



## **Autism CRC Health Hub**

# Online resources about Autism Spectrum Disorders for health professionals

### A snapshot of resources - for adults and health professionals

This guide was written in December 2014 by Dr Kate van Dooren<sup>1</sup>, Ms Cindy Nicollet<sup>2</sup> and Professor Nick Lennox<sup>3</sup>.

The purpose of this resource is to provide a brief overview of online resources for health professionals who want to build their understanding of and enhance their skills related to providing health care to adults with autism spectrum disorders (ASD). The aim is to equip health professionals with information that leads to the provision of high quality health-related care to adults with ASD.

This resource was developed through the Autism CRC project called *Tools, strategies and techniques developed to improve the health and wellbeing for adults with ASD*. This project aims to enhance health and wellbeing in adults with ASD and their families. It also focuses on providing better information to general practitioners, psychiatrists and other health professionals about the physical and mental health issues frequently associated with ASD.

#### Online resources for health professionals

Health professionals may access the Internet as a source of information about ASD, including how to improve their own delivery of high quality health care to adults with ASD. The Internet allows health professionals to reach out globally for educational resources and examples of best practice. However, finding relevant and high quality information may be difficult for health professionals if they are time poor or unfamiliar with autism-related websites.

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<sup>&</sup>lt;sup>2</sup> Ms Nicollet is a psychologist undertaking her PhD through (Autism CRC) and QCIDD

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#### What we did

We performed an online search on Google using keywords related to adults, autism and health to find resources for health professionals regarding adults and ASD. We read all relevant websites and briefly assessed the quality of the material they presented using three criteria, including whether: (1) the date of publication and (2) nominated date of review were provided on the site and (3) 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.

#### What we found

We describe the sites we found in the table below. There are far fewer websites for health professionals about adults with ASD than exist for children with ASD. Locating the websites listed in the table below required careful reading and review of websites, which would be time-consuming and burdensome for health professionals. Few sites listed the sources of information or date of production which makes it difficult to evaluate the usefulness, relevance or timeliness of information provided. However, 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 adults with ASD.

#### What this means

Adults with ASD 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 adults with ASD, 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 quality assess.

Information specific to Australians with ASD is scarce.

Very little specific advice for health professionals who work with adults with ASD is offered.

Importantly, none of the resources we found were produced by adults themselves. There is an urgent need for more (i) specific information for health professionals, (ii) information that is coproduced by adults, and (iii) Australian-specific information.

#### **Next steps**

As part of Program 3 of the Autism CRC, our team will use the information presented here, as well as discussions with adults with ASD and health professionals, to develop an online suite of health and wellbeing tools for adults with ASD and the health professionals who support them. We are also working with adults with ASD to conduct a more detailed quality analysis of these websites and to develop an easy-to-use tool for assessing the quality of online information. For more information about this project, please contact Dr Kate van Dooren at <a href="mailto:k.vandooren@uq.edu.au">k.vandooren@uq.edu.au</a>.



## Autism-related sites with information for health professionals

About the Site		Brief Indicators of Quality		
Author (Country)	Description	Date Produced	Nominated Date for Review	Lists sources of information used
Clearinghouses – compilations of re	sources relevant to health professionals			
Research autism (UK)	Research Autism – Improving the quality of life (researchautism.net) Publications, factsheets and reports	Yes	Yes	Yes
Wales Autism Research Centre (UK)	Autism Research Policy Practice Hub (autismrpphub.org) Articles and resources, group discussions	No	No	Yes
Academic Autistic Spectrum Partnership In Research and Education (AASPIRE) (USA)	Health toolkit: Partnering with Autistic Adults to Develop Tools to Improve Primary Healthcare (Autismandhealth.org)  These primary care resources aim to improve healthcare access and quality for people on the autism spectrum, and also has information for health professionals.	Yes	No	No
Mental Health Needs				
Australian Psychology Society (Australia)	Understanding and Managing ASD (psychology.org.au/publications/tip_sheets/autism/#s8) Targets psychologists with a standalone webpage that includes information on assessment and treatment as well as 'tips' for practice	Yes	No	No
Royal College of Psychiatrists (UK)	Good practice in the management of autism (including Asperger Syndrome) in adults (rcpsych.ac.uk/ usefulresources/publications/collegereports/cr/cr191.aspx)  Standards of care for adults written primarily for psychiatrists other than those in the specialties of intellectual disability and child and adolescent psychiatry	Yes	Yes	No
National Autistic Society (UK)	Mental health and Asperger Syndrome (autism.org.uk/working-with/health/mental-health-and-asperger-syndrome.aspx)  Article concentrating on mental health in people with high-functioning autism or Asperger syndrome although references will be made to autism per se where appropriate. Emphasis on depression, anxiety and obsessive compulsive disorder.	No	No	Yes
Health Care Needs				
National Institute for Health and Clinical Excellence (United Kingdom)	Autism: recognition, referral, diagnosis and management of adults on the autism spectrum (nice.org. uk/guidance/CG142)  Online, evidence-based, printable guides on guidance, tools and resources for health professionals and members of the public	Yes	Yes	Yes



About the Site		Brie	Brief Indicators of Quality		
Author (Country)	Description	Date Produced	Nominated Date for Review	Lists sources of information used	
University of Washington and Washington State Oral Health Program (USA)	Oral health fact sheet for dental professionals: Adults with ASD (depts.washington.edu/sodent2/wordpress/wp-content/media/sp_need_pdfs/Autism-Adult.pdf) Online printable PDF for dental professionals describing prevalence, manifestations and management	Yes	No	No	
National Autistic Society (UK)	Dental care and autism (autism.org.uk/working-with/health/information-for-dentists.aspx) Information for dentists about treating patients with an autism spectrum disorder (ASD) including a leaflet to help people with an ASD and dental teams to prepare for a dental visit	No	No	No	
National Autistic Society (UK)	Guidance for eye care professionals (autism.org.uk/working-with/health/guidance-for-eyecare-professionals.aspx)  Printable page providing guidance for eye care professionals about treating patients with autism, and is written by eye care professionals who work with individuals on the autism spectrum	Yes	No	No	
Adapting the clinical environment	, communication and attitude change				
National Autistic Society (UK)	Patients with ASD: guidance for health professionals (autism.org.uk/working-with/health/patients-with-autism-spectrum-disorders-guidance-for-health-professionals.aspx) Printable pages outlining appointments, communication, examinations, sensory issues	Yes	No	Yes	
National Autistic Society (UK)	Top transition tips for mental health professionals (autism.org.uk/working-with/health/top-transition-tips-for-mental-health-professionals.aspx)  Tips for working with people to transition into adult mental health services	No	No	No	
Welsh Assembly Government (UK)	ASD: Primary health care settings* (wales.gov.uk/docs/dhss/publications/110127asdprimary-healthen.pdf) Impact of ASD in primary health care settings, accessing health care, appointments, waiting areas, communication, examinations/hypersensitivities, treatment and follow-up, referral on to other services	Yes	No	No	



About the Site		Brief Indicators of Quality		
Author (Country)	Description	Date Produced	Nominated Date for Review	Lists sources of information used
Welsh Assembly Government (UK)	ASD: Information for Dentists and Opticians in Wales * (wales.gov.uk/docs/dhss/publications/110309asdinfoen.pdf) General implications for ASD for practice, general strategies for care, dentistry and ASD, ophthalmology and ASD	Yes	No	No
Welsh Assembly Government (UK)	ASD: A guide for people working with older adults (awares.org/pkgs_files/librarydoc_1058.pdf) Includes discussion on impact of ASD for services to older persons, hints for making your service and practice more autism-friendly	Yes	No	No
East of England A2A Network of Learning Disability (United Kingdom)	Guidance on undertaking audits of reasonable adjustments made for adults with a learning disability/autism using acute hospital services (rcpsych.ac.uk/pdf/MCN Guidance Reasonable adjustments FINAL 4 4 13c.pdf)  Printable guide aiming to enable acute hospital NHS Trusts to put in place systems to monitor and report on the effectiveness of reasonable adjustments made to meet the needs of adults with a learning disability and/or autism	Yes	No	No
The Centre for Autism and Related Disabilities (USA)	Autism and the hospital waiting room (card-usf.fmhi.usf.edu/docs/resources/CARD_HospitalSupport. pdf) Online printable guide about what health professionals need to know to 'understand autism'	No	No	No
ASD Info Wales (UK)	AASPIRE Healthcare Toolkit (asdinfowales.co.uk/home.php?page_id=8524)  Video with accompanying PowerPoint presentation and PDF: Speak slowly and clearly, highlight on the file that patient has ASD, arrange an appointment at the beginning and end of the appointment, whenever possible allow extra time	No	No	No
Autism Victoria (AMAZE) (Australia)	Working with individuals on the spectrum: Information for those supporting individuals with ASD (amaze.org.au/discover/supporting-individuals-with-asd/) No targeted information for upskilling, but general information on the role these professionals play and links to general ASD information	Yes	No	Yes



About the Site		Brief Indicators of Quality		
Author (Country)	Description	Date Produced	Nominated Date for Review	Lists sources of information used
Royal College of Nursing, supported by Department of Health (UK)	The Autism Act 2009: developing specialist skills in autism practice (rcnpublishing.com/userimages/ContentEditor/1373364280087/Autism-booklet-2011.pdf)  Printable PDF for health and social care organisations outlining Environments and sensory issues; communication, information and processing; use of reasonable adjustments to change personal behaviour and attitudinal barriers	No	No	No
Skills for care and skills for health (UK)	Autism skills and knowledge list, for workers in generic social care and health services (skillsforhealth.org.uk/service-area/autism/) Printable checklist related to attitudes, awareness, knowledge and skills, and specialist development	Yes	No	No

<sup>\*</sup> Offers some specific information for the discipline the resource targets