

# Mackay HealthPathways Autism Initiative

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# **FINAL REPORT**

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# Mackay HealthPathways Autism Initiative

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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

The Mackay HealthPathways Autism Initiative was implemented to identify and develop clinical HealthPathways to assist in the health management of children, adolescents and adults on the autism spectrum.

HealthPathways is a web-based health information site, developed by Streamliners NZ, which assists clinicians to guide patients through the complexities of the health system. HealthPathways provides support to clinicians, mainly general practitioners, for assessing and managing patients with the inclusion of appropriate tools and resources and provides clear referral pathways for the local area.

The Autism HealthPathways were originally scoped and designed specifically for the Mackay Hospital and Health Service region with the long-term intention to share content across the national and international HealthPathways community.

Within the Australian primary health care sector, specifically in general practice, there is a deficit of evidence-based knowledge and understanding of the life span health care needs of people on the spectrum <sup>1,2</sup>. Due to this, there is:

- A lack of consistent management guidelines and standards.
- Limited follow up of physical, mental/emotional and oral health issues.
- Limited support for GPs available in a single point/pathway.
- Limited professional development opportunities for regional, rural and remote GPs in the area of autism.
- No established or emerging Cycle of Care (an annual cycle of care is a detailed set of patient management steps that GPs can claim through Medicare) to support appropriate preventative health assessments for people on the spectrum.

To better define the needs of the Mackay Hospital and Health Service region, work and advisory groups were established to participate in education events and complete questionnaires to outline the barriers and enablers to healthcare for people on the spectrum as perceived by health professionals, individuals on the spectrum, and their caregivers.

# **Working group**

The first local health professional working group involved thirty-six participants from various health disciplines. The working group commenced with viewing an online Autism TEDTalk, followed by an



overview of the Mackay HealthPathways Autism Initiative Research Project. The work group concluded with a brainstorming exercise exploring the barriers and enablers to healthcare. As part of this phase of the research, health professionals (medical, nursing, allied health and other health related professionals) completed questionnaires on their clinical practice, past training about autism, their experiences of providing health care to autistic people including the diagnostic process and their experience and confidence in working with autistic patients across the lifespan.

Data highlighted health professionals mostly worked full time and had been practicing for an average of 18.2 years (SD 14.8). Most of the health professionals reported working with children in their clinical practice. Health professionals reported between 1-25% of their patients were on the autism spectrum, with between 1-25% of these patients having a co-occurring intellectual disability. Less than a fifth of health professionals had completed autism or intellectual disability training.

Over 50% of health professionals reported limited experience to no experience working with autistic patients. This was more pronounced for adult patients, where 82% of health professionals reported limited to no experience working with autistic adults. There is a similar trend for confidence in working with autistic patients; health professionals had more confidence working with children and young people than adults.

Health professionals lacked confidence regarding their knowledge of local referral pathways post autism diagnosis with 58%, 72% and 87% reporting limited to no confidence in referring children, young people and adults respectively. Health professionals also had low levels of confidence regarding their understanding of assistance or services available to autistic people with 63%, 61% and 94% reporting limited to no confidence for children, young people and adults respectively.

Overwhelmingly, when asked what would improve service provision in the Mackay region, health professionals wanted improved access to diagnosis and process services (e.g., shorter wait times, no-low cost services, services for adults). Health professionals also wanted more education and confidence building activities around autism across the lifespan and more support groups for adults and families.

The second work group included local consumers, utilising existing relationships to access events and local support groups to coordinate discussions and capture feedback using questionnaires on barriers and enablers to healthcare. The questionnaires provided consumer experiences in receiving care in the local context and was completed by autistic people (n=2) and caregivers (n=7). Questions related to their or their child's health and wellbeing, healthcare utilisation and experiences of receiving health care including the diagnostic process, support post diagnosis and how well their health professionals were able to accommodate their or their child's needs.



The autistic people were adults and just over half of the caregivers were reporting on supporting a child or young person on the spectrum. One adult and two of the children also had an intellectual disability. Participants self-rated or their caregivers rated their health as good or excellent with only one participant rating their health as fair. Almost all the participants had a regular GP with one participant looking for a new GP after recently moving. When asked about how well their GPs were able to accommodate their or their child's needs, 78% of participants reported the GP did this very well or well.

Participants also reported several barriers to specialist services. For autistic adults or caregivers of autistic adults, they found services and supports stopped when the individual turned eighteen or left school. Additionally, there was a lack of experienced psychiatrists in the area which resulted in one participant not being able to have their medication changed, as the GP wanted further input. Caregivers of children and young people also reported a lack of paediatricians and psychologists who were experienced with autism and accessible without long wait times or high costs.

All but one participant was diagnosed in childhood with length of time to get a diagnosis ranging from two months to three years. The majority (86%) of participants reported they were given a formal report of their autism diagnosis. When asked to rate the diagnostic process on a scale from no stress to major stress, 37% of participant's rated the experience caused major stress. Post diagnosis support varied with two participants not referred to anyone after their diagnosis. Others were most commonly referred to occupational therapists, speech pathologists and local support groups by their GP. Over 85% of participants took it upon themselves to organise support post diagnosis, often seeking out physiotherapists, occupational therapists and psychologists.

# **Advisory group**

The information sourced from the working groups and individualised questionnaires was collated and applied to help inform the advisory group with the development and implementation of the Autism HealthPathways. The advisory group was comprised of subject matter experts (health professionals specialising in the field of autism, health professionals on the spectrum and family/caregivers of those on the spectrum) and a GP clinical editor (GP responsible for all content in the HealthPathways) who were responsible for developing the HealthPathways.

Once the Autism HealthPathways were drafted and ready for review, a two-week feedback process began, providing over three hundred health professionals access to review the work and suggest constructive feedback. To provide consistency within the study, any health provider who participated in the health professional work group was sent a personal invitation to review the draft Autism Pathways. Once all feedback was incorporated into the final Autism HealthPathways and approved



by the advisory group/project team, the Autism HealthPathways were published on the live site and a notification of the new pathways posted on the Mackay HealthPathways home page.

