AutismCRC

Tools, strategies, and techniques developed to improve the health and wellbeing for autistic adults

FINAL REPORT

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world’s first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families, and people on the autism spectrum.

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults, we use the terms 'autistic person', 'person on the autism spectrum' or ‘person on the spectrum’. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being ‘diagnosed with Autism Spectrum Disorder’.

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1. Executive Summary

1.1. Introduction

Autism research in the adult space has been a long-neglected field, particularly in health and healthcare, despite clear health disparities between autistic and non-autistic people. Autistic adults experience gaps in healthcare provision and numerous barriers to accessing healthcare. Additionally, health professionals are also often under skilled, have low autism knowledge and low confidence when working with this cohort.

Our body of work focused on understanding and improving health and wellbeing for autistic adults by developing tools, strategies, and techniques. In our '*Understand'* area of work, we aimed to understand the health and wellbeing field in autism in adulthood through reviewing existing information and collecting people's experiences. In our '*Improve'* area of work, we designed tools, programs, and resources to improve health and wellbeing for autistic adults.

1.2. Understand

To understand the current landscape for resources, we reviewed existing information and conducted small projects to develop understanding through experiences. We reviewed academic and grey literature to establish the existing resources and training, including at the intersection of autism, intellectual disability, and health status and lastly, the barriers to accessing healthcare for autistic adults.

In working to understand through experiences, we sought to develop our understanding from autistic adults through projects that looked at the diagnostic experience for adults, oral health, diabetes, and anxiety. We also sought the experience of health professionals providing healthcare to autistic adults.

1.3. Improve

In our efforts to improve the health and wellbeing of autistic adults, we focused on three areas: access to healthcare, health and wellbeing, and improving access to health resources. Our improving access to healthcare work saw the development of a tool, the Autism CHAP, to support annual health assessments. We also investigated the utility of an American tool, the AASPIRE toolkit, in an Australian setting. We also delivered training to GPs and identified GP training priorities for future education initiatives.

We aimed to improve health and wellbeing of autistic adults through the delivery of cooking classes and a program to support the management of anxiety, ACT on your life. Lastly, we sought the view of autistic adults with intellectual disability and health professionals to understand what made an accessible and appropriate health information website.

1.4. Conclusion

This body of work consisted of multiple projects that together worked to understand and improve autistic adults' access to healthcare. This revealed that autistic adults face significant barriers to accessing healthcare, and the healthcare professionals also face difficulties in understanding how best to work with autistic adults. Further, this program worked to improve the health of autistic adults through improving access and directly through selected projects to improve aspects of health and well-being. This program has demonstrated that there are several significant areas that require further research and development and has laid the groundwork for future projects to build on.

2. Introduction

Autism research in the adult space has been a long-neglected field, particularly in health and healthcare. autistic adults experience significant health disparities dying at an earlier age than non-autistic people (Hwang, Srasuebkul, Foley, Arnold, & Trollor, 2019). Additionally, autistic adults experience high rates of physical and mental health conditions such as gastrointestinal disorders, depression and anxiety (Croen et al., 2015). Many autistic adults also experience gaps in healthcare provision, with significantly more autistic people reporting unmet healthcare needs than non-autistic people (Nicolaidis et al., 2013). This may be partly due to the numerous barriers autistic adults experience when accessing healthcare. autistic adults experience difficulties around communicating with their health professionals, the sensory environment of clinical spaces, and difficulties navigating the complex health system including limited referral pathways and options (Bradshaw, Pellicano, van Driel, & Urbanowicz, 2019). Health professionals also often report low levels of skill and knowledge as well as low confidence when working with this cohort (Unigwe et al., 2017; Zerbo, Massolo, Qian, & Croen, 2015).

2.1. Body of work

Program 3 aims to directly facilitate paths towards fulfilling lives for autistic adults and their families. Our body of work, Project 3.3, focused on understanding and improving health and wellbeing for autistic adults by developing tools, strategies, and techniques. In our *understand* area of work, we aimed to understand the health and wellbeing field in autism in adulthood through reviewing existing information and collecting people's experiences. In our *improve* area of work, we designed tools, programs, and resources to improve health and wellbeing for autistic adults.

Throughout our work, we engaged with autistic people, their supporters and health professionals. Some specific projects included individuals who were part of the research team or who were consulted about project work. In 2018, an autistic research advisory group was established called the QCIDD Community Council. This consisted of autistic individuals who were also health professionals, parents of autistic children and supporters of autistic adults. The group provided input into research and met regularly throughout Project 3.3.

The two areas of our research, understanding and improving, have been used to structure this report and the project aligned under each area are represented in Figure 1. As our body of work consisted of multiple projects, rather than one large project, details of each project are presented as a structured abstract.

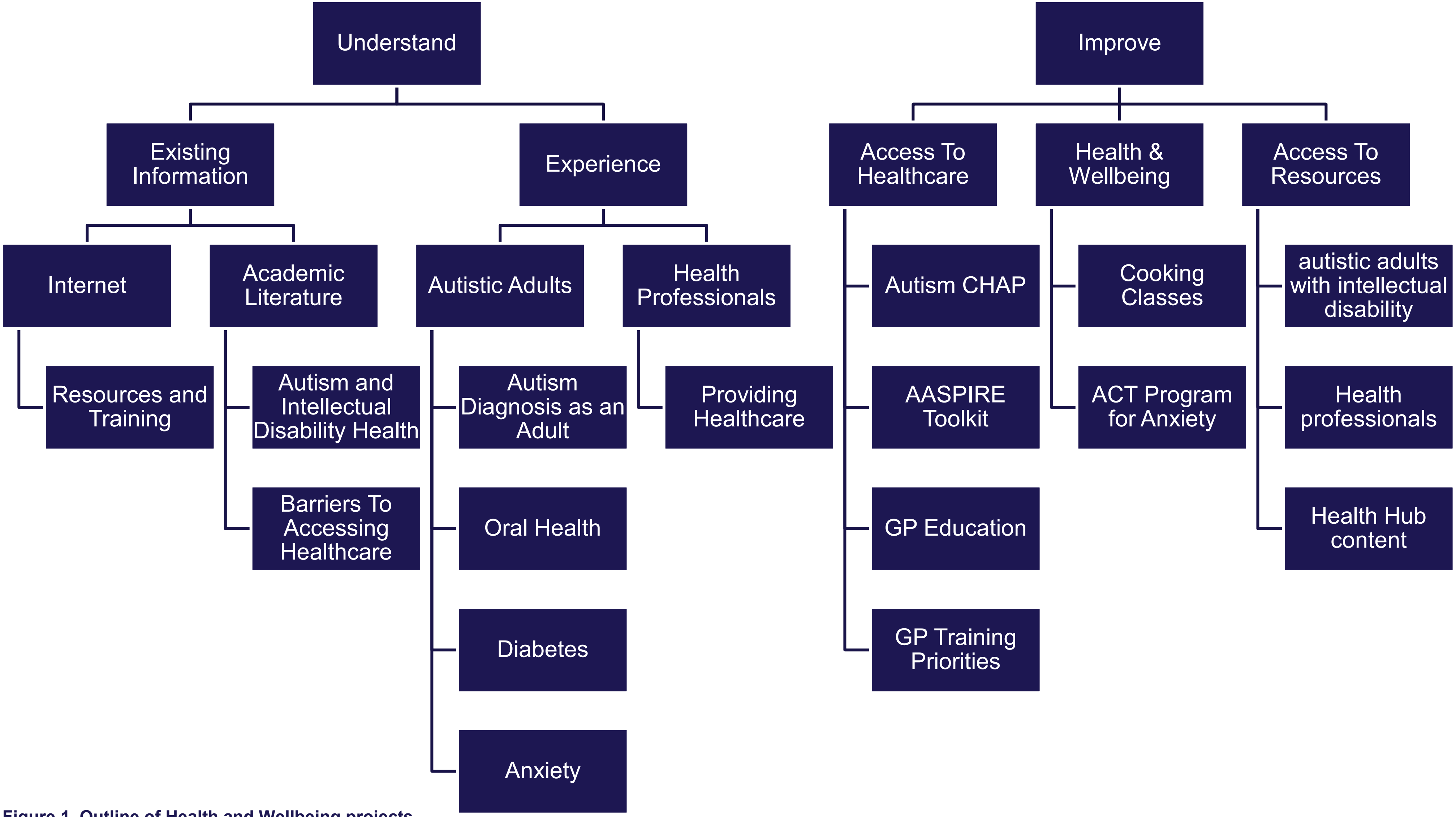

Figure 1. Outline of Health and Wellbeing projects

3. Understand existing information

3.1. Internet: Review of resources and training

3.1.1. Introduction

The Internet is a source of autism information, health information and health tools for autistic people, their supporters and health professionals. It provides an avenue to share resources globally and can help improve the delivery of quality healthcare to autistic adults. Given health professionals are often time-poor and may be unfamiliar with autism-related websites, they may have trouble identifying high quality and relevant resources.

