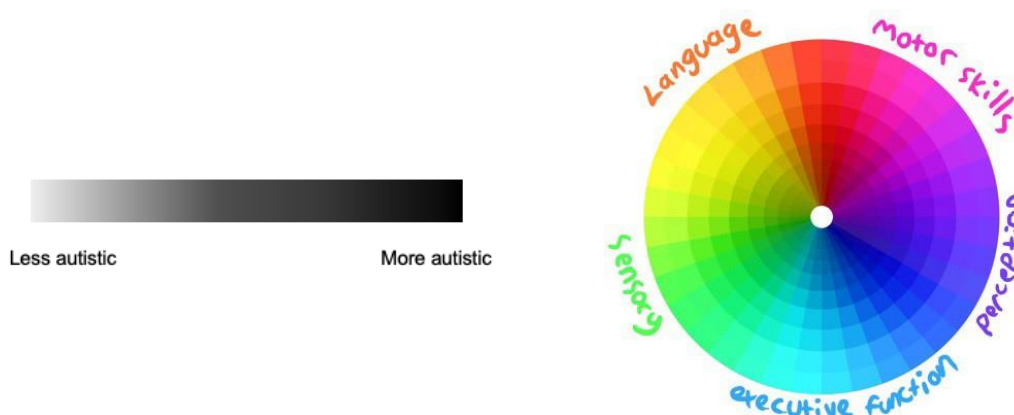


Figure 1. Autism represented using a linear spectrum and colour wheel.

Colour wheel from *Understanding The Spectrum – A Comic Strip Explanation* by Rebecca Burgess, 2019, *The Art of Autism* (<https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation>). Copyright Rebecca Burgess.

Table 1 shows the how perceptions of a 'high-functioning' autistic person may be viewed from a neurotypical perspective compared to the autistic person's experiences.

Table 1. Perspectives on autism

Neurotypical view of high functioning	Autistic response to the neurotypical view
If an autistic person appears to have a normal conversation and act reasonably normally, they are assumed to be able to handle neurotypical situations just fine.	New situations, loud noises, and lack of routine can be overwhelming or distressing and potentially lead to autistic meltdown (expressed through behaviour). Attempting to conform to neurotypically-normed expectations and requests such as 'don't fidget,' 'be more organised,' and 'sit still' (known as masking) can lead to or exacerbate stress and anxiety.

Perceptions of the outside world that differentiate a person with ASD from their "typical" peers vary according to the autistic individual and their age, however there are fundamental challenges that impact most people with ASD (McAuliffe et al., 2020). In a study by Griffith et al. (2012), individuals with autism reported multiple difficulties when engaging in social communication and interaction including recognising and interpreting social nuances, understanding cues such as when to end conversation, and using eye contact. Autistic individuals also reported making a conscious effort to understand the unwritten 'rules of social interaction' and feelings of apprehension about being perceived negatively by others. Furthermore, intense sensory input such as bright lights or loud noises can be overwhelming or lead to sensory overload, presenting an additional challenge for some individuals.

Others may misunderstand the challenges experienced during social interaction by people with autism, and form inaccurate assumptions. Autistic people may be assumed to lack a desire for meaningful relationships or be unable to experience a full range of emotions (Santhanam & Hewitt, 2021). Studies have shown that most people with autism do want to develop meaningful relationships (Santhanam & Hewitt, 2021), however their differences in social communication may be misinterpreted by neurotypical people as being uninterested (Jaswal & Akhtar, 2018). Similarly, autistic people may have difficulty recognising or interpreting the feelings of others, however this is due to miscommunication rather than a lack of emotion. This phenomenon is known as "double empathy problem," where two neurologically distinct people who have alternate modes of communication and understanding may have difficulty connecting, as with autistic and non-autistic adults (Milton, 2012). This disconnect can lead to feeling alien and misunderstood, as explained by one autistic young man who stated, "I wish I could live on Planet Autistic" (McAuliffe et al., 2020).

