



Scottish

Learning Disabilities

Observatory

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**Scottish Learning Disabilities Observatory
Newsletter Volume 3, June 2016**

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June 2016

Newsletter Welcome

Welcome to the Scottish Learning Disabilities Observatory newsletter, which in this edition has a focus on autism.

The Scottish Strategy for Autism was published in 2011, providing a roadmap for action to help build a more inclusive society for all people with autism, with improvements in diagnostic services and healthcare at its core. You can read more about this on page 3, in an article kindly written by Annette Pyle, the team leader for learning disability and autism policies, Scottish Government.

So what is the Observatory's particular contribution to supporting the goals of the autism strategy? The role of evidence in achieving health improvement for the whole population is uncontested. For people with autism, as well as for people with learning disabilities, we have been tasked with trying to identify these population groups within existing datasets, to build a better understanding of their health, health care, and health inequalities. Of course this work includes a significant number of people with both autism and learning disabilities; about 20% of people with learning disabilities have autism, and about 20% of people with autism have learning disabilities. For both groups there are significant gaps in the evidence-base, and also in current availability of routine data to generate new evidence. It is vital that we change this, as incomplete evidence can result in confusion or misleading representation of information.



The Observatory has an important role to play in supporting the goal of health improvement for people with autism, and throughout this issue we will be highlighting some of the work we are currently undertaking to better understand the health and healthcare of people with autism.

Every year April the 2nd is World Autism Awareness Day, and this year the Secretary-General of the United Nations, Ban Ki-Moon, made a call for "...advancing the rights of individuals with autism and ensuring their full participation and inclusion as valued members of our diverse human family who can contribute to a future of dignity and opportunity for all." With 42% of people known to have autism in Scotland reporting that their day to day activities are limited a lot by health problems, compared with only 9% for people who do not have autism (www.sldo.ac.uk), we still have a long way to go in achieving these aspirations. Our hope is to contribute to positive change by providing the evidence that can underpin more effective action to address the significant inequalities experienced by autistic people.

We would like to extend thanks to all of our contributors who have helped put this issue together and in particular we would like to thank Kabie Brook from Autism Rights Group Highland who has provided a frank and personal reflection on her experiences as an autistic woman in her review of "Life on the Autism Spectrum: A Guide for Girls and Women". Special thanks also to Chris Gilberg, who has made a sustained and prolific contribution to research to benefit people with autism internationally, and whose humble and honest description of his life's work gives us all plenty to think about!

As always, we welcome your feedback and encourage you to get in touch with us to share your ideas, thoughts, and comments.

Professor Sally-Ann ("Anna") Cooper
Director of the Scottish Learning Disabilities Observatory

The Scottish Strategy for Autism

By Annette Pyle, The Scottish Government

The 'Scottish Strategy for Autism' published in 2011 highlighted the need for strategic action both nationally and locally. In 2015, the 26 recommendations made in the strategy were reframed as four strategic outcomes:

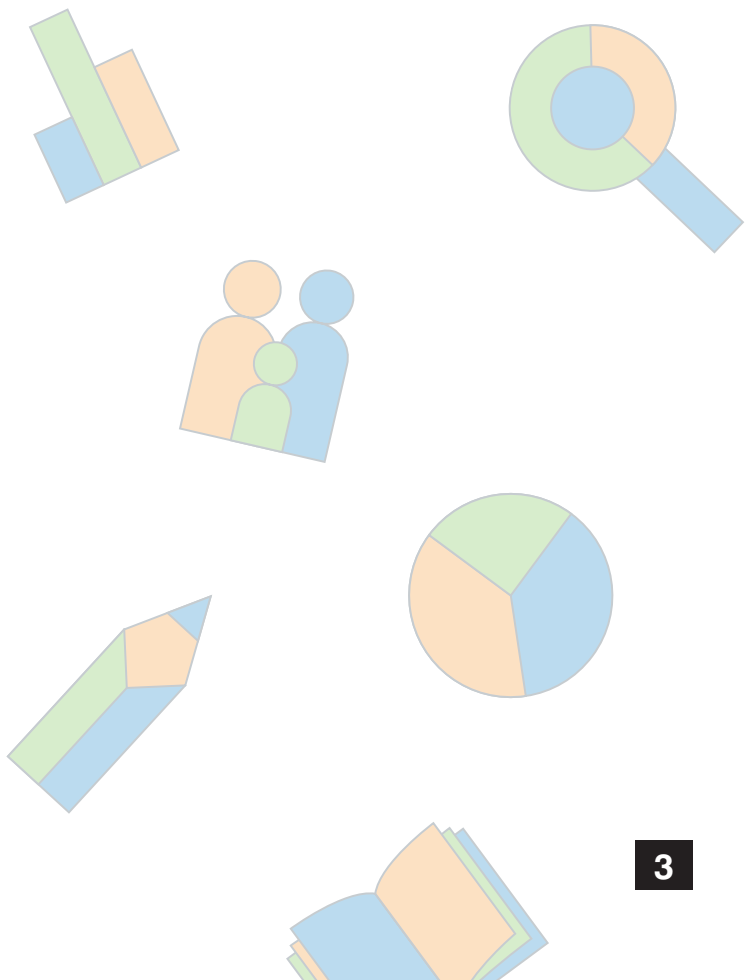
1. **A Healthy Life:** People with autism enjoy the highest attainable standard of living, health and family life and have timely access to diagnostic assessment and integrated support services.
2. **Choice and Control:** People with autism are treated with dignity and respect, and services are able to identify their needs and are responsive to those needs.
3. **Independence:** People with autism are able to live independently in the community with equal access to all aspects of society.
4. **Active Citizenship:** People with autism are able to participate in all aspects of community and society.



The outcomes approach outlines a greater emphasis on cross policy partnership working. Ensuring the inclusion of people with autism across all policy areas is a key priority within the approach. The work the Scottish Learning Disabilities Observatory is doing to increase the visibility of people with autism in routinely collected health and social care data is also vital to our approach. By supporting this work the Scottish Government is acknowledging the critical role that