This project aimed to review existing online resources that aim to upskill health professionals to work more effectively with autistic adults.

3.1.2. Research design and methods

An online search on Google was performed in 2013 using keywords related to adults, autism, and health to find resources for health professionals regarding autistic adults. We read all relevant websites and briefly assessed the quality of the material they presented using three criteria, including whether:

- the date of publication,
- nominated date of review were provided on the site, and
- the site listed information sources used in its development.

We didn't include formal courses (for example, online training courses offering continuing professional development points) in this review, because they often require face-to-face time, a time commitment, payment or registration with an association or organisation.

3.1.3. Findings

There are fewer websites and resources available for health professionals including specific information on autism in adulthood than about autistic children.

It did take consider time to identify, read and review the content on these websites. Only a few websites and resources reported sources of information or date of production, which make it difficult for a non-expert to judge the quality of the content. These may pose barriers to health professionals seeking and finding accurate and relevant resources.

Some good sites do exist, particularly in relation to upskilling health professionals around the changes they can make to the physical environment, communication and attitudes when working with autistic adults.

3.1.4. Conclusions

autistic adults have the need for, and the right to access, appropriate, accessible, acceptable health care that helps them to achieve the highest quality of life. But health professionals receive very little specific training or professional development in working with autistic adults, so delivering a high standard of care to this group may be difficult. Some online help is available to health professionals, but it is difficult to find and to make an informed decision about its quality. Information specific to autistic Australians is scarce, as is advice for health professionals who work with autistic adults. Importantly, none of the resources we found were produced by adults themselves. There is an urgent need for more specific information for health professionals, information that is co-produced by autistic adults, and Australian-specific information.

For more information, see van Dooren, Nicollet, and Lennox (2014)

3.2. Academic literature: Autism and intellectual disability health

3.2.1. Introduction

Little is known about intersection of autism, intellectual disability, and health status. With less than 2% of autism research funding directed towards adults, the health-related needs of autistic adults are relatively poorly understood. Poorer still is our understanding of the needs of those adults with co-occurring autism and intellectual disability. This lack of understanding represents a significant knowledge gap, particularly given that the needs of this group are likely to be unique and nuanced.

The aim of this research was to map the limited evidence base relating to the physical health of adults living with co-occurring autism and intellectual disability and present a commentary on this overlooked group.

3.2.2. Research design and methods

From our existing knowledge of the literature, we knew there was no research agenda around the health needs of adults with co-occurring autism and intellectual disability. Therefore, a systemic approach would not be useful. In 2015, we looked to review the autism literature and the intellectual disability literature to determine what is known about the population with both diagnoses. We focused on synthesising an understanding of prevalence of co-occurring autism and intellectual disability, physical health-related needs, and evidence-based guidelines available to primary health practitioners working with this population. The secondary aim of the review was to identify research gaps to direct future research.

3.2.3. Findings

Our synthesised approach found that both the autism and intellectual disability literature presents disparate estimates on the prevalence of co-occurring autism and intellectual disability. Further, there is a clear paucity of evidence around the physical health needs of adults with co-occurring autism and intellectual disability and as a result, little evidence to inform and guide clinical and other practice.

3.2.4. Conclusions

It is apparent that a distinct research agenda relating to co-occurring autism and intellectual disability—particularly as it relates to adulthood and physical health—does not exist. Consequently, we have had to explore the separate intellectual disability and autism literatures to better understand where research gaps lie. In doing so, we have argued for the need for a dedicated research effort to improve health and wellbeing among adults with co-occurring autism and intellectual disability.

For more information, see van Dooren, McPherson, and Lennox (2016)

3.3. Academic literature review: Barriers to accessing healthcare

3.3.1. Introduction

autistic adults have higher rates of some physical and mental health conditions and experience significant health disparities. Contributing to this health disparities is the accessibility of health services.

The aim of this project was to understand the factors that influence access to and provision of healthcare for autistic adults.

3.3.2. Research design and methods

We conducted a review of the literature on the barriers and facilitators to health care for autistic adults without intellectual disability. Articles relating to individuals over 18 years were included over an 11-year period. The review was framed by the first author's personal insight as an autistic adult navigating the healthcare system.

3.3.3. Findings

autistic adults experience barriers at the patient level, provider level and system level. Patient-level factors included communication issues, anxiety, sensory differences, socio-economic factors, and previous experiences with health-care professionals. Provider-level factors included a lack of provider knowledge, training and incorporating communication accommodations and supports. System-level factors included accessibility of health-care facilities and limited referral pathways.

There are a limited number of health supports available to autistic adults. Available supports are the Academic autistic Spectrum Partnership in Research and Education (AASPIRE) healthcare toolkit which include the Autism Healthcare Accommodations Tool (AHAT), the National Institute of Health and Clinical Excellence (NICE) guidelines and the UK Royal College of General Practitioners (RCGP) Autism Spectrum Conditions Toolkit.

3.3.3.1. Conclusions

autistic adults experience a range of barriers across multiple levels when accessing healthcare. These contribute to the unmet healthcare needs of this population. It is important to develop autism training for health professionals to overcome some of these challenges including around communication, creating "autism friendly" clinical environments and working more effectively with their autistic patients.

For more information see Bradshaw et al. (2019)

4. Understand through experiences

4.1. Autistic adult: Diagnosis experiences in adulthood

4.1.1. Introduction

Ideally, an autism diagnosis should occur in early life. However, due to several factors and challenges, there is a growing number of adults seeking a diagnosis. This experience, particularly within the Australian context, has not previously been extensively researched and is not well-understood.

This project aimed to explore the experiences of adults who seek an autism diagnosis as an adult.

4.1.2. Research design and methods

This qualitative study used two unique data sets: online written submissions and interview transcripts. Australian adults who identified as being autistic were eligible to participate. A total of 36 participants were involved in this study, with a median age of 42 years (range = 27 – 80 years) and a gender distribution of 24 females and 12 males. Twenty-two completed an online submission answering the question "From your perspective, what are the most important considerations to address when developing a national guideline for the diagnosis of autism spectrum disorder in Australia?" Online submissions had to be written in English and had a limit of 100 words. Semi-structured interviews were conducted with 14 participants, where experiences before, during and after diagnosis were discussed. Online submissions and interview transcripts were imported into NVivo 11 and were analysed using thematic analysis.

4.1.3. Findings

Three major themes emerged from the data describing experiences prior to, during and following an autism diagnosis in adulthood.

Experiences prior to an autism diagnosis were focused primarily on the motivators that ultimately led to diagnosis, such as awareness of other family members having an autism diagnosis and personal feelings of being "different" while growing up.