The suite of Mackay Autism HealthPathways (and associated supporting pathways) were finalised for release to the Mackay Hospital and Health Services community on 18<sup>th</sup> July 2019. The Mackay Autism HealthPathways suite consists of the following pathways:

- Autism Spectrum Disorder in Children and Adolescents
- Adult Disability Support
- Autism Spectrum Disorder Assessment in Adults
- Autism Spectrum Disorder Support
- Challenging Behaviours in Adults with Intellectual Disability
- Health Assessment for People with an Intellectual Disability
- Intellectual Disability in Adults Genetics
- Mental Illness in Adults with Intellectual Disability

To coincide with the launch of the Mackay Autism HealthPathways suite, "The Spectrum - though their eyes, through their lives" symposium was organised and consisted of a free half day education session designed for health professionals. The symposium's aim was to clarify autism health management within the primary care context. The symposium was attended by 65 health professionals who had the opportunity to listen to four guest speakers with expertise in each area of autism across the lifespan (child, adolescent and adult).

# **HealthPathways Evaluation Data**

Since the go live of the Autism HealthPathways, page views/utilisation has been tracked and monitored utilising Google Analytics. With the implementation of the Autism HealthPathways, Google Analytics has captured the use of the Autism HealthPathways, which has been accessed roughly 2,000 times as at December 2020.

As part of the evaluation, health professionals (predominantly General Practitioners) were asked to complete a short questionnaire about their confidence in managing autistic patients across the lifespan, their use of the Autism HealthPathways and their satisfaction in using the Autism HealthPathways (if used). Due to the anonymous nature of the Phase one questionnaire, it was not possible to recontact health professional participants to complete the evaluation or match previous responses. The evaluation was difficult due to COVID-19. Sixteen health professionals completed the evaluation questionnaire with only one participant having used the Autism HealthPathways in



clinical practice. All other health professionals viewed the suite as part of completing the questionnaire.

In terms of experience working with autistic patients, 50% of participants reported limited experience working with children and young people with 75% of participants having limited experience working with adults. This group of participants were more confident working with autistic patients than the participants who completed the first questionnaire.

Over 50% of participants reported feeling confident across all age groups. Like the pre-implementation questionnaire pre-Autism HealthPathways, health professionals lacked confidence regarding their knowledge of local referral pathways post autism diagnosis with 75%, 75% and 87% reporting limited to no confidence for children, young people and adults respectively. One participant had previously viewed the Autism HealthPathways, looking at the Autism Pathways for children. The participants who had not used the Autism HealthPathways prior to the questionnaire reported they hadn't been aware of the suite, had not yet needed to look at them, or had not had the time.

#### **Conclusions**

This project developed the first HealthPathways for the management of autistic patients across the lifespan. A key element in the development and implementation of the Autism HealthPathways was the amount of stakeholder engagement and promotion undertaken. Two education sessions were provided, with the aim to ensure a high level of stakeholder engagement from local health professionals was maintained during the project lifecycle. The autism-specific education sessions reinforced a reciprocal communication mechanism. This provided local health professionals with resources and education, while allowing the project team to source valuable feedback from the participating health professionals using surveys, discussions and whiteboard exercises. The Autism HealthPathways are now accessible online via Mackay HealthPathways with 243 GPs based in the Mackay HHS region, being able to access these valuable resources.

At the completion of this project, it was identified that the next steps should be to:

- develop an Autism HealthPathways sharing agreement between Autism CRC and Streamliners to enable widespread uptake of the Autism Pathway suite
- share all study resources developed for the purpose of the Mackay HealthPathways Autism
   Initiative with other HealthPathways regions including questionaries, promotional and
   communication materials to enable additional research and quality activities as an expansion of
   the original study



 upload the Mackay HealthPathways go live symposium video education resources and interviews onto Mackay HealthPathways for sharing with the greater HealthPathways community to enhance education opportunities and promotion.

Since the completion of this project an agreement between Autism CRC and Streamliners means that Autism HealthPathways are now available for adoption and adaptation in 43 health regions, caring for more than 28 million people across Australia, New Zealand and the United Kingdom.

To ensure the Autism HealthPathways suite continue to be a useful resource for health professionals, there needs to be ongoing evaluation as the different sites take up the HealthPathways so it can be continually refined to meet the needs of the local health professionals. Additionally, the suite needs to be regularly reviewed, as per standard HealthPathways protocol, to ensure the content is up-to-date and in line with current best practice.

# 2. Introduction

HealthPathways is a web-based health information site, developed by Streamliners NZ, which assists clinicians to guide patients through the complexities of the health system. HealthPathways provides support to clinicians, mainly general practitioners (GPs), for assessing and managing patients with the inclusion of appropriate tools and resources and provides clear referral pathways for the local area.

#### To date there are:

- 32 HealthPathways sites in Australia.
- 11 HealthPathways sites in New Zealand.
- 3 HealthPathways sites in the United Kingdom.
   (For the full list of regions see <a href="https://www.healthpathwayscommunity.org/">https://www.healthpathwayscommunity.org/</a>)

Within the Australian primary health care sector, specifically in general practice, there is a deficit of evidence-based knowledge and understanding of the lifespan health care needs of people on the spectrum.<sup>1,2</sup>

#### Consequently, there is:

- a lack of consistent management guidelines and standards.
- limited follow up of physical, mental/emotional and oral health issues.
- limited support for GPs available in a single point/pathway.



- limited professional development opportunities for regional, rural and remote GPs in the area of autism.
- no established or emerging Cycle of Care (an annual cycle of care is a detailed set of patient management steps that GPs can claim through Medicare) to support appropriate preventative health assessments for people on the spectrum.