Research has shown a higher prevalence of co-occurring conditions in the autistic population when compared to the general population (Lai et al., 2019). This includes attention deficit hyperactivity disorder (ADHD), sleep problems, and mental health conditions such as depression, anxiety disorders, bipolar disorder, and obsessive-compulsive disorder. It is essential to understand that these co-occurring conditions can contribute to other behavioural and/or mental health challenges and should be holistically considered as part of personalised ongoing support. Many people with autism have difficulties with expressive language and may attempt to express their feelings through behaviour as an alternative (Chiang, 2008). This behaviour may be challenging, such as self-injury or aggression. Children who are non-verbal or have low verbal (spoken) language skills may experience higher rates of challenging behaviour.

It is important to note that challenging behaviour often occurs as part of an involuntary physical and emotional response to nervous system overload during autistic meltdown (Bedrossian, 2015). Autistic meltdown occurs when a person with autism is overwhelmed and does not feel that they are able to escape the stressors, instead releasing their distress through behaviour. Stressors can include sensory overload, excessive cognitive demand, intense frustration, unfamiliar situations, and unexpected changes, in addition to typical stressors in adult life e.g., work demands or financial issues. Once a meltdown is in progress, an autistic person will usually need to wait until the episode ends before they are able to self-regulate again due to their heightened senses and emotions. Episodes of autistic meltdown can be distressing for both the individual and those around them, however calm and deliberate strategies (such as reducing sensory stimulation or moving to a private environment) can support the individual until the episode passes.

Although most people in Australia are aware of autism, there is often misunderstanding about autistic people amongst the general community including a lack of knowledge as to how to effectively support them (Jones et al., 2021). These misconceptions can be harmful, such as the idea that autism is a “curable” condition, that people grow out of autism, or that autistic people are more likely to be violent. The impact of these inaccurate perceptions extends to the provision of support for autistic people, with many adults with autism who require support receiving insufficient support or none at all.

Support Services for Adults with Autism

Autistic individuals reported endeavouring to fit into a support system that is not designed to accommodate them effectively (Griffith et al., 2012). Adults with autism usually consulted their general practitioner (GP) to initially seek support, however many GPs’ lack of knowledge regarding autism in adults led the individuals to avoid GPs in favour of their own strategies. Autistic people in middle adulthood reported that their attempts to obtain formal support were unsuccessful due to a similar lack of knowledge amongst health and social service professionals. Young adults experienced additional challenges navigating supports, particularly when coordinating the complexities of transitioning from the school system to the adult service system (Kerr et al., 2018). Support is crucial throughout the transition to adulthood as this period can be particularly challenging for autistic young adults, who often experience co-occurring mental health conditions during this time (Pillay et al., 2021).

Co-occurring mental health conditions such as depression and anxiety are often considered part of an individual’s autism diagnosis, meaning that they are expected to access mental health support through the disability sector (Pillay et al., 2021). However, skills in the disability sector can be inadequate to support their mental health needs, and a lack of collaboration between sectors further limits appropriate support for autistic young adults.

For individuals who do not live in metropolitan areas, service options can be limited and some people may need to live away from their local area to access the support they need (Washington et al., 2019). Currently, few therapists cover vast geographical areas in rural and remote Australia, and service delivery is generally based on a “hub and spoke model” (Roufeil & Battye, 2008). Within this model, therapy teams are situated in a “hub” and deliver outreach services along “spokes” to autistic individuals living in remote locations.

Service providers described many influencing sociocultural and socio-political factors when supporting adults on the autism spectrum (Pillay et al., 2021). While collaborative relationships and open communication were vital in maintaining effective partnerships, support service staff indicated that various challenges existed in their roles. Many families of young adults with autism had limited knowledge of available support services or how to access them, resulting in some autistic young adults receiving support that was not effective for their individual needs, or lacking support altogether. Furthermore, some families had high expectations of both support services and the young adult due to their limited knowledge of

support services. Other influencing factors noted by support staff included staff availability, staff training, and managing misconceptions about autism in the broader community (Pillay et al., 2021).

National Disability Insurance Scheme

The critical goals of the National Disability Insurance Scheme (NDIS) are to enhance levels of participation in society, provide a range of service options to meet individual needs and circumstances, improve access to support, and reduce the gap between individuals with and without disabilities. (National Institute of Labour Studies Flinders University, 2013). However, many autistic adults feel a lack of support regarding NDIS planning and choice of services.