Experiences during the autism diagnostic process were varied in terms of logistic factors, approaches, and barriers. Logistic factors included who, where and how the assessment was conducted. Approaches that were valued included strengths-focused assessments where rapport was built with a key contact person and tailored communication was utilised. Frequent barriers to diagnosis included the cost of assessment, availability of appropriately skilled assessors, masking strategies hindering symptom identification (particularly among women) and sensory distress associated with assessment locations.

Experiences following autism diagnosis were typically positive, characterised by empowerment and self-realisation due to receiving the autism diagnosis. However, negative experiences were also reported, such as stigma. Many of the participants reported unmet support needs and difficulty in accessing important supports following diagnosis.

4.1.4. Conclusions

The online submissions and interviews revealed varied autism diagnostic experiences of adults in Australia, and unmet needs in the current diagnostic system were highlighted. Participants found psychological benefits of having an autism diagnosis. Access to autism diagnosis for Australian adults may be improved with the new nationwide diagnostic guideline and by upskilling health professionals in adult assessment to increase the number of services available. The context in which assessments are undertaken need to be considered, particularly reducing the need for lengthy travel that may cause anxiety or sensory overload and using a ‘sensory friendly’ environment. Finally, the cost of assessments should be subsided for equitable access.

> *This body of work contributed to the National Guideline for the Assessment and Diagnosis of Autism (Whitehouse, Evans, Eapen, & Wray, 2018).*

4.2. Autistic adult: Oral health experiences

4.2.1. Introduction

Currently, there is limited research that focuses on dental health of autistic people across the life span. The scarce evidence base suggests that autistic people’s oral health needs are not being met and individuals experience autism-specific barriers to accessing oral healthcare. This can lead to poor health outcomes (Morgan et al., 2012; Oswald et al., 2013; Pradhan, Slade, & Spencer, 2009; Wallace et al., 2015).

This study aimed to compare the oral health of autistic and non-autistic adults living in Australia.

4.2.2. Research design and methods

autistic adults, supporters and non-autistic adults were invited to participate in an online survey about the oral health and dental needs of autistic adults. Recruitment materials were widely distributed amongst QCIDD and Autism CRC networks.

The survey consisted of a set of questions for autistic adults, supporters, and non-autistic adults. All three surveys contained the same questions; however, all questions were phrased to be individualised to each group. The survey consisted of 124 items including demographic questions, the Autism Quotient (AQ-50) autism screening tool, oral health status, dental healthcare needs, dental visiting experience, sensory sensitivities, and perceived barriers to dental care.

4.2.3. Findings

In total, 21 autistic adults, 5 supporters and 18 non-autistic adults completed the survey. Five autistic adults reported a diagnosis of an intellectual disability. The average ages of the autistic and non-autistic participants were 37.1 (SD 13.5), and 23.2 (SD 5.7) years respectively with approximately half of both groups identifying as male. About three quarters of autistic participants lived in moderate-high disadvantaged suburbs in terms of access to services and facilities, while this was true for 58.9% of the non-autistic participants according to the Index for Relative Socio-economic Advantage and Disadvantage (IRSAD) (Australian Bureau of Statistics (ABS), 2013). autistic adults on average had a high autism quotient (AQ) score of 40 (SD ± 7.9), while non-autistic adults had an average AQ score of 17.44 (SD ± 6.9), a statistically significant difference ($p<0.001$).

Oral hygiene habits for autistic and non-autistic adults were similar. Twenty-four autistic adults and all non-autistic adults brushed teeth at least once a day with most participants brushing their teeth independently. Over three quarters (84.6%) of autistic adults, and nearly all (94.5%) of non-autistic adults brushed teeth at least 6 times a week. Most adults from both groups used fluoride toothpaste. A larger proportion of autistic adults (42.3%) used an electric toothbrush in comparison to non-autistic adults (11.1%). Mouthwash was used for daily oral care by 34.6% of autistic adults and 50.0% of non-autistic adults.

Most participants had visited a dentist in the past with two autistic (7.7%) and four non-autistic (22.2%) participants having never visited a dentist. Nine autistic participants had visited a dental practitioner once every six months, while this was true for one non-autistic adult. Most non-autistic adults visited a dentist once every 2 years or only for a dental problem. A majority of both autistic and non-autistic adults (70.8% and 85.7%) had their dental check-up/treatment at a private dental clinic. More autistic adults felt that their overall wellbeing was affected by the condition of their teeth, lips, mouth, and jaws, in comparison with non-autistic adults (p=0.009).

Most autistic and non-autistic adults (68.2% and 64.3%) had a neutral to very bad rating of their last dental visit. More autistic adults (62.5%) *vs.* non-autistic adults (21.4%) would have been uneasy, afraid, or extremely afraid if they had to visit the dentist the next morning (p=0.074). Based on the experiences of autistic adults, they find it more difficult to have a dental practitioner clean their teeth compared to non-autistic adults (p=0.013). More than half (58.3%) of autistic adults felt that their last dental practitioner was not specialised in working with people with disabilities including autism. In addition, 13 autistic adults felt that their dental practitioner did not show sensitivity to their needs, compared to eight non-autistic adults who felt this way.

Sixteen autistic adults expressed that they are more exposed to sensory stimuli when they visit the dentist. A large proportion of autistic adults were very sensitive to sound (p=0.003) and lights (p=0.07) in comparison to non-autistic adults. Most autistic adults (65.4%) felt that their sensory sensitivities made dental appointments challenging, which was significantly high (p = .003) compared to non-autistic adults (11.8%).

4.2.4. Conclusions

In summary, autistic adults experience similar barriers when accessing oral healthcare as non-autistic adults, however autistic adults experienced autism-specific barriers such as sensory sensitivities and finding a practitioner who can meet their needs, which may not be addressed in oral healthcare systems.

4.3. Autistic adult: Lived experiences of diabetes

4.3.1. Introduction

Managing diabetes is complex, requiring individuals to undertake self-management activities daily and to frequently access healthcare. Diabetes significantly impacts mental wellbeing, with existing mental health conditions increasing the risk of poor mental health outcomes. Despite well-documented barriers to healthcare in autistic adults, there is no research exploring the experiences of autistic adults managing diabetes or other chronic health conditions.

This research aimed to understand the lived experience of autistic adults living with diabetes.

4.3.2. Research design and methods

Guided by a participatory and phenomenological approach, autistic adults with type 1 or 2 diabetes were recruited to participate in semi-structured interviews about their lived experience as an autistic person living with diabetes. An autistic research advisor living with diabetes provided input in developing the research direction and interview guide. The interview addressed diabetes self-management, healthcare access, mental health, diet, and physical activity. Interview transcripts were thematically analysed with input from the autistic advisor.

4.3.3. Findings

Experiences of managing diabetes were analysed from the perspective of autistic adults. Three key themes were identified during the analysis. Firstly, participants described autism to have distinct influences on diabetes self-management. autistic factors both strengthened and acted as a barrier to diabetes self-management. autistic factors such as preferences for routine and rigid behaviour facilitated adoption of medication and insulin regimens for some participants. autistic burnout, a condition where an individual is exhausted, withdrawn, experiencing executive function problems and generally reduced functioning, was a key barrier to diabetes self-management, causing difficulties in managing, planning, and implementing diabetes tasks. For example, difficulties in executive functioning resulted in participants frequently forgetting to follow their insulin and/or medication routines, plan health meals, and attend diabetes appointments. Masking influenced diabetes self-management as participants were unwilling to inform health professionals of challenges to their diabetes self-management that they attributed to their autism. Masking further resulted in participants accepting diabetes care and advice that did not meet their needs.

Secondly, avoiding autistic burnout was a greater priority than diabetes self-management. Self-care activities that prevented autistic burnout were prioritised over diabetes self-management activities. Preventing autistic burnout was important to enabling diabetes self-management as burnout meant participants were unable to complete key self-management activities, including insulin and medication use. Persistent emotional distress during autistic burnout also influenced blood glucose levels. Most participants did not report experiences of diabetes burnout. Lastly, health professionals separated autism and diabetes when providing healthcare. This led to diabetes care and advice that failed to meet autistic adults’ needs as autism influenced diabetes self-management in various ways.