Autism is a lifelong condition, in 2018 the ABS recorded 205,200 Australians on the autism spectrum, a 25.1% increase from the 164,000 recorded in 2015<sup>23</sup>, with the numbers of adults presenting with the condition increasing.<sup>5</sup> However, increasing demand for autism identification and support is not matched with correlating education and awareness in health professionals, leaving a large gap in quality provision of services.<sup>6</sup>

# 2.1 Current Health Care Gaps

## 2.1.1 A lack of consistent management guidelines and standards

Internationally, the UK provides a guideline outlining recommendations on identification, assessment and intervention for the management of autistic people. This guideline provides direction to health care professionals world-wide in the care of autistic adults. Likewise, Scotland has established guidelines which have been adopted globally to ensure consistency and best practice methods are used for the recognition and treatment of children and young people with autism.8 In Australia, there has been significant work undertaken by Autism CRC regarding the early identification and intervention of children and young people, however, there remains limited guidance across the entire lifespan. At the commencement of the study, Australia had not developed minimum national standards in the assessment and support of autism, which has been recognised as a national priority to improve early intervention and outcomes for people on the autism spectrum9. However, in 2018 Autism CRC released The National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders is the first unified approach to the assessment and diagnosis of autism in Australia. The Guideline defines clinical best practice and a new diagnostic standard. It aims to make the practice of assessing and diagnosing autism clearer and more consistent throughout the country so that individuals and their families receive the best possible care.

## 2.1.2 Limited knowledge and experience in providing care to autistic patients

Kamp-Becker et al.<sup>10</sup> identifies that although autistic adults are recognised as having a lower quality of health, there have been few studies completed across the lifespan to quantify this. In a



retrospective study, adults on the spectrum experienced higher rates of hypertension, hyperlipidaemia, obesity and diabetes.<sup>11</sup> Unigwe et al.<sup>12</sup> found in their UK study that GPs reported limited confidence in managing their autistic patients and a desire for further training on autism. Knowledge of the impact of autism on physical and oral health varies and the content taught to health professionals in their training varies by profession, university and country. Imran et al.'s<sup>13</sup> survey of baseline knowledge of autism in health care professionals in Pakistan determined a poor understanding of the condition, many having the misconception autism can be outgrown. It was also revealed allied health interventions such as speech therapy would unlikely be recommended to the patient and family. Likewise, Rahbar et al.'s<sup>14</sup> survey of 348 GPs in Pakistan established less than 50% had heard of autism and held many misconceptions regarding identification and management. The Centre of Population and Urban Research at Monash University reports there is no formal assessment process of overseas trained doctors to identify if they have the skills and knowledge to manage specific needs of the Australian population, <sup>15</sup> and many of these doctors are used to satisfy hard to fill regional and remote Australian positions.

In 2020, Urbanowicz et al.<sup>16</sup> published an Australian study to describe the experiences, views, and needs of health professionals providing care to adults on the spectrum. The study comprised of 78 health professionals of which 42 were from disability-specific or autism-specific settings across Australia. The health professionals who participated completed an online survey designed to capture their experience in providing health care to adults on the autism spectrum. The results of the study highlighted two-thirds of the health professionals strongly agreed or agreed they felt knowledgeable (63%) and strongly agreed or agreed they felt competent (62%) in providing care to this population.<sup>16</sup> Fifty-nine percent strongly agreed or agreed they felt confident in providing care to adults on the autism spectrum. A higher proportion of health professionals working in disability-specific or autism-specific settings strongly agreed or agreed to feeling competent, knowledgeable, or confident, or any combination of these three variables, providing care to autistic adults in comparison to professionals not working in these settings.<sup>16</sup> It was also identified over 80% of the participants would appreciate access to further training, particularly in behaviour and mental health management and communication.<sup>16</sup>

# 2.1.3 Limited support for GPs available in a single point/pathway

It has been identified children are diagnosed at a later age in regional and remote areas of Australia<sup>9</sup> which is inconsistent with best practice of early identification and intervention. Tonge & Brereton<sup>17</sup> affirm GPs are vital in surveillance for signs of autism, and completion of screening and first line assessment. Garg et al.'s<sup>1</sup> survey of GPs in NSW identified the need for established,



comprehensive pathways in the management of autism. Additionally, local referral pathways would assist early treatment and support.

# 2.1.4 Limited professional development opportunities for regional, rural and remote GPs in the field of autism

Havercamp et al.<sup>18</sup> in their analysis of the effectiveness of integrating autism training in medical students' curriculum discovered training positively influenced participant's knowledge of autism and ability to work with autistic patients. However, variances in training, particularly in country of origin, lead to inconsistency in knowledge amongst health providers.<sup>13,14</sup> Furthermore, GPs outside of metropolitan areas are impacted by isolation, requiring an integrated approach to professional development to optimise access.<sup>19</sup> To date, there are very few formal educational activities for GPs in Australia focussing on autism identification and support.<sup>2</sup>

# 2.1.5 Lack of established or emerging Cycle of Care to support preventative health assessments for people on the spectrum

Needs of autistic people change over the life cycle, and GPs would benefit from a framework to identify needs specific to the developmental stage.<sup>2</sup> Similar to a Diabetes Annual Cycle of Care,<sup>20</sup> autistic people would benefit from a checklist to ensure future health problems are prevented. Likewise, an Annual Cycle of Care promotes client self-efficacy, while prompting GPs and other treating health professionals to referral pathways and supports relevant to autism.<sup>20</sup> Once an autism cycle of care is identified, all members of the multidisciplinary care team will better understand appropriate development of a general practice management plan (GPMP) and team care arrangement (TCA) to provide better healthcare access.<sup>21</sup>

Therefore, in order to address this gap, the Mackay HealthPathways Autism Initiative aimed to assist in the health management of children, adolescents and adults on the spectrum through the development of child/adolescent and adult HealthPathways for the Mackay Region and a long term aim to share content across the national and international HealthPathways community.