While some choices may be technically available, the services needed do not exist or are not always funded, or individuals are not empowered to explore the available options and to make a suitable decision. This is especially the case for those with complex needs who overwhelmingly experience the NDIS as unsupportive. Some individuals reported further challenges including availability of specialists, insufficient travel funding, and difficulties 'proving' their need to access NDIS support (Parliament of Victoria Family and Community Development Committee, 2017).

In addition to the lack of perceived NDIS support, gaps were identified in the incidence of autistic people in culturally and linguistically diverse (CALD) communities. To deliver suitable services and supports to autistic people within these communities in Victoria, the Victorian Government must be aware of the occurrence and needs of autistic people in these communities (Parliament of Victoria Family and Community Development Committee, 2017).

The lack of culturally appropriate services also creates a barrier for Aboriginal and Torres Strait Islander people with autism. It is recommended that Aboriginal Early Days autism information sessions should be held within local Aboriginal agencies and delivered by Aboriginal liaison officers. This was highlighted in the Federal Report into Autism (Parliament of Victoria Family and Community Development Committee, 2017, p. 41):

"Jackie lives in a rural town where services for autistic people are limited. Jackie stated that when her son was diagnosed, she was very reluctant to disclose his diagnosis. She was afraid he would be treated differently because of a white person's label given to him. She expressed the importance of cultural understanding when going through the diagnostic and assessment process and the importance of the same level of understanding in the therapeutic process. When specialists are invited into the home in the Indigenous communities, they ultimately become a part of the extended family. A lack of knowledge and understanding of culture creates fear and misinterpretation of Aboriginal home life."

Evidence Base for Services Supporting Adults with Autism

The evidence base concerning services for autistic adults remains limited and highly variable in global research. The studies reviewed for this scope included research papers across the United Kingdom, United States of America, Canada, and Australia. However, none of the reviewed studies accepted a systems point of view or produced new findings emphasising the importance of advancing complex systems of care and related outcomes. What the research did suggest was that systems should involve a focus on four core areas:

- i) the creation and distribution of new information,
- ii) a network-based approach to enable collaboration within and across disciplines and organisations,
- iii) the use of modelling strategies to guide decision-making procedures strategically, and
- iv) produce the systemic change to encourage better functioning and internal organisation (Leischow et al., 2008).

The wide variety of service-related subject areas identified within the research reflects the need for a diverse range of adult autistic service systems that can coordinate, improve, and promote better outcomes for adults on the autism spectrum (Lemire et al., 2017).

3.2. Best Practice Themes when Supporting Adults with Autism

While there is need for further research into the best practices for day services, some key themes did emerge from the literature which are discussed below. A summary of these themes was presented to Vivid on the 8th of June 2021 for their input into how these themes aligned to their current practices and future development.

Each section below elaborates on the key themes that were found, and is accompanied with a summary table including Vivid's response as to how these might relate to their services.

Principles Underpinning Quality Support

Quality support for people with autism is person-centred, active, and tailored to the individual's communication and relationship style preferences. These themes from the literature are discussed below and summarised in Table 2 at the end of this subsection.

Person-centred Support

A person-centred approach supports individuals to make decisions about their life and achieve their aspirations through placing them at the centre of the service. Person-centred support prioritises the whole person rather than their disability, and considers individual factors such as age, culture, language, life experience, and identity. This approach is strengths-based (focusing on what the person can do), tailored to individual needs, and acknowledges the person as the expert on themselves. The overall aim of person-centred support is for them to build and maintain autonomy and control over their life, with the person's support networks included as partners (NSW Government, 2021). A relationship exists between autistic adults' quality of life and having their needs met through individualised formal supports. Unmet needs in accommodation, interpersonal relationships, daytime activities, and information specific to autism are strongly associated with a reduced quality of life (Renty & Roeyers, 2006).

Providing opportunities for choice can facilitate autonomy for individuals with autism to make decisions about their life, such as how they spend their time or the type of support they receive. Opportunities to make decisions can also support development of problem-solving skills, greater independence, and improved overall quality of life (Rispoli et al., 2013). Furthermore, presentation of choice in tasks, activities, or environmental adjustments can reduce the presentation of challenging behaviour in people with autism, such as attempting to escape from task demands.