4.3.4. Conclusions

Creating environments that empower autistic adults in chronic disease management is vital to improving the pervasive health inequities experienced by this group. Our findings indicate prevailing models for diabetes self-management poorly reflect autistic adults' diabetes self-management experiences and priorities. It is fundamental to develop a wider understanding of autistic influences on health management to understand if current models of health management suit the needs of autistic individuals. The findings from this research will inform the development of autism-specific diabetes resources for autistic individuals, their support people, and health professionals.

4.4. Autistic adult: Experiences of anxiety

4.4.1. Introduction

Anxiety is one of the most common co-occurring mental health conditions for autistic adults with more autistic adults diagnosed with an anxiety disorder than non-autistic people (Hepburn, Stern, Blakeley-Smith, Kimel, & Reaven, 2014; Hofvander et al., 2009; Maddox & White, 2015). At the time of this project, little in the academic literature was known about the experience of anxiety by autistic adults.

The aim of this research was to gain an understanding of the experiences of anxiety and anxiety therapies by autistic adults.

4.4.2. Research design and methods

During 2015 autistic adults were recruited through QCIDD and Autism CRC networks to share their experiences of anxiety. Participants were interviewed and data from four participants (2 female and 2 male) were analysed using descriptive thematic analysis. Interviews were conducted in the participant's preferred manner (Skype n=1, telephone n=1, face-to-face n=1, written responses n=1). The duration of verbal interviews ranged from 44 minutes to 2 hours.

4.4.3. Findings

Participants had varied experiences of anxiety. Participants found change, unpredictability and social interactions contributed to anxiety experiences as did difficult sensory environments. Participants had learnt to identify the physical and behavioural cues they were experiencing anxiety: shaking, clenching jaw, tightening of fists, tightening around the body, feeling an increased heartrate, feeling unease and engage in stims.

Participants had developed strategies to live with their anxiety, sometimes with the support of a mental health professional. This included finding distraction, such as playing with pets, meditation, mindfulness, doing a body scan, talking to a trusted person/ close family or friend, walking, and reading. Participants often practised tasks or routines, such as traveling to a new place prior to needing to visit.

Participants had mixed experiences of behavioural therapy such as Cognitive Behaviour Therapy and Dialectical Behaviour Therapy, which are common psychological therapies recommended for management of anxiety. They reported that some of the strategies around thinking were unhelpful, like changing the way you think, used in Cognitive Behaviour Therapy, as participants felt the process was challenging their thoughts and saying, "*your thoughts are wrong, are faulty, and they're bad and we need to change that*". Participants reported that other strategies, like acknowledging that an experience or feeling would pass, used in Dialectical Behaviour Therapy were helpful.

Participants expressed disappointment in their therapist's lack of understanding of autism and found the treatment protocol not suitable for their needs. Some participants shared that speaking with a professional about their anxiety, without the structure of a traditional therapy, was helpful, as were commonly used techniques like body scan and breathing exercises. Participants recommended having a very structured treatment course where all activities were planned, so that the environment and framework of treatment is provided in the beginning of treatment.

4.4.4. Conclusions

This project provided insight into the experiences of autistic adults living with anxiety. Importantly, the experiences around the use of different psychological therapies provides direction to future research which should consider how to design therapies that better meet the needs and preferences of autistic patients. The learning from this project informed the development of an Acceptance and Commitment program, ACT on your Life, described below in 5.1.

4.5. Health professionals: Providing healthcare survey

4.5.1. Introduction

Health professionals play an integral role in the health and healthcare experiences of autistic adults: we know that many autistic people experience difficulties accessing healthcare. Health professionals are in a unique position to influence experiences and outcomes.

The aim of this project was to describe the experiences, views, and needs of health professionals providing healthcare to autistic adults.

4.5.2. Research design and methods

We conducted an online survey and distributed it to health professionals across Australia. A purposive, snowball sampling strategy, was used to recruit health professionals with and without experience in providing healthcare to autistic people.

4.5.3. Findings

78 health professionals, most commonly working as medical practitioners, nurses, or occupational therapists completed the survey. Approximately half of the participants worked in a disability- or autism-specific setting.

Many of the participants felt knowledgeable (63%) and competent (62%) in providing care to autistic adults with slightly less (59%) feeling confident in providing care to autistic adults. For those participants working in disability- or autism-specific settings, these rates were higher when compared to those not working in these settings. Over 80% wanted further training, particularly in behaviour and mental health management, and communication.

4.5.4. Conclusions

Most health professionals reported feeling competent, knowledgeable, or confident, or a combination of these three variables, in providing health care to autistic adults but still wanted more training in specific areas. Future research should seek to co-design training programs with autistic adults for different professionals who work with autistic adults in their preferred format.

For more information, see Urbanowicz et al. (2020)

5. Improve access to healthcare

5.1. Autism CHAP

5.1.1. Introduction

The Comprehensive Health Assessment Program (CHAP) is a tool to support an annual health assessment for a person with intellectual disability. Evidence from past studies shows the CHAP to be effective in improving health actions, especially in health promotion areas such as vision and hearing tests and immunisations (Lennox, Ware, Bain, Taylor Gomez, & Cooper, 2011). Significantly more clinical health actions were found in the CHAP group, compared to the usual care group, which suggest that the CHAP group received better health care.

The Autism CHAP is a paper-based booklet that contains three sections: 1) the first section is for individuals or their supporter to complete. It contains questions asking about the physical and mental health over the past 12 months; 2) the second section is for the GP or practice nurse to complete whilst conducting a thorough health review of the individual, including a plan for further actions; and 3) the third section contains information for the GP and nurse about providing healthcare to patients with disability.

This research aimed to develop a version of the CHAP, adapted specifically for autistic adults with intellectual disability and conduct a small pilot.

5.1.2. Research design and methods

This was a cross-sectional, mixed-methods project evaluating the feasibility and acceptability the Autism CHAP. A formative evaluation (Bauman & Nutbeam, 2014) approach was used to adapt the CHAP for autistic adults with co-occurring intellectual disability and to evaluate the adapted CHAP (Autism CHAP) with a group of autistic adults with co-occurring intellectual disability, their supporters and GPs.

5.1.2.1. Autism CHAP development

Following a review of the literature, we adapted the CHAP to include autism specific items about sensory differences, diagnosis of autism, gastrointestinal health and eating habits. The adapted version of the CHAP, the Autism CHAP, was then sent for feedback to a larger group, consisting of autistic adults, parents of an autistic adults with co-occurring intellectual disability, health professionals and academics with expertise in the health of autistic people and/or people with intellectual disability.

5.1.2.2. Participants

To pilot the Autism CHAP, we recruited autistic adults required a self-reported diagnosis of autism and intellectual disability, their supporters, and GPs. Supporters were required to support the autistic adult during the completion of the Autism CHAP and during their GP appointment. GPs were those who administered the Autism CHAP. Where possible, we aimed to recruit participants to represent individual health triads (the autistic adult with co-occurring intellectual disability, their supporters, and their GP).

Participants were recruited from across Australia through our established connections with autism and disability services providers. autistic adults with co-occurring intellectual disability were recruited either via project advertisements shared by our established networks or via autism and disability services provider staff. Project advertisements included an outline of the project and who to contact for more information or to participate. We contacted key contacts within each organisation and asked them to identify autistic adults that fulfil the study’s inclusion criteria and seek their/their substitute decision maker’s permission for researchers to contact them about participating in the study. Key contacts within each organisation were responsible for returning the completed consent-to-be-contacted form to our research team.

Once recruited, a survey to collect demographic and health service use data for completed for each autistic participant. The autistic adult and supporter (if required) then completed the Autism CHAP and made an appointment to see their GP. After the GP appointment, the supporter and GP completed a survey to provide their feedback on the experience. autistic participants were invited to participate in an interview to share their experience.