Specifically, the study objectives were to:

- 1. understand the barriers and enablers to the provision of health care to children, adolescents and adults on the spectrum.
- 2. develop and implement evidence-based clinical care pathways for children/adolescents and adults on the spectrum.
- 3. evaluate health professional satisfaction with the pathway.



The Autism HealthPathways for children, adolescents and adults on the spectrum were developed in accordance with established HealthPathways governance processes, which consisted of four phases:

- 1. development of work and advisory groups
- development of draft Autism HealthPathways for children, adolescents and adults on the spectrum
- 3. development and implementation of the final Autism HealthPathways
- 4. evaluation of the Autism HealthPathways.

The study also involved four participant groups: work groups, advisory groups, feedback participants and evaluation participants. Work groups and questionnaires were used to collect data on the barriers and enablers for the provision of health care to individuals on the spectrum and to evaluate health professional satisfaction with the Autism HealthPathways. The HealthPathways Administration System (DOT) was used to collect feedback data on the draft Autism HealthPathways.

# 3. Research Design and Methods

The Autism HealthPathways for children, adolescents and adults on the spectrum were developed in accordance with established HealthPathways governance processes. This process consisted of four phases:

# 3.1 Phase One - Development of work and advisory groups

The first phase of the study involved the development of two distinct groups; a work group and an advisory group.

The **work group** was split into two groups and included local health professionals in group one and children, adolescents and adults on the spectrum and/or their caregivers in group two.

The local health professional work group was held on the 23 May 2018 with 36 participants across varying disciplines (medical, nursing, allied health and other health related professionals). The health professional work group commenced with viewing an online Autism TEDTalk, followed by an overview of the Autism Initiative Research Project by project leads. The work group concluded with a brainstorming exercise discussing and exploring healthcare barriers and enablers within the local context.



In addition to the health professional work group evening, 19 local health professionals (medical, nursing, allied health and other health related professionals) completed a questionnaire to gain insight into confidence levels in their management of the health and wellbeing factors associated with Autism. Information captured from the local health professional work group and the completed questionaries were collated and used to inform the Autism HealthPathways development.



The second work group was comprised of local consumers including autistic individuals and their caregivers. Input was sought from consumers in two ways: 1) discussions with consumers at local autism events and support groups and 2) questionnaires completed by consumers. The questionnaires provided consumer experiences in receiving care in the local context which was completed by a total of nine consumers.





Health professionals and individuals on the spectrum and/or their caregivers were given the opportunity to participate and provide their perspective regarding the barriers and enablers associated with the provision of health care delivered to people on the spectrum in the local context.



Their perspective was paramount to the development of effective clinical care pathways and assisted to mitigate the risk of utilising assumptions.

A series of questionnaires were developed to allow individualised input from health professionals, adolescents and adults on the spectrum and/or their caregivers. For example, health professionals were asked to identify areas of practice they felt confident/not confident in, whereas these questions were not included in the children, adolescents and adults on the spectrum and/or their caregivers. Descriptive statistics were used to analyse participant demographics and responses.

Data collected for this study was directly sourced from the participant or from the participant's caregiver. Additionally, this study contained no personal data (e.g. address, DOB etc. was not collected or recorded) and all questionnaires and notes recorded were de-identified and placed in an electronic database which was password protected and stored on a secure server.

The **advisory group** comprised of subject matter experts (health professionals specialising in the field of autism, health professionals on the spectrum and family/caregivers of those on the spectrum) and a GP clinical editor (GP responsible for all content in the HealthPathways). The advisory group was instrumental in developing the Autism HealthPathways and was guided by the perspectives provided by the work group participants.

# 3.2 Phase Two - Development of draft clinical care pathways for autism (Autism HealthPathways)

The second phase of the study involved the creation/development of the draft Autism HealthPathways. This work was produced by the advisory group/project team. The advisory group/project team relied on a variety of data sources to inform the development of the drafts including:

- review of existing national and international resources
- notes captured from the Health Professional Autism working group discussion
- completed questionnaires from health professionals and consumers establishing the barriers and facilitators to primary health care for individuals on the spectrum across the lifespan.

# 3.3 Phase Three - Development and implementation of the final Autism HealthPathways

The third phase of the study involved the upload of the draft Autism HealthPathways onto the Mackay HealthPathways draft site which prompted a two-week feedback period. The two-week



feedback period gave over 300 health professionals access to review the draft Autism HealthPathways. To provide consistency within the study, any health provider who participated in the health professional work group was sent a personal invitation to review the draft Autism HealthPathways.

The feedback provided by participants was crucial in further developing the draft Autism HealthPathways as it involved input, involvement and local perspective for the pathway drafting process. This ensured the pathways were applicable to the local area prior to the Autism HealthPathways being finalised and released (go live) on the HealthPathways platform for use within the local community.

The HealthPathways Administration System (DOT) was used to collect the feedback data. This database platform enables tracking of processes, management of feedback, scheduling of reviews/partial updates and reporting. All feedback is captured within one database, which the HealthPathways team uses to manage and track the pathways. When pathway feedback has been received, reviewed, and actioned, the process is set to "complete". This process is finalised, and a record of the draft process remains in the database and forms part of the development and maintenance history of the HealthPathways.

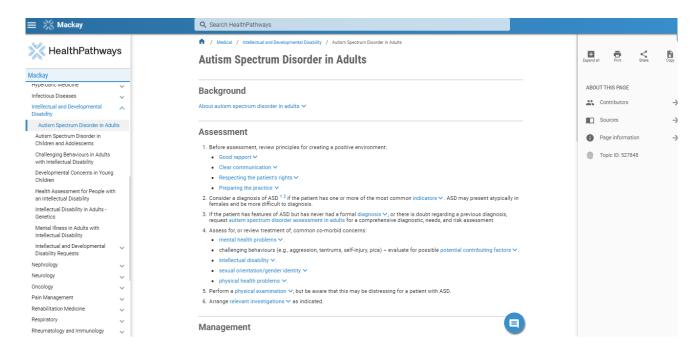
Once all feedback was incorporated into the final Autism HealthPathways and approved by the advisory group/project team, the Autism HealthPathways were published on the live site and a notification of the new HealthPathways posted on the Mackay HealthPathways home page.