Consideration should be given towards the physical environment when supporting autistic people, such as space, aesthetics, noise, and lighting. While environmental needs vary between individuals, particular attention should be given to sensory factors such as excessive noise or echoing, bright lights or strong smells, which can become overwhelming for autistic people (Griffith et al., 2012). Excessive sensory input, unpredictable circumstances, or unfamiliar situations can create excessive demand for autistic people and lead to distress, which in turn, can increase the likelihood of autistic meltdown and related behaviour. A variety of communication methods and support tools can be used to establish consistent, predictable environments that embrace individualised routines and activities. These support tools include personalised activity schedules which can decrease challenging behaviour in individuals and young people with autism spectrum disorders through providing clear and predictable structure (Lequia et al., 2012).

Active Support

The principle of Active Support emphasises incorporating activities into daily life to facilitate meaningful engagement, rather than completing targeted therapy tasks (Bircanin et al., 2021). Active Support is often used to support a range of needs including people with autism, developmental disability, or intellectual

disability, and promotes independence and autonomy for service recipients through maximising opportunities for choice and control over their own lives. Promoting autonomous decision-making can facilitate service recipients to learn what forms of support they like and work best for them and provide a foundation for co-design. Through co-design, support workers can collaboratively make decisions with service recipients by incorporating their voices and views around the support they receive.

Supporting autistic people to participate in meaningful activities such as domestic, leisure, and employment tasks requires individualised support by carers and support staff. Bennett et al. (2005) found that people with a formal autism diagnosis received more support services overall, and service recipients who did not have a formal diagnosis recorded a lower quality of life. Although these differences were not maintained when participants' level of disability was accounted for, unmet needs for those who were not formally diagnosed remained. A higher quality of life and level of participation in activities was also reported in service recipients whose carers had a better understanding of autism. These findings indicate a need for individualised support strategies that are specific to autism and the person's needs beyond their diagnostic label.

Participation in recreational activities is linked to increased quality of life in autistic adults, including those with high levels of perceived stress (Bishop-Fitzpatrick et al., 2017). Autistic adults frequently report high levels of stress, which is associated with reduced overall quality of life. These findings suggest that encouraging and supporting autistic adults to engage in recreational activities can help moderate levels of perceived stress and improve their general wellbeing and quality of life.

Communication and Relationships

People with autism often have preferences in their mode of communication, which can vary depending on setting and the person's relationship to the communication partner. While communication preferences vary between individuals, qualitative analysis in Howard and Sedgewick's study (2021) revealed common themes across 245 surveyed autistic adults. Across all participants, it was apparent that autistic adults disliked phone calls due to various aspects of the communication medium. These included auditory processing difficulties, insufficient processing time, and intense anxiety. Participants reported further challenges interpreting social situations during phone calls due to the lack of non-verbal cues such as body language and facial expression.

Findings from Howard and Sedgewick's study (2021) indicated that autistic adults consistently preferred written modes of communication, such as text message or email. Participants stated that writing allowed them to process information and plan what they want to say, while removing the expectation of immediate responses. Further benefits included the structured nature of writing, increased predictability, and a greater sense of control over interactions. Autistic adults explained that verbal communication often presented sensory challenges such as bright lights in face-to-face settings, feeling overwhelmed, and difficulty filtering out background noise.

The adults with autism in Howard and Sedgewick's study (2021) emphasised the importance of supported communication in response to their needs. Valuable methods of support included having others proofread important written communications and the presence of a trusted person such as a family member or advocate. Participants specified that their communication difficulties were often related to their autistic traits and having communication support available was key for building relationships and promoting overall inclusion and wellbeing.

Autistic adults often felt it was necessary to mask (hide their autistic traits in order to appear more neurotypical) when communicating with non-autistic people (Howard & Sedgewick, 2021). Attempting to maintain eye contact, facial expression, and the pace of conversation were reported to be uncomfortable and tiring, and autistic adults indicated that the conscious effort required to mask negatively impacted their ability to communicate. Conversely, the participants did not feel required to mask when communicating

with other autistic people. Participants reported that they felt more comfortable when interacting with other autistic people as they would not be judged for their differences and felt more accepted.

Summary

Table 2 provides a summary of the key principles from the literature related to quality support for people with autism.