5.1.3. Findings

The Autism CHAP was piloted with seven autistic adults with co-occurring intellectual disability, five supporters and four GPs. Two autistic adults participated in an interview (see Table 1). Six participants had a regular GP and three had previously done a health assessment with their GP. All participants usually visited their GP with a supporter and for five of the participants this was usually a paid support worker. For support workers, they reported knowing the participant between 2-4 years (mean 3, SD 1). GPs had been practicing medicine between 12-41 years (mean 25, SD 12).

Table 1. Autism CHAP participant demographics

	Age Mean (SD)	Male gender N (%)
Autistic participants	37 (10)	6 (85.7)
Supporters	43 (12)	2 (40.0)
GPs	48 (11)	3 (75.0)

Four of the participants had been reviewed by a dentist in the last six months and GPs noted no signs of dental pathology for five participants with one participant referred to a dentist. Six participants were taking prescription medications with an average of 3 medications (range 0-11). During the CHAP appointment, three of the participants had their eyes checked, five had their hearing checked and an otoscopy.

Individuals and their supporters generally found the Autism CHAP beneficial and useful. One support person reported that they had “*learned a lot of medical things*”. GPs in the pilot reported the Autism CHAP assisted with a thorough review of the patient and provided new knowledge about autism and intellectual disability health.

5.1.3.1. Revision of Autism CHAP

After the pilot, revisions were made to the Autism CHAP based on the pilot findings, input from our Community Council, a group of autistic adults, and from content experts. Additional content and prompts about common health problems in this population as well as questions about sensory needs, sexual health, and parenting. Changes were made to ensure clear and unambiguous terminology and removal of normative language.

5.1.4. Conclusions

The Autism CHAP provides GPs with timely autism and intellectual disability specific knowledge that is pertinent to the care of their patient. It provides an avenue to establish a clear action plan between patient, supporters, and the GP. More input from GPs and practice nurses are needed before the tool is finalised. The wider use of this tool has the potential to significantly improve health outcomes for autistic adults with intellectual disability, a group that is often overlooked in healthcare.

5.2. AASPIRE toolkit

5.2.1. Introduction

autistic adults often have challenges accessing healthcare services. Inaccessible communication by health professionals, the sensory environment of healthcare settings and fear or anxiety regarding the visit all contribute to these challenges. Health professionals who see autistic adults report low levels of confidence in their ability to successfully provide services to this population. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) developed an online healthcare toolkit to improve healthcare interactions between autistic adults and their primary care providers. This tool was developed and trialled in the United States.

This study aimed to explore experiences of autistic adults using the AASPIRE healthcare toolkit in Australia.

5.2.2. Research design and methods

Semi-structured interviews were conducted with six autistic adults about their experiences and perceptions of utilising the toolkit with their respective health professionals in an Australian healthcare setting.

5.2.3. Findings

Participants identified that the toolkit facilitated their interactions with the health professionals, by providing structure to questions, supplementing new knowledge, and increasing their individual confidence. They also offered suggestions for changes to tailor the toolkit for use in Australia.

5.2.4. Conclusions

Overall, participants felt that the toolkit had potential to be implemented in Australia. Future research should seek to explore the experiences of autistic adults using a version of the toolkit adapted for use in Australia, as well as exploring the views of health professionals utilising it.

5.3. GP education: Check program

5.3.1. Introduction

One avenue for GPs to participate in continuing professional development is through the Royal Australian College of General Practitioners *check* program. Check is an independent learning program written by experts and undergoes a peer review process. Each unit inclusive clinical cases with question and answers followed by multiple choice questions. It also provides links to external resources.

We contributed three cases across three units:

- Urbanowicz, A., Cadman, M., Small, J., & Harley, D. (2017). Daniel's dad is worried about his development. *Check* unit 541 Paediatric health, August 2017.
- Urbanowicz, A., Cadman, M., Sellen, M., & Franklin, C. (2017). Charlotte's anxious and doesn't want to go to school. Check unit 542 Adolescent health, September 2017.
- Cadman, M., Urbanowicz, A., Sellen, M., Franklin, C., & Harley, D. (2017). Malcolm's behaviour is becoming increasingly difficult to manage. *Check* unit 543 Vulnerable populations, October 2017.

These were available to GPs to complete over the 2017–2019 triennium.

5.3.2. Research design and methods

At the end of each unit, GPs complete evaluation questions. These ask GPs to rate, a three-point scale, the degree to which the learning outcomes were met, how well their leaning needs were met and the relevance of the activity to their clinical practice. We collected this data for the three activities our cases were included in for the 2017-2019 period.

5.3.3. Findings

For each unit, the following number of GPs completed the activity:

- Paediatric health n=2283 (n=1879 completed evaluation survey)
- Adolescent health n=1788 (n=1450 completed evaluation survey)
- Vulnerable populations n=947 (n=947 completed evaluation survey)

Across the three units, over 70% of GPs reported their learning outcomes were entirely met by the activity. Similarly, over 70% of GPs also reported their own learning needs had been met by the activity. GPs also often found the activity was relevant to their individual general practice with 89.4% for the paediatric unit, 87.7% for the adolescent unit and 79.2% for the vulnerable population unit (see Table 2).

Table 2. GP Evaluation question responses

	Paediatric health n=1879	Adolescent health n=1450	Vulnerable populations n=947
Activity learning outcomes were entirely met	77.06%	79.31%	73.50%
Learning needs were entirely met by activity	78.02%	76.55%	71.91%
Activity entirely relevant to individual general practice	89.41%	87.72%	79.20%

5.3.4. Conclusions

Continuing professional development is a key avenue to deliver education and training about autism in adulthood for health professionals. To meet expectations of health professionals, partnering with existing continuing professional development to deliver content can assist with completion of the training. Continuing professional development, particularly for GPs, is important and needs to be a continual focus as activities expire after periods of time.

5.4. Identifying GP training priorities

5.4.1. Introduction

There is limited literature about the experiences of Australian autistic adults using general practitioner (GPs) services and of GPs providing care to autistic adults. There is also no co-produced or autistic informed training available for GPs about autistic healthcare in adulthood.

This project aims to investigate the GP experiences of autistic adults, from the perspective of autistic adults and supporters (i.e., family member, supporters) and explore the experiences of GPs providing care to autistic adults in Australia. This evidence will be used to provide recommendations on what is required to GP training.

5.4.2. Research design and methods

This project was guided by an advisory group of autistic adults and general practitioners. We used a qualitative study design and conducted in-depth interviews with autistic adults, supporters, and

GPs in their mode of choice (online video/audio, telephone, email, or instant message). Prior to the interview, participants completed a demographic questionnaire. During the interview we asked about knowledge of autism, patient provider communication, COVID-19 related accommodations, and training needs of GPs. Interviews were digitally recorded and transcribed verbatim and analysed using thematic analysis.

5.4.3. Findings

Preliminary findings suggest autistic adults feel like their concerns are dismissed by GPs possibly due to stigma and lack of knowledge, appointments are too short and there is pressure to discuss only one concern per visit.

5.4.4. Conclusions

The findings from this research are being used to inform the development of GP training modules to ultimately improve the healthcare experiences and health outcomes of autistic adults.

6. Improve health and wellbeing

6.1. Cooking classes

6.1.1. Introduction

Mealtimes are a valuable experience for individuals in several ways through providing nutrition to promoting mental health and wellbeing. There is scant research about food for young autistic adults, a population particularly underrepresented in academic literature.

This study had two aims; (1) to investigate the lived experience of mealtimes for young autistic adults, particularly the enablers and barriers to enjoyable mealtimes and (2) evaluate a cooking program for young autistic adults.

6.1.2. Research design and methods

A cooking program was designed and delivered in 2016 to 10 young autistic adults. The cooking program consisted of two blocks of three cooking classes with a maximum of six young people in each block. Each class was attended by two co-facilitators who provided instructional assistance to participants if they had any questions or needed modelling of techniques or skills. The content in each class and the accompanying recipes centred around the three main meals of the day and built food preparation and cooking skills.