On the 18 July 2019 the following new HealthPathways were developed, existing supporting pathways localised and published to the live Mackay HealthPathways site:

- Autism Spectrum Disorder in Adults
- Autism Spectrum Disorder in Children and Adolescents
- Adult Disability Support
- Autism Spectrum Disorder Assessment in Adults
- Autism Spectrum Disorder Support
- Challenging Behaviours in Adults with Intellectual Disability
- Health Assessment for People with an Intellectual Disability
- Intellectual Disability in Adults Genetics
- Mental Illness in Adults with Intellectual Disability



Figure 1: Screenshot of Mackay Autism Spectrum Disorder in Adults HealthPathways



To support the go live of these valuable resources, a local education and pathway promotional event was coordinated for 31 August 2019. "The Spectrum - though their eyes, through their lives" symposium was a free half day education event open to all health professionals, with an aim to clarify autism health management within the primary care context.

The event was supported with four presentations:

- Ms Anne Crowley Lived experience.
- Dr Michalis Yiallourides Early intervention in the autism spectrum.
- Dr James Best The fecundity of the unexpected autism, adolescence and Africa.
- Assoc. Prof. David Harley Anti-psychotic and anti-depressant medication in adults on the spectrum.





Additionally, numerous communications were arranged at the time of the Autism HealthPathways go live including:

- local media interviews with television and radio broadcasters.
- articles in local newsletters Integrated Health newsletter with over 300 subscribers, Mackay
   HHS newsletter and Northern Queensland PHN newsletter.
- article in the International HealthPathways Community newsletter.

The Northern Queensland Primary Health Network (NQPHN) kindly funded a videographer for the education event which captured the entire event and semi-structured interviews pre-event involving key project members and local GPs. The purpose of these recordings was to load the presentations and interviews onto the Mackay HealthPathways platform as an education opportunity and to share across the greater HealthPathways Community.

Since the go live of the Autism HealthPathways, pageviews/utilisation has been tracked and monitored using Google Analytics. Usage during the last quarter of 2019 post go live event was exceptionally positive and during this period the Autism pathways were in the top ten accessed HealthPathways. Further review and analysis of the full Google Analytics data will be discussed in the Findings section of this report.

A follow-up of the Autism HealthPathways use in General Practice was originally planned to commence in the first quarter of 2020, however this was severely impacted by the global pandemic which later affected utilisation and evaluation data.

# 3.4 Phase Four - Evaluation of the Autism HealthPathways

The final phase of the study involved evaluating health professional (predominantly General Practitioner) satisfaction with the Autism HealthPathways. Local health professionals were asked to complete a short questionnaire regarding their:

- confidence in managing the health and wellbeing factors associated with autism.
- use of the Autism HealthPathways.
- satisfaction in using the Autism HealthPathways (if used).

Evaluation participants provided key information to help determine the effectiveness of the Autism HealthPathways in improving the patient's journey through a complex healthcare system. As highlighted previously, post event appointments and evaluations were severely impacted by the global pandemic. A total of sixteen evaluations were successfully completed however limited usage



of the pathways was identified. Full analysis of the findings will be detailed further in the Findings section of this report.

The evaluation of the Autism HealthPathways will form part of the Mackay HealthPathways program and continue to be reviewed and updated as required to ensure effectiveness in supporting care and appropriate referral pathways.

# 4. Findings

Questionnaires completed by local health professionals and local support groups, as well as notes from the forum discussion, were used to collect data on the experiences of provision of health care to individuals on the spectrum. Additional questionnaires were completed by health professionals to evaluate satisfaction with the Autism HealthPathways. The number of health professionals who have attended the various educational sessions delivered throughout this project are also reported and the number of times the Autism HealthPathways have been utilised. Data was analysed using descriptive statistics and thematic analysis where appropriate.<sup>22</sup>

# 4.1 Understanding the current experiences of the provision of health care to autistic people

As part of Phase One, autistic people (n=2), caregivers (n=7) and health professionals (n=19) completed questionnaires about their experiences of the provision of health care to autistic people. The questionnaire asked about the diagnostic process, support post diagnosis, self-reported general health and wellbeing (autistic participants and caregivers only) and health professionals experience and confidence working with autistic patients.

The autistic people were adults and just over half of the caregivers were reporting on supporting a child or young person on the spectrum. One adult and two of the children also had an intellectual disability. Most of the health professionals where Caucasian and female with a mix of professions (see Table 1).



Table 1: Demographics of autistic participants, their caregivers and health professionals included in Phase One

	Autistic po	eople (N=9)	Health professionals (N=19)		
	Reported by autistic person (N=2) n (%)	Reported by carer (N=7) n (%)	n (%)		
Age (years)					
0-7	-	1 (14%)	-		
8-17	-	3 (43%)	-		
18-24	1 (50%)	3 (43%)	2 (10%)		
25-34	1 (50%)	-	3 (16%)		
35-54	-	-	6 (32%)		
55+	-	-	8 (42%)		
Gender					
Female	1 (50 %)	3 (43%)	14 (74%)		
Male	1 (50 %)	4 (57%)	5 (26%)		
Ethnic background					
Caucasian	1 (50.00%)	6 (86%)	1 (79%)		
Aboriginal and Torres Strait Islander	-	1 (14%)	-		
Asian	1 (50.00%)	-	4 (21%)		
Relationship to autistic individual					
Parent	-	6 (86%)	-		
Sibling	-	1 (14%)	-		

Health professionals mostly worked full time and had been practicing for an average of 18.2 years (SD 14.8). The majority of health professionals worked in a practice or organisations with twenty or more other health professionals. Only 39% of health professionals reported working with adults. Health professionals reported between 1-25% of their patients were on the autism spectrum, with between 1-25% of these patients having a co-occurring intellectual disability. Only 18% of health professionals had completed autism or intellectual disability training (see Table 2).