Table 2. Summary of Principles Underpinning Quality Support

Theme	What does it look like?	Is this a priority? (High, Medium, Low)	How does it currently look? What would/could it look like?	What would need to happen? (actions, resources)
Person-centred support	<p>Responsive to individual needs</p> <p>Individual care and health support</p> <p>Provision of an environment that meets individuals' needs and preferences</p> <p>Opportunities for choice</p> <p>Mindful of individual needs (if group support)</p>	High	<p>Current state: Generic programs and support</p> <p>Future state: Nuanced programs and support</p>	Identification of features for program content to deliver best outcomes for specific client cohorts; "add on" options to individualise programs
Active support	<p>Support for participation in meaningful activities</p> <p>Activity engagement</p> <p>Development of new and independent skills</p> <p>Opportunities for autonomy</p>	High	<p>Current state: Uneven levels of program quality, staff skill and engagement</p> <p>Future state: High quality programs run by engaged staff who consistently promote best outcomes for individual clients and who consistently contribute to building the knowledge base</p>	<p>Improving program quality</p> <p>Education of staff</p> <p>Implementation of systems which resist inertia in achieving best outcomes for clients</p> <p>Development and implementation of programs which aid active engagement and support</p>
Communication and relationships	<p>Respectful</p> <p>Positive interactions with staff</p> <p>Support for communication</p>	Medium	<p>Current state: Good client/staff relationships and more broadly (such as with the community)</p> <p>Future state: More social activities</p>	Development of social groups, advocacy groups, special interest groups and supported holidays

Theme	What does it look like?	Is this a priority? (High, Medium, Low)	How does it currently look? What would/could it look like?	What would need to happen? (actions, resources)
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Opportunities to engage with others and develop friendships (in group support)

Organisational Structure and Processes

Organisational structure and processes that influence support for people with autism include systemic factors; staffing, training and support; and a culture of continuous improvement. These are discussed below and summarised in Table 3 at the end of this subsection.

Systemic Factors

Support staff interviewed in a study by Pillay (2018) described various factors at a systemic level that influence the provision of support services across multiple domains. Staff indicated that the transition process for young adults from the school system to adult support services was particularly complex, and recent changes to service models did not allow enough time for young adults to develop necessary skills for employment. This also presented challenges for the young adults themselves, such as sudden changes in routine, increased anxiety, and insufficient time to build relationships with unfamiliar people. When supporting young adults through the transition from school, an in-depth understanding of autism, appropriate resourcing, and strategic planning such as individualised transition plans and targeted goals were considered crucial.

Funding was often a limitation for service providers, and support staff expressed concern for students who were ineligible for funding or did not have a formal autism diagnosis (Pillay, 2018). Staff indicated that these students were more likely to miss out on funding and support later in life and in adulthood. For service providers themselves, funding was linked to the organisation’s performance indicators such as benchmark hours. Support staff explained that the government lacked understanding of the complexities when supporting autistic young adults, and some clients were not receiving the best fit for their needs due to external expectations. The focus on organisational demands such as performance indicators meant that these external pressures often took priority over the individual needs of young adults with autism.

At times, the combined focus on meeting performance indicators and the complex nature of supporting autistic young adults became overwhelming for support services (Pillay, 2018). Staff explained that providing support for autistic young adults was not always successful, and young adults who required less extensive support may be prioritised due to the organisation’s performance requirements and other demands.

Staffing, Training, and Support

Many services in rural and remote areas experience difficulty recruiting and retaining allied health professionals (Johnsson et al., 2016). Green and Lonne (2005) reported high levels of occupational stress amongst allied health workers living and working in small rural communities. The nature of rural wellbeing work can contribute to occupational stress through factors such as working across dual and multiple roles (including roles in professional and public spirit), cultural 'isolation,' distortion of work and home, and lack of anonymity. Prolonged occupational stress can lead to burnout in individual staff members, as well as shortages of professionals in speciality areas.

Surveyed support service staff working with children with autism in rural Australian towns revealed that they received insufficient supervision or collaboration with other professionals (Johnsson et al., 2016). Respondents indicated that they would like support between fortnightly and monthly, however half of all respondents reported that they did not engage in any supervision or collaboration with other staff. Rural locations created an additional barrier to accessing support, as most staff were required to travel at least three hours away to access opportunities for professional development.