After participating in the cooking program, four young adults participated in semi-structured interviews and a Photovoice task to provide feedback on their experience. Thematic analysis of the interviews was undertaken.

6.1.3. Findings

The findings relating to the first aim highlighted a tension between pleasure and enjoyment in mealtimes and the potential for discomfort or distress related to the food or circumstances. Predictability and choice were important, although participants appreciated novelty. Participants reported both enjoying social interaction along with valuing eating alone in different contexts. Aligned to this, participants reported that they frequently chose to eat the same types of foods in familiar settings.

In terms of feedback on the cooking program, overall, participants enjoyed the cooking classes. The classes assisted participants in developing experience with cooking and eating food with others. Half of the participants identified that because of participating in the classes, they developed more confidence regarding cooking, using recipes and cooking for others. Participants recommended a need to limit the number of attendees in any one class and to be considerate of access to the cooking school via public transport and enough space to undertake hands-on work.

6.1.4. Conclusions

The overall format of the classes was appropriate. Future classes need to be near public transport, keep classes size small and utilise a space with enough room to comfortably work that meet the sensory needs of participants. Independence in being able to cook for oneself is an important life skill and future research with larger numbers of participants is needed.

For more information, see Nicollet, Zale, and Urbanowicz (2016)

6.2. Acceptance and Commitment Therapy Program for Anxiety

6.2.1. Introduction

Cognitive Behaviour Therapy or CBT is the dominant approach to managing anxiety. However, there is little evidence for its use with autistic adults and emerging evidence is growing around the use of Acceptance and Commitment Therapy (ACT). ACT has the general goal of increasing psychological flexibility and has six core processes: contact with the present moment, values, committed action, self as context, cognitive diffusion and acceptance (Hayes, Luoma, Bond, Masuda, & Lillis, 2006).

6.2.1.1. The program

A program using the principles of ACT was designed to meet the needs of autistic adults and their management of anxiety. Briefly, the program involved eight weekly sessions and individuals were expected to complete homework between sessions.

- Session one focuses on building a therapeutic relationship and identifying past and current strategies around managing anxiety.
- Session two focuses on exploring the effectiveness of past and current strategies to manage anxiety.
- Session three focuses on control being the problem not the solution to managing anxiety.
- Session four focuses on discussing values and identifying goals and activities I to move closer to living a valued life.

- Session five focuses on expanding goals and activities the individual has identified to work on to move towards living a valued life.
- Session six focuses on the power of language and its effect on feelings and behaviour.
- Session seven is a review session; revisiting core ACT concepts based on the individual's progress.
- Session eight consolidates the individual's progress through the program.

The aim of this project was to assess the effectiveness of a novel ACT program to improvement management of anxiety by running a small pilot with pre/post measures.

6.2.2. Research design and methods

Participants were recruited through QCIDD and Autism CRC networks. Participants needed to be over 18, have an autism and anxiety disorder diagnosis, an IQ score over 80 and able to travel to attend eight one-on-one sessions. Participants were not excluded if they were currently on any medication for the management of anxiety or any other physical or mental health condition.

Eight measures were taken prior and following completion of the program. Three of these measures were also delivered halfway through, at approximately five weeks into the program (see Table 3).

Table 3. Summary of measures

Measure	Pre	Mid	Post
Personal Need for Structure (PNS) Questionnaire (Thompson, Naccarato, Parker, & Moskowitz, 2001)	X		X
Acceptance and Action Questionnaire (AAQ-II) (Bond et al., 2011)	X	X	X
Valued Living Questionnaire (VLQ) (Wilson, Sandoz, & Kitchens, 2010)	X		X
Hamilton Anxiety Scale (HAM-A) (Hamilton, Schutte, & Malouff, 1976)	X	X	X
Intolerance of Uncertainty Scale (IUS-12) (Sexton & Dugas, 2009)	X		X
Toronto Alexithymia Scale (TAS-20) (Taylor, Bagby, & Parker, 1992)	X	X	X
Highly Sensitive Person Scale (HSP) (Aron & Arons, 1997)	X		X
Five Facet Mindfulness Questionnaire (FFMQ) (Baer, Smith, Hopkins, Kreietemeyer, & Toney, 2006)	X		X

To identify whether there was a significant change scores before and after the anxiety program, for the whole group, a Wilcoxon's signed rank-test was performed for each measure. The reliable change index was a used to calculate significant changes of scores from an individual over a period of time.

6.2.3. Findings

There was a significant decrease in scores for the Toronto Alexithymia Scale and the Highly Sensitive Person Scale ($p < .05$). All other tests showed non-significant changes, however, all measures showed the expected directional change. These results overall indicate that there was a significant decrease in alexithymia for participants post-program, as well as a significant decrease in sensory sensitivity for participants post-program.

The reliable change index found three participants had significant changes in results in more than one measure. The Intolerance of Uncertainty Scale, the Highly Sensitive Person Scale, and the Five Facet Mindfulness Questionnaire showed the greatest number of significantly changed scores. These results indicate that there was a significant decrease in the intolerance of uncertain scenarios, a significant decrease in sensory sensitivity, and a significant increase in mindfulness, due to each respective measure, that was experienced by four of nine participants post-program.

6.2.4. Conclusions

The ACT program shows promise for supporting autistic adults to manage their anxiety as the measures demonstrated the expected directional changes in most instances. More research is needed to test the utility of this program. Further, the measures we use to assess change in key outcomes should be reviewed with autistic adults to ensure the measures are appropriate and reflective of the autistic experience.

7. Improve access to resources

7.1. autistic adults with intellectual disability: Designing an accessible website

7.1.1. Introduction

autistic adults with intellectual disability are diverse and have a range of life experiences. autistic adults with intellectual disability have poorer physical and mental health than non-autistic adults (Mannion & Leader, 2013). Dunn, Rydzewska, MacIntyre, Rintoul, and Cooper (2018) argue autistic adults with intellectual disability have unique support needs around health and wellbeing that may not be met by current autism or intellectual disability supports.

Access to health information is an area of need. Little is known about how autistic adults with intellectual disability and their support people look for and use health information. Given the health and wellbeing needs of autistic adults with intellectual disability (van Dooren et al., 2016), it is particularly important to ensure the Health Hub tools and resources are accessible and reflect these needs.

The aim of this project was to provide design recommendations to the Autism CRC for refining their website to deliver the health and wellbeing tools, strategies and techniques developed and tested in Autism CRC Program 3 that incorporate the unique needs of autistic adults with intellectual disability and their support people.

7.1.2. Research design and methods

The project used an inclusive research approach to engage with autistic adults with intellectual disability and their support people to inform the design recommendations for an online health information website. In this project, three integrated approaches supported the inclusive approach of the research team: a research team including non-autistic researchers and an autistic general practitioner (GP), Autism CRC Inclusive Research Practice Guides and a co-design framework. A suite of strategies was used to support the inclusion and engagement of participants.

Semi-structured interviews were conducted with two autistic adults with intellectual disability and three of their support people to identify how they use health information and their preferences and needs regarding the design of websites.

7.1.3. Findings

Through this project, we identified eight key design recommendations to improve the useability of the Health Hub website for autistic adults with intellectual disability and their support people.

- Use ‘cards layout’ to improve the visual presentation of information on the home page.
- Provide ability to sort or filter pages based on audience or topics.
- Be consistent in how information is presented.
- Consider the readability of content.
- Utilise images and graphics to support text.
- Consider the way the content on pages looks visually.
- Provide links to tell a cohesive story
- Provide more information about the attachments

7.1.4. Conclusions

It is imperative that as a provider of online health information, we present and deliver online information tailored to the preferences and needs of this population regarding website design and accessibility. It is important these recommendations are considered alongside international standards such as the Web Content Accessibility Guidelines (World Wide Web Consortium (W3C), 2018) to ensure the Health Hub is as accessible as possible.