Table 2: Clinical experiences of health professionals in Phase One

	Health professionals (N=19) n (%)	
Health profession		
GP	3 (16%)	
Nurse	5 (26%)	
Paediatrician	3 (16%)	
Allied health	8 (42%)	
Employment status		
Full time	10 (55%)	
Part time	7 (39%)	
Not currently working	1 (6%)	
Size of practice		
Alone	1 (6%)	
2-5 other health professionals	3 (18%)	
6-10 other health professionals	2 (12%)	
11-20 other health professionals	3 (18%)	
20+ other health professionals	8 (47%)	
No response	2 (12%)	
Age (years) of patients (multiple responses)		
0-7	16 (89%)	
8-17	15 (83%)	
18+	7 (39%)	

Over 50% of health professionals reported limited experience to no experience working with autistic patients. This was more pronounced for adult patients, with 82.35% of health professionals reporting limited to no experience working with autistic adults. This was a similar trend for confidence working with autistic patients; health professionals had more confidence working with children and young people than adults (see Figure 2).





Figure 1: Confidence levels of health professionals working with autistic patients by age group, in Phase One

# 4.2 Diagnosis experiences

# 4.2.1 Autistic people and caregivers

For autistic individuals (n=2) and caregivers (n=7), the reported length of time to get a diagnosis ranged from two months to three years with children diagnosed from four to seven years old and the only participant to be diagnosed as autistic in adulthood was diagnosed at 38 years old. The majority (86%) of participants reported they were given a formal report of their autism diagnosis. Looking to the quality of information about autism given at diagnosis, only 25% and 12.5% of participants were respectively satisfied or very satisfied.

A diagnosis helped family members to understand the individual and led to support services like therapy services and school support:

"As soon as I understood what was going on, we were able to help him" (caregiver to son aged 18)

The autistic individual diagnosed as an adult also found support and acceptance from the autistic community.

When asked to rate the diagnostic process on a scale from no stress to major stress, 37% of participant's rated the experience caused major stress. It was an emotional process which was draining on relationships and financially (travel, time off work to travel, cost of health professional). Participants reported they had to draw on an existing skill set (e.g., as a childcare worker) to assist with the process. For those outside the child sector and health sector, they struggled to find information. There was a clear lack of appropriate and accessible services in the Mackay region,



with one family choosing to fly to Brisbane rather than wait to see a local paediatrician. Related to this, participants reported they had to pay for timely services with professionals experienced with autism, with one participant recommending to "pay the money to see the best" and another to "follow your gut" when choosing professionals or seeking out second opinions. Once diagnosed, participants needed information on what that meant for their child and how to best support their child. For those in rural and remote areas, it was important to consider how to do this in a cost-effective way and considering the wider family context (e.g., if needing to spend time travelling).

Post diagnosis support varied. Two participants were not referred to anyone after their diagnosis with the most common referrals to occupational therapists, speech pathologists and local support groups by their GP. Over 85% of participants took it upon themselves to organise support post diagnosis, often seeking out physiotherapists, occupational therapists and psychologists.

## 4.2.2 Health professionals

For health professionals (n=19), only two occupational therapists and three paediatricians utilised diagnostic tools, with none of the GPs using any formal tools. Eight nine percent of health professionals reported they would refer a child whom they suspected to be autistic to a paediatrician and 53% would refer an adult to a psychiatrist. However, over 30% of health professionals did not know who to refer an adult patient to for a diagnosis.

Almost 60% of health professionals reported a clearer pathway to diagnosis, like utilising the HealthPathways platform, would have made the referral process easier when supporting their patients seeking a diagnosis. Health professionals would also like to see better communication between services and health professionals (e.g., monitoring observations, updates on test results). There was also a need for education on the diagnosis process, knowing about local services and their wait times.

When asked about their role in providing support post autism diagnosis, 41% of health professionals reported their role was to coordinate care or follow up on aspects of their patient's health. The three GP participants all reported they would commence their patient on a GP management plan post diagnosis. Thirty five percent of health professionals also saw advocating and referring to support groups as part of their role post autism diagnosis.

Health professionals lacked confidence regarding their knowledge of local referral pathways post autism diagnosis with 58%, 72% and 87% reporting limited to no confidence for children, young people and adults, respectively. Health professionals also had low levels of confidence about their



understanding of assistance or services available to autistic people with 63%, 61% and 94% reporting limited to no confidence for children, young people and adults, respectively.

# 4.3 Health care utilisation, provision and barriers

# 4.3.1 Autistic people and caregivers

Participants self-rated or their caregivers rated their health as good or excellent with only one participant rating their health as fair. Almost all the participants had a regular GP with one participant looking for a new GP after recently moving. Participants saw their GP between zero times a year up to 20 twenty times a year (mean five visits, median three visits). Some participants were also currently seeing a paediatrician, psychiatrist or occupational therapist.

When asked about how well their GPs were able to accommodate their needs, 78% of participants reported their GP did this very well or well. This dropped slightly for specialists, with 67% of participants reporting their specialists did this very well or well.

Participants also reported several barriers to specialist services. For autistic adults or caregivers of autistic adults, they found services and supports stopped when the individual turned eighteen or left school. Additionally, there was a lack of experienced psychiatrists in the area which resulted in one participant not being able to have their medication changed, as the GP wanted further input. Caregivers of children and young people also reported a lack of paediatricians and psychologists who were experienced with autism and accessible without long wait times or high costs. Being in a rural or remote area also added to these barriers with reduced access to specialists and services, longer waiting times, and people required to travel long distances to receive care.