Generally, available professional development opportunities focused on disability, adolescent, and family support, and did not align with respondents' areas of need (Johnsson et al., 2016). Survey results indicated respondents' lowest perceived level of skills and confidence was in management of challenging behaviour, and participants expressed additional need for education in the early signs and diagnosis of autism. Of the surveyed staff, over half were willing to trial the use of online technology for professional development, indicating there is potential to address barriers to training and support for rurally located professionals through virtual means.

Culture of Continuous Improvement

A review by Shattuck et. al. (2020) found that most research about services for autistic adults focused on the services delivered, while research about the improvement of services at a system level was limited and often inconsistent. To improve service systems, there needs to be more involvement of a wide range of stakeholders, including input from the autistic community themselves. Future research should also include frameworks for understanding and interventions for improving service systems, as well as consideration towards the coordination between transdisciplinary team members.

Research has also illustrated that community engagement within the public sector usually leads to small-scale change. This is because large-scale change is risky, with a high chance of failure along with a loss of political investment if not undertaken carefully and systematically. To succeed in bringing about the most significant change, a participatory approach is recommended that includes a profound exploration and presentation of:

- new mental models,
- new ways of doing business, and
- transforming stakeholders to become co-creators (Corrigan, 2012).

Summary

Table 3 summarises the key themes from the literature related to organisational structures and processes for services that support people with autism.

Table 3. Summary of Themes Relating to Organisational Structure and Processes

Theme	What does it look like?	Is this a priority? (High, Medium, Low)	How does it currently look? What would/could it look like?	What would need to happen? (actions, resources)
Leadership	Collaborative hands-on leadership	High	Current state: Variable quality of client facing management	Organisation of staff teams to support best client outcomes
	Effective management and support for staff		Future state: Skilled, autonomous and responsive staff teams	Upskilling of management and staff

Theme	What does it look like?	Is this a priority? (High, Medium, Low)	How does it currently look? What would/could it look like?	What would need to happen? (actions, resources)
Staffing, training, and support	<ul style="list-style-type: none"> Clear roles Understanding of disability Provision of adequate training Provision of admin and planning time 	High	<p>Current state:</p> <ul style="list-style-type: none"> Uneven skills and engagement of staff <p>Future state:</p> <ul style="list-style-type: none"> Staff intellectually engaged in the development and delivery of programs and outcomes, both at the individual and organisational level 	Education of staff
Culture of continuous improvement	<ul style="list-style-type: none"> Understanding quality Embedding evaluation processes Benchmarking/comparing outcomes Critical reflection as part of everyday practices Regular review of processes 	High	<p>Current state:</p> <ul style="list-style-type: none"> Overall a poor comprehension amongst client facing staff of risk and quality; good risk and quality systems <p>Future state:</p> <ul style="list-style-type: none"> Continuous improvement embedded as a key driver of person centred and active support 	Education of staff

Engagement with Users and in the Community

Support and services for people with autism require engagement with community, involving users and families in service design and evaluation, and particular attention to good practice in engaging with Aboriginal, Torres Strait Islanders, and other communities. The literature related to these areas is discussed below and summarised in Table 4 at the end of this subsection.

Facilitating Engagement in the Community

While the general community in Australia is aware of autism, there is a notable disconnect between their knowledge and understanding of autistic people, including how to support them (Jones et al., 2021). Compared to older demographics, younger non-autistic people were more likely to understand that the experience of autism is different for each individual. Additionally, younger participants were less likely to believe that autistic people are violent or should go to a specialist school. This suggests that contact with autistic peers in mainstream schooling and increased public discussion of autism may address and break down some misconceptions about autism.

People with lived experience surveyed in Jones' study (2021) indicated that the awareness of autism amongst the community did not include how to support autistic people or how autism may affect their behaviour. Higher levels of community awareness were reported in relation to more stereotypical or externally visible traits of autism, such as stimming and social challenges. However, those with lived experience reported markedly lower levels of awareness of more internalised aspects of autism, such as

sensory challenges, anxiety in unpredictable situations, literal use of language, or the need for extra processing time. Public discussion and education around autism may help address the discrepancies between the community's understanding of autism and the experiences of people with autism, in order to facilitate inclusion for autistic people and promote their engagement with the community.