For more information, see Brooker, Baker, Harley, and Urbanowicz (2021)

7.2. Health professionals: Designing a useful website

7.2.1. Introduction

Our online resource for health professionals and autistic adults, the Health Hub, provides free tools, resources, and information that aim to improve health and wellbeing for autistic adults. However, little is known about how to make this health hub accessible and appropriate for health professionals working with autistic adults.

The aim of this study was to understand how to create an online platform that is useful, accessible, and appropriate for health professionals to support them to provide high quality care to autistic adults.

7.2.2. Research design and methods

We conducted 5 focus groups and 12 qualitative interviews with 34 health professionals across QLD, Victoria, NSW, and WA in 2015. Health professionals were psychologists, counsellors, occupational therapists, GPs, psychiatrists and other medical practitioners, social workers, and nurses. We asked questions about what made a successful website, what content was essential to the website and how to tell health professionals about the website.

7.2.3. Findings

Participants told us that useful websites were ones that were user friendly and attractive and presented a mixture of visual and written content with few unnecessary words. Website features including the ability to navigate the site with no more than two to three clicks, and printable content (such as PDFs) were also identified as priorities.

The information on websites should address common questions or concerns experienced by autistic adults, such as sleep, oral health, nutrition and eating issues, anxiety, gender identity, fatigue, gastrointestinal concerns, abuse, epilepsy, and constipation. This information needs to be accurate and up to date with references for all information sources.

Health professionals also shared their tips for communicating with autistic adults and adapting their clinical spaces to better meet the needs of autistic patients. Participants noted that it is difficult for busy and time-poor health professionals to spend their time learning more about autism. Suggestions included using peak bodies (e.g., Australian Medical Association) and commonly accessed e-newsletters and websites to raise interest and knowledge amongst health professionals.

Importantly, participants offered the following tips to autistic adults, in the hopes of making appointments easier and to avoid stress:

- Remember to take your health history to appointments. It could be useful to write things down.
- If you can’t make an earlier booking, you might like to ask if you can be told if there are cancellations for a sooner appointment.
- Ask for the first appointment of the day to avoid delays and long waits in the waiting room.
- Ask for a quiet space to wait.
- Bring a ‘this is my communication style’ checklist to your appointment and show the health professional straight away.

- Make notes during your appointment so you can remember what was discussed.

7.2.4. Conclusions

Designing an appropriate and accessible website that meets the needs of health professionals and autistic adults is important and specific information tailored for each audience is necessary. Health professionals have shared what makes a website useful to them, but we also need to seek the views of autistic adults and in particular autistic adults with intellectual disability.

For more information, see Urbanowicz, van Dooren, Nicollet, and Lennox (2016)

7.3. Health hub

In looking to provide an accessible avenue for autistic adults to find health information, in 2014 Autism CRC developed a website, the Health Hub (https://www.autismcrc.com.au/knowledge-centre/resource/health-hub-resources). This website aimed to provide information that supports autistic adults to achieve their health and wellbeing goals and aspirations. Currently, the following resources are available on the Health Hub website, although some have now been superceded by more recent research and resources.

- Health, human rights, and you
  - Collation of resources to help individuals to better understand health, human rights, and the right to health and wellbeing (van Dooren, 2015).
- Quality and safe healthcare
  - Information for individuals about their rights to access healthcare, to receive safe care, and to be afforded respect and privacy, communication and participation and the opportunity to comment on service provision (van Dooren & Higgins, 2015).
- Tools for health professionals
  - See section 5.3 and van Dooren et al. (2014) for more information.
- Questions for judging the quality of autism websites
  - A list of questions to help individuals judge the quality of the websites they visit, based on the DISCERN tool (van Dooren, Falkmer, Bennett, den houting, & Wilson, 2015).
- Understanding autism and what you need to know
  - See section 7.1 and Urbanowicz et al. (2016) for more information.
- Emergency communication board

    - A resource is designed to enhance communication between patients and paramedics (Department of Communities (Disability and Community Care Services) & Department of Community Safety (Queensland Ambulance Service), n.d.).
- GPs and mental health
    - Findings from a review of literature and relevant resources about the management of mental ill health.
    - For more information, see Foley and Trollor (2015).
- Spectrum cooking program
    - See section 5.3 and Nicollet et al. (2016) for more information.

For more information, see www.autismcrc.com.au/healthhub

8. Conclusion

Our body of work (Figure 1) has contributed to furthering the field of health and wellbeing for autistic adults. We developed understanding of the healthcare needs of autistic adults, highlighting many important experiences around diagnosis, and managing long term health conditions including diabetes and oral healthcare. We gained insight into the experiences, views, and needs of health professionals providing healthcare to autistic adults, highlighting the need for further education in this area. In response, we developed a variety of tools, resources, and strategies to improve access to healthcare, health and wellbeing and access to resources. Importantly, we were able to deliver training to GPs via a continuing professional development activity as well as other health professionals throughout our work.

In planning future research in this area, we need to continue to build relationships between autistic adults, health professionals, and researchers to conduct quality research that is reflective of the autistic community's priorities and is inclusive of autistic participants needs. All tools, resources, and strategies to improve health and healthcare delivery need to be co-designed with autistic adults, health professionals, and researchers to ensure they are accessible, appropriate, and useful to each end user.

We need to continue to raise the importance of health and wellbeing research, education for health professionals and improved health service delivery for autistic adults. It is vitally important we continue to advocate and contribute towards education and training of health professionals about autism in adulthood, particularly given the growing attention this area is receiving with the Disability Royal Commission (Disability Royal Commission, 2020) and the Select Committee on Autism inquiry (Select Committee on Autism, 2019). All education and training must be co-designed, reflect the autistic community's priorities and evaluated to demonstrate its effectiveness. Lastly, the tools, resources, and strategies developed as part of our body of work, such as the Autism CHAP and the anxiety program provide practical clinical solutions to some of the problems identified in the 'understanding' component of this work.

To conclude, we wish to recognise the journey and advocacy by the autistic and autism communities which have got us to this point. We must all continue to work together to improve health and wellbeing research, health services, and health outcomes for autistic adults.

9. References

Aron, E. N., & Arons, A. (1997). Sensory-processing sensitivity and its relation to introversion and emotionality. *Journal of Personality and Social Psychology, 73*(2), 345-368.

Australian Bureau of Statistics (ABS). (2013). Census of Population and Housing: Socio-Economic Indexes for Areas (SEIFA), Australia, 2011. Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2033.0.55.001~2011~Main%20Features~IRSAD~10004

Baer, R. A., Smith, G. T., Hopkins, J., Kreietemeyer, J., & Toney, L. (2006). Using self-report assessment methods to explore facets of mindfulness. *Assessment, 13*(1), 27-45.

Bauman, A., & Nutbeam, D. (2014). *Evaluation in a nutshell: a practical guide to the evaluation of health promotion programs* (Vol. 2ndition.). North Ryde, N.S.W: McGraw-Hill.

Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., . . . Zettle, R. D. (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire - II: A revised measure of psychological inflexibility and experiential avoidance. *Behavior Therapy, 42*(4), 676-688.