# 4.3.2 Health professionals

Across the lifespan, health professionals identified key barriers around a lack of services and long wait times. They were concerned with referring to the right services and having their patients seen in a timely manner. Specifically, in children, GPs recognised that their concerns may not align with the parents and balancing advice around "allowing parents to 'parent' in their own way" was a challenge. Arising from the brainstorming discussion as part of the working group, health professionals (n=36) saw education for patients, clearer diagnosis processes, communication and the continuity of care as key areas of need. For adolescents, health professionals reported coordination issues, especially around diagnosis, and the lack of support within the school system both in terms of supporting the student and the teacher. Health professionals also saw a need to start transition planning for adult services. In adults, health professionals acknowledged the



complexity of many of these patients, often who have multiple diagnoses or a misdiagnosis. They saw a need for support for families and a need to work on National Disability Insurance Scheme (NDIS) service provision.

Overwhelming, when asked what would improve service provision in the Mackay region, health professionals wanted improved access to diagnosis and services (e.g., shorter wait times, no-low cost services, services for adults). Health professionals also wanted more education and confidence building activities around autism across the lifespan and more support groups for adults and families.

# 4.4 Satisfaction with Autism HealthPathways

Due to COVID-19, evaluation of the Autism HealthPathways was difficult. Due to the anonymous nature of the Phase one questionnaire, it was not possible to recontact health professional participants to complete the evaluation or match previous responses. Sixteen health professionals completed the evaluation questionnaire with only one participant having used the Autism HealthPathways in clinical practice. All other health professionals viewed the suite as part of completing the questionnaire. The questionnaire asked questions about health professionals experience and confidence working with autistic patients, their usage of the Autism HealthPathways and their perceptions on the utility of the HealthPathways.

Health professionals were mostly aged between 35 and 54 years, female and Caucasian. Most participants where GPs, worked full time and had been practicing for an average of 17.1 years (SD 11.8). Unlike participants who completed the first questionnaire, the majority of health professionals worked across the lifespan with only one participant not working with children. Additionally, most health professionals worked in smaller practices or organisations with 6 to 10 other health professionals, compared to the majority of participants in the first questionnaire who worked in organisations with 20 other health professionals. Health professionals reported between 1-25% of their patients were on the autism spectrum, with between 1-25% of these patients having a co-occurring intellectual disability. Only 13% (n=2) of health professionals had completed autism or intellectual disability training (See Table 3).



Table 3: Clinical experiences of health professionals in Phase Four

	Health professionals (N=16) n (%)
Age range	
18-24	-
25-34	4 (25%)
35-54	6 (38%)
55+	6 (38%)
Gender	
Female	12 (75%)
Male	4 (25%)
Ethnic background	
Caucasian	15 (94%)
Asian	1 (6%)
Health profession	
GPs	12 (80%)
Nurses	3 (20%)
Employment status	
Full time	11 (69%)
Part time	5 (31%)
Size of practice	
Alone	-
2-5 other health professionals	2 (13%)
6-10 other health professionals	8 (50%)
11-20 other health professionals	5 (31%)
20+ other health professionals	1 (6%)
Age (years) of patients (multiple responses)	
0-7	15 (94%)
8-17	15 (94%)
18+	16 (100%)

In terms of experience working with autistic patients, 50% of participants reported limited experience working with children and young people with 75% of participants having limited experience working with adults. This group of participants were more confident working with autistic patients than the participants who completed the first questionnaire. Over 50% of participants reporting feeling confident across all age groups. Similar to the health professional



participants in Phase One, health professionals lacked confidence regarding their knowledge of local referral pathways post autism diagnosis with 75.00%, 75.00% and 87.50% reporting limited to no confidence for children, young people and adults respectively (see Figure 3).



Figure 2: Confidence Levels of Health Professionals working with autistic patients by age group, in Phase Four

One participant had previously viewed the Autism HealthPathways, looking at the Autism Pathways for children and commented they would utilise the Pathway again in the future. The participants who had not used the Autism HealthPathways prior to the questionnaire reported they hadn't been aware of the suite, had not yet needed to look at them, or had not had the time. All participants were demonstrated the Autism HealthPathways Suite post completion of the evaluation questionnaires with positive verbal feedback received about the resources.

# 4.5 Usage of Autism HealthPathways

Since the go live of the Autism HealthPathways, page views/utilisation has been tracked and monitored utilising google analytics. Page view counts do not necessarily reflect the number of health professionals viewing the pages as the same professional could of access the pages multiple times. Usage during the last parts of 2019 post go live event was exceptionally positive and during this period the Autism HealthPathways were in the top ten HealthPathways used. Usage dropped off over the 2019-2020 Christmas period and continued to decline due to COVID-19. Since July 2020, there is an upwards trend of primary health care professionals accessing the Autism HealthPathways. Since launch, the Autism HealthPathways have been used just under 2,000 times as of 31 December 2020 (see Table 4).



Table 4: Usage of the Autism HealthPathways Suite

Pathways titles	Jun – Dec 19	Jan – Jun 20	Jun – Dec 20	Total
Autism Spectrum Disorder in Adults	266	50	89	405
Autism Spectrum Disorder in Children and Adolescents	334	78	147	559
Challenging Behaviours in Adults with Intellectual Disability	63	18	35	116
Health Assessment for People with an Intellectual Disability	39	26	25	90
Intellectual Disability in Adults - Genetics	26	8	36	70
Mental Illness in Adults with Intellectual Disability	51	15	31	97
Adult Disability Support	48	45	70	163
Autism Spectrum Disorder Assessment in Adults	81	18	64	163
Autism Spectrum Disorder Support	56	18	66	140
Total	964	276	563	1803

As of 31 December 2020

#### 4.6 Attendance at educational sessions

Mackay health professionals had the opportunity to attend educational sessions throughout this project.