Involvement of users and families in service design and evaluation

Support providers can tailor services to effectively support the needs of autistic people through the use of co-design and collaborative approaches (Peña et al., 2020). By incorporating the voices of the autistic community, services can ensure that support is designed to reflect the needs and goals of autistic people. Furthermore, including an autistic perspective ensures that the success of provided support is measured in ways that are meaningful to them. Community-based, participatory approaches facilitate the inclusion of people with autism by regarding them as the experts on their own lives and considering their experiences as part of the decision-making process.

Engagement with the autistic community is imperative to understanding the diversity amongst individuals with autism (Jose et al., 2020). Acknowledgement and incorporation of their perspectives allows organisations to build and maintain trusting relationships, while increasing the potential for more impactful research and design (Jose et al., 2020; Peña et al., 2020). In order to maximise benefits of co-design, certain considerations should be implemented throughout consultation with the autistic community in order to ensure the process is accessible and inclusive for those involved (Jose et al., 2020).

When collaborating with people who have autism, accommodation should be provided for potential differences in communication methods and related needs. It is important to discuss preferred modes of communication with autistic consultants and provide appropriate adjustments, while maintaining transparency and clarity through frequent contact. Further consideration should be given towards the structure of communications to ensure that they are accessible and effective, particularly when using email. In order to minimise cognitive or processing demands, email communications should remain brief and avoid multiple topics in the same email.

Effective engagement and co-design with the autistic community requires clear expectations and explicitly defined roles for each team member from the commencement of the partnership. People with autism involved in collaborative design should be provided with meaningful opportunities to engage in the process, including consideration for key leadership roles. It is essential that these opportunities are supplemented by appropriate support to facilitate full participation in project activities. This includes management of team expectations, assessment of time and resource requirements, and reimbursement of expenses incurred by autistic people through their involvement.

Engagement with Aboriginal, Torres Strait Islander, and other Culturally Diverse Communities

The true prevalence of autism in Aboriginal and Torres Strait Islander people is unclear. Some evidence suggests Aboriginal and Torres Strait Islander people are diagnosed with autism at lower rates compared to non-Indigenous people, however this is not necessarily due to lower prevalence (Bailey & Arciuli, 2020). Rather, this reflects the greater acceptance of individual differences in some Aboriginal communities and reduced access to services including diagnosis and support.

In Aboriginal and Torres Strait Islander communities, cultural differences exist in the way disability is perceived (Bailey & Arciuli, 2020). Some Aboriginal people believe that disability is an individual difference to be supported by the wider community, rather than considered for intervention as is more common in Western cultures. Furthermore, some Aboriginal communities consider labelling people in terms of their abilities or impairments to be disrespectful. Gaps in awareness and understanding of autism amongst Aboriginal and Torres Strait Islander communities were consistently reported by carers and services providers, reflecting these cultural differences. The influence of cultural differences is further

demonstrated by hesitancy towards diagnostic labels such as autism spectrum disorder amongst some members of the Aboriginal community.

Aboriginal and Torres Strait Islander families reported some common challenges with non-Indigenous families such as affordability of services, availability of services in rural and remote settings, and complexities around both government and service provider policies (Bailey & Arciuli, 2020). However, they indicated additional challenges unique to their experiences, including perceived racism and disrespect when interacting with some service providers. Other difficulties included rushed consultations and inappropriate communication, including excessive jargon. Carers reported feeling dismissed or looked down upon, including perceptions of being “told” how to support their children by mostly non-Indigenous service providers.

Many families preferred to access support through Aboriginal Community Controlled Health Organisations, highlighting the importance of culturally appropriate services and cultural awareness amongst staff (Bailey & Arciuli, 2020). Engagement and collaboration with Aboriginal and Torres Strait Islander communities is recommended to improve cultural competency and training amongst providers, deliver culturally safe services, and support collaborative decision-making (Department of Health & Human Services [DHHS], 2019). This includes employing Aboriginal disability coordinators, recruitment of Aboriginal workers to assist families navigating health systems, and hosting support groups through local Aboriginal health services (Bailey & Arciuli, 2020; Department of Health & Human Services, 2019). Consideration should also be given towards the ongoing impacts of colonialism and racism on the health and wellbeing of Aboriginal and Torres Strait Islander people, and the influences of lived experience on service delivery (Bailey & Arciuli, 2020).

Summary

Table 4 presents a summary of themes from the literature related to engagement.

Table 4. Summary of themes relating to engagement with users and in the community

Theme	What does it look like?	Is this a priority?	How does it currently look? What would/could it look like?	What would need to happen? (actions, resources)
Facilitate engagement in community	Support to establish and maintain relationships with family, friends, community	Medium	Current state: Ad hoc support Future state: Structured support, tailored to the needs of individuals	Development, implementation and commitment to building networks of support groups – client, family, community service organisations
Users and families are involved in service design and evaluation	Co-design of services Active partnerships, with users and families involved in service design and delivery Input into outcome measures and evaluation of service	High	Current state: Very limited Future state: Structured, as well as informal, collection and analysis of data	Commitment to, and implementation of a system to support, the ground up development and review of programs
Engagement with CALD, Aboriginal, and Torres Strait	Active partnership and open communication	Medium	Current state: Very limited engagement Future state:	Ascertain how Vivid can provide supports to these communities – what do they need from us, why

Islander communities	Development of culturally respectful materials and communications		Collaborative, mutually beneficial, relationship; a template for Vivid's engagement with all minority groups	don't they access supports from us?
Cultural competency	Training in cultural competency Employ staff from diverse backgrounds	Medium	Current state: Homogenous staff and client cohorts Future state: Diverse cohorts and an acute awareness of, and responsiveness to, minorities	Recruitment of diverse staff and clients Development of programs and supports Education of staff

3.3. Summary and Recommendations

Research has illustrated that adults with autism often face various challenges when accessing support that effectively addresses their needs, particularly when transitioning from the school system to the adult support system (Pillay, 2018). Incorporating person-centred approaches and supporting autistic adults to engage in meaningful activities can improve their quality of life and mitigate stress (Bishop-Fitzpatrick et al., 2017; Renty & Roeyers, 2006; Rispoli et al., 2013). When supporting people with autism, consideration should be given towards their individual communication preferences. Many autistic people have a preference for written forms of communication, and support workers should be conscious of potential negative impacts on an individual's communication that result from masking (Howard & Sedgwick, 2021).

The general community in Australia has some understanding of autism and its presentation, however this knowledge is often limited to the more salient or stereotypical traits of autism (Jones et al., 2021). Public education can increase community awareness of the internal experiences of autistic people, as well as their challenges and related support needs. Furthermore, promotion of accurate information and public discussion can help address misconceptions about autism at a community level.

Collaborative, participatory approaches such as co-design ensure that supports and other services are designed to effectively address the needs of the autistic community in a meaningful way (Peña et al., 2020). By incorporating the voices of the autistic community as part of the decision-making process, organisations can build trust, maintain relationships, and facilitate further opportunities for impactful outcomes (Jose et al., 2020; Peña et al., 2020). Effective co-design should be inclusive and accessible with consideration given towards individual needs such as communication preferences, clarity of expectations, and cultural diversity. Autistic Aboriginal and Torres Strait Islander people often face barriers to accessing diagnosis and support, hence engagement with these communities is crucial in developing culturally safe services. This includes employment of Aboriginal and Torres Strait Islander disability coordinators, and provision of appropriate cultural competency training (DHHS, State Government of Victoria, Office of Disability 2021).

Systemic factors such as changes to service models, external requirements, and funding limitations have implications for the delivery of support through service providers (Pillay, 2018). External demands such as performance indicators are prioritised as they are linked to the provision of funding. Fulfilment of these requirements can be overwhelming for service providers, and often leads to compromise in the quality of support provided to service recipients.

Support workers and health professionals working in rural locations experience unique challenges in their settings, which result in high levels of work-related stress and lower retention rates amongst staff (Green & Lonne, 2005; Johnsson et al., 2017). Due to the geographical isolation associated with remote areas, access to support such as supervision, mentoring, and relevant professional development is limited or entirely unavailable (Johnsson et al., 2017). Delivery of professional learning through virtual technology may be a

potential method of overcoming these barriers and increasing accessibility to relevant and effective support.

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