



AutismCRC

# Mackay HealthPathways Autism Initiative

Autism HealthPathways

## EXECUTIVE SUMMARY

Ms Antoniette (Toni) Simmons

Dr Katie Brooker

Dr Anna Urbanowicz

Ms Emma Jean Moohin

Dr Aaron Kennedy

Associate Professor David Harley

April 2021



Australian Government  
Department of Industry, Science,  
Energy and Resources

**AusIndustry**  
Cooperative Research  
Centres Program

[autismcrc.com.au](http://autismcrc.com.au)

---

# Mackay HealthPathways Autism Initiative

## Autism HealthPathways

### EXECUTIVE SUMMARY

**Ms Antoniette (Toni) Simmons**

Mackay Hospital and Health Service

**Dr Katie Brooker**

QLD Centre for Intellectual and  
Developmental Disability | Mater Research  
Institute, University of QLD | Autism CRC

**Dr Anna Urbanowicz**

RMIT University | QLD Centre for Intellectual  
and Developmental Disability | Mater  
Research Institute, University of QLD

**Ms Emma Jean Moohin**

Mackay Hospital and Health Service

**Dr Aaron Kennedy**

Mackay Hospital and Health Service

**Associate Professor David Harley**

QLD Centre for Intellectual and  
Developmental Disability | Mater Research  
Institute, University of QLD | Autism CRC

**Project number:** Project 3.046RI

**ISBN:** 978-1-922365-26-2

**Citation:** Simmons, A., Brooker, K., Urbanowicz, A., Moohin, E.J., Kennedy, A. & Harley, D. (2021)  
Mackay HealthPathways Autism Initiative: Autism HealthPathways. Final Report. Brisbane. Autism  
CRC

Copies of this report can be downloaded from the Autism CRC website [autismcrc.com.au](http://autismcrc.com.au).

**Copyright and disclaimer**

The information contained in this report has been published by the Autism CRC to assist public knowledge and discussion to improve the outcomes for people on the autism spectrum through end-user driven research. To this end, Autism CRC grants permission for the general use of any or all of this information provided due acknowledgement is given to its source. Copyright in this report and all the information it contains vests in Autism CRC. You should seek independent professional, technical or legal (as required) advice before acting on any opinion, advice or information contained in this report. Autism CRC makes no warranties or assurances with respect to this report. Autism CRC and all persons associated with it exclude all liability (including liability for negligence) in relation to any opinion, advice or information contained in this report or for any consequences arising from the use of such opinion, advice or information.

---

## Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants – University of Queensland

### **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](http://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'.

---

## 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 participants 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 questionnaires, 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.

## References

1. Garg P, Lillystone D, Dossetor D, Kefford C, Chong S. An exploratory survey for understanding perceptions, knowledge and educational needs of general practitioners (GPs) Regarding autistic disorders in New South Wales (NSW), Australia. *Journal of Clinical and Diagnostic Research*. 2014;8(7):PC01-PC09.
2. Garg P, Lillystone D, Dossetor D, et al. A framework for developing a curriculum regarding autism spectrum disorders for primary care providers. *Journal of Clinical and Diagnostic Research*. 2015;9(10):SC01-SC06.

## 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

Guided by evidence based research, integrity and peer review



### Cooperation

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



AutismCRC

#### Autism CRC

The University of Queensland  
Long Pocket Precinct  
Level 3, Foxtail Building  
80 Meiers Road  
Indooroopilly Qld 4068

T +61 7 3377 0600

E [info@autismcrc.com.au](mailto:info@autismcrc.com.au)

W [autismcrc.com.au](http://autismcrc.com.au)



@autismcrc



Australian Government  
Department of Industry, Science,  
Energy and Resources

**AusIndustry**  
Cooperative Research  
Centres Program