The Autism Pathways Symposium in August 2019 attracted 65 (GPs, Specialists, Nursing, Allied Health and Education staff) attendees with exceptional feedback received on the post-event evaluation survey. Thirty-two attendees completed the post-event evaluation survey and when asked if the session was relevant to their practice/profession 62% stated entirely relevant. Fifty three percent of attendees felt the session entirely met their overall learning needs on this subject. The post event evaluation survey also assisted to determine additional interest areas for future events see Table 5.

Table 5: Five most common interest areas for future autism educational events

Topic	Attendee responses (N=31) N (%)
Autism screening & appropriate referral for further assessment	23 (74%)
Autism assessment & diagnosis process	22 (71%)
Autism in adulthood – health & welling	21 (68%)
Transition to adulthood – employment & community participation	20 (65%)
Inclusive education practices for schools	16 (52%)



Overall feedback and comments captured on the post-evaluation survey as follows:

"Fantastic series of speakers with rich information shared with the audience"

"This was a brilliant professional development event, with a range of quality content and speakers"

"Excellent information and delivery, the sharing of personal experience of family members with Autism assisted the engagement with the information and enhanced my empathy and compassion for families who have experience with Autism"

"This was done very well, and I thoroughly enjoyed it. I think if I were to change anything, I would perhaps include an Allied health professional to expand on the referral process and other treatment modalities. The reason for this is so there is another point of view in what the treatment/management team would be. It was a great symposium and I cannot wait for the next one"

# 5. Limitations

Local engagement in the study was positive, however, it was identified questionnaire completion rates were poor, particularly by GPs. Multiple strategies were implemented to improve completion rates including face-to-face engagement, however this still produced limited participation and it is well known that recruiting GPs to research is extremely difficult.<sup>3</sup>

To mitigate the poor completion rates, the final evaluation questionnaire was converted to a semi-structured interview style evaluation which was reviewed and approved by the Townsville Hospital and Health Service Human Research Ethic Committee. The approval of the semi-structure interview was received in December 2019 with the intention of undertaking Autism HealthPathways engagement sessions with general practice in January 2020 prior to arranging evaluation sessions. Unfortunately, January 2020 saw the start of the COVID-19 global pandemic which severely impacted all engagement and evaluation activities for this study.

During 2020 we saw a reduction in all face-to-face interactions and all remote communications, while education sessions and communications with health professionals become COVID-19 focused. This was also evident in our Google Analytics data. The entire COVID-19 HealthPathways suite became the most viewed pathways across local, national and international



HealthPathways sites. Therefore, due to the change in environment, it was decided to recommence the evaluation questionnaires as the main method to capture post-implementation data. A total of sixteen evaluation responses were collected in total, twelve of which were GPs. Only one GP had used the pathways with positive feedback and the evaluations gave the opportunity to demonstrate the suite to the additional eleven GPs. Consequently, with greater engagement outside of a pandemic environment we may have seen more usage and a positive change within the data.

# 6. Implications for Research Practice

The Mackay HealthPathways Autism Initiative allowed for the first known evidence-based clinical care HealthPathways to be developed and implemented for people on the spectrum across their lifespan. The Autism HealthPathways gave health professionals access up-to-date and evidence-based information to assist their clinical decision-making. In the long term the aim is to ensure people on the spectrum receive high quality and consistent care, ultimately improving their health and wellbeing outcomes.

The development of the Autism HealthPathways for children/adolescents and adults on the spectrum has numerous benefits for the community including:

- improved understanding of the barriers and enablers to the provision of health care to people on the spectrum
- enhanced access to appropriate care for people on the spectrum within the Mackay region and greater HealthPathways community as a direct result of the development and implementation of clinical care pathways, which includes the delivery of autism education specific for primary care providers.

Mackay HealthPathways is part of a wider HealthPathways Community and consequently all HealthPathways will be shared across all regions under the permission of the Autism CRC. Currently there are 46 sites across Australia, New Zealand and the United Kingdom utilising HealthPathways with additional sites to sign up nationally and internationally. This would mean widespread implementation of the Autism HealthPathways throughout much of Australia and contribute greatly to the future utilisation of the health and wellbeing tools developed within the Autism CRC Programs. Furthermore, relevant tools and resources developed by Autism CRC Program can be integrated within the Autism Pathways allowing for greater uptake of Autism CRC tools and resources by health professionals across Australia.



Ultimately, if utilised, the primary care provided to people on the spectrum across Australia may be improved and an increase in health provider confidence.

# 7. Conclusion

This project developed the first HealthPathways for the management of autistic patients across the lifespan. A key element in the development and implementation of the Autism HealthPathways was the amount of stakeholder engagement and promotion undertaken. Two education sessions were provided, with the aim to ensure a high level of stakeholder engagement from local health professionals was maintained during the project lifecycle. The Autism specific education sessions reinforced a reciprocal communication mechanism. This provided local health professionals with resources and education, while allowing the project team to source value feedback from the participating health professionals using surveys, discussions and whiteboard exercises. The Autism Pathways are now accessible online via Mackay HealthPathways with 243 GPs based in the Mackay HHS region, being able to access these valuable resources.

**Note:** Since the completion of this project an agreement between Autism CRC and Streamliners means that Autism HealthPathways are now available for adoption and adaptation in 43 health regions, caring for more than 28 million people across Australia, New Zealand and the United Kingdom.

The key next steps from this study are to:

- share all study resources developed for the purpose of the Mackay HealthPathways Autism Initiative with other HealthPathways regions including questionaries, promotional and communication materials to enable additional research and quality activities as an expansion of the original study.
- upload the Mackay HealthPathways go live symposium video education resources and interviews onto Mackay HealthPathways for sharing with the greater HealthPathways community to enhance education opportunities and promotion.

To ensure the Autism HealthPathways suite continue to be a useful resource for health professionals, there needs to be ongoing evaluation as the different sites take up the HealthPathways so it can be continually refined to meet the needs of the local health professionals. Additionally, the suite needs to be regularly reviewed, as per standard HealthPathways protocol, to ensure the content is up to date and in line with current best practice.



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# **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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