Bradshaw, P., Pellicano, E., van Driel, M., & Urbanowicz, A. (2019). How Can We Support the Healthcare Needs of autistic Adults Without Intellectual Disability? *Current Developmental Disorders Reports, 6*(2), 45-56. doi:10.1007/s40474-019-00159-9

Brooker, K., Baker, A. R., Harley, D., & Urbanowicz, A. (2021). *Online Health Information and Me: Enabling the utilisation of the Autism CRC Health Hub webpages by autistic adults with intellectual disability and their support people*. Brisbane: Cooperative Research Centre for Living with Autism

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism, 19*(7), 814-823. doi:10.1177/1362361315577517

Department of Communities (Disability and Community Care Services), & Department of Community Safety (Queensland Ambulance Service). (n.d.). Emergency communication board. Retrieved from https://www.autismcrc.com.au/knowledge-centre/resource/emergency-communication-board

Disability Royal Commission. (2020). Public hearing 10: Education and training of health professionals in relation to people with cognitive disability. *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.* Retrieved from https://disability.royalcommission.gov.au/public-hearings/public-hearing-10

Dunn, K., Rydzewska, E., MacIntyre, C., Rintoul, J., & Cooper, S.-A. (2018). The prevalence and general health status of people with intellectual disabilities and autism co-occurring together: a total population study. *Journal of Intellectual Disability Research*, epub ahead of print. doi:10.1111/jir.12573

Foley, K., & Trollor, J. (2015). Management of mental ill health in people with autism spectrum disorder. *Australian Family Physician, 44*, 784-790. Retrieved from http://www.racgp.org.au/afp/2015/november/management-of-mental-ill-health-in-people-with-autism-spectrum-disorder/

Hamilton, M. C., Schutte, N. S., & Malouff, J. M. (1976). Hamilton anxiety scale (HAMA). *Sourcebook of Adult Assessment: Applied Clinical Psychology*, 154-157.

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: model, processes and outcomes. *Behaviour Research and Therapy, 44*(1), 1-25. doi:10.1016/j.brat.2005.06.006

Hepburn, S. L., Stern, J. A., Blakeley-Smith, A., Kimel, L. K., & Reaven, J. A. (2014). Complex Psychiatric Comorbidity of Treatment-Seeking Youth With Autism Spectrum Disorder and Anxiety Symptoms. *Journal of Mental Health Research in Intellectual Disabilities, 7*(4), 359-378. doi:10.1080/19315864.2014.932476

Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., . . . Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry, 9*(1), 35. doi:10.1186/1471-244X-9-35

Hwang, Y. I., Srasuebkul, P., Foley, K. R., Arnold, S., & Trollor, J. N. (2019). Mortality and cause of death of Australians on the autism spectrum. *Autism Research, 12*(5), 806-815. doi:10.1002/aur.2086

Lennox, N., Ware, R., Bain, C., Taylor Gomez, M., & Cooper, S. A. (2011). Effects of health screening for adults with intellectual disability: a pooled analysis. *British Journal of General Practice, 61*(584), 193-196. doi:10.3399/bjgp11X561186

Maddox, B. B., & White, S. W. (2015). Comorbid Social Anxiety Disorder in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 45*(12), 3949-3960. doi:10.1007/s10803-015-2531-5

Mannion, A., & Leader, G. (2013). Comorbidity in autism spectrum disorder: A literature review. *Research in Autism Spectrum Disorders, 7*(12), 1595-1616. doi:10.1016/j.rasd.2013.09.006

Morgan, J. P., Minihan, P. M., Stark, P. C., Finkelman, M. D., Yantsides, K. E., Park, A., . . . Must, A. (2012). The oral health status of 4,732 adults with intellectual and developmental disabilities. *The Journal of the American Dental Association, 143*(8), 838-846. doi:10.14219/jada.archive.2012.0288

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine, 28*(6), 761-769. doi:10.1007/s11606-012-2262-7

Nicollet, C., Zale, R., & Urbanowicz, A. (2016). Spectrum Cooking: Evaluation of cooking classes for young adults on the autism spectrum. Retrieved from https://www.autismcrc.com.au/knowledge-centre/resource/spectrum-cooking-program

Oswald, D. P., Gilles, D. L., Cannady, M. S., Wenzel, D. B., Willis, J. H., & Bodurtha, J. N. (2013). Youth with special health care needs: transition to adult health care services. *Maternal and Child Health Journal, 17*(10), 1744-1752.

Pradhan, A., Slade, G. D., & Spencer, A. J. (2009). Factors influencing caries experience among adults with physical and intellectual disabilities. *Community Dentistry and Oral Epidemiology, 37*(2), 143-154. doi:10.1111/j.1600-0528.2008.00455.x

Select Committee on Autism. (2019). Terms of Reference. Retrieved from https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Terms_of_Reference

Sexton, K. A., & Dugas, M. J. (2009). Defining distinct negative beliefs abouts uncertainty: Validating the factor structure of the Intolerance and Uncertainty Scale. *Psychological Assessment, 21*(2), 176-186.

Taylor, G. J., Bagby, R. M., & Parker, J. D. A. (1992). The revised Toronto alexithymia scale: Some reliability, validity, and normative data. *Psycotherapy and Psychosomatics, 57*, 34-41.

Thompson, M. M., Naccarato, M. E., Parker, K. C. H., & Moskowitz, G. B. (2001). The personal need for structure and personal fear of invalidity measures: Historical perspectives, current applications, and future directions. In *Cognitive Social Psychology: The Princeton Symposium on the Legacy and Future of Social Cognition*. London: Lawrence Eribaum Associates.

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. *67*(659), e445-e452. doi:10.3399/bjgp17X690449 %J British Journal of General Practice

Urbanowicz, A., Parkin, T., van Dooren, K., Girdler, S., Ciccarelli, M., & Lennox, N. (2020). The experiences, views, and needs of health professionals who provide care to adults on the autism spectrum. *Research and Practice in Intellectual and Developmental Disabilities*, 1-14. doi:10.1080/23297018.2020.1735943

Urbanowicz, A., van Dooren, K., Nicollet, C., & Lennox, N. (2016). Understanding autism and what you need to know. Retrieved from https://www.autismcrc.com.au/knowledge-centre/resource/understanding-autism-and-what-you-need-know

van Dooren, K. (2015). Health, human rights and you. Retrieved from https://www.autismcrc.com.au/knowledge-centre/resource/health-human-rights-and-you

van Dooren, K., Falkmer, M., Bennett, M., den houting, J., & Wilson, J. (2015). Questions for judging the quality of autism websites. Retrieved from https://www.autismcrc.com.au/knowledge-centre/resource/questions-judging-quality-autism-websites

van Dooren, K., & Higgins, J. P. (2015). Quality and safe healthcare. Retrieved from https://www.autismcrc.com.au/knowledge-centre/resource/quality-and-safe-healthcare

van Dooren, K., McPherson, L., & Lennox, N. (2016). Mapping the Needs of Adults with Autism and Co-Morbid Intellectual Disability. *Current Developmental Disorders Reports, 3*(1), 82-89. doi:10.1007/s40474-016-0071-0

van Dooren, K., Nicollet, C., & Lennox, N. (2014). Online resources about Autism Spectrum Disorders for health professionals. A snapshot of resources − for adults and health professionals. Retrieved from http://www.autismcrc.com.au/online-tools-health-professionals

Wallace, B., Browne, A., Varcoe, C., Ford-Gilboe, M., Wathen, N., Long, P., & Parker, J. (2015). Self-reported oral health among a community sample of people experiencing social and health inequities: cross-sectional findings from a study to enhance equity in primary healthcare settings. *BMJ Open, 5*(12). doi:10.1136/bmjopen-2015-009519

Whitehouse, A., Evans, K., Eapen, V., & Wray, J. (2018). *A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia*. Brisbane: Cooperative Research Centre for Living with Autism

Wilson, K. G., Sandoz, E. K., & Kitchens, J. (2010). The valued living questionnaire: Defining and measuring valued action within a behavioral framework. *The Psychological Record, 60*, 249-272.

World Wide Web Consortium (W3C). (2018, 24 March 2018). Introduction to Web Accessibility. Retrieved from https://www.w3.org/WAI/fundamentals/accessibility-intro/

Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System. *Journal of Autism and Developmental Disorders, 45*(12), 4002-4014. doi:10.1007/s10803-015-2579-2

Our values

Inclusion

Working together with those with the lived experience of autism in all we do

Innovation

New solutions for long term challenges

Evidence

Guided by evidence-based research and peer review

Independence

Maintaining autonomy and integrity

Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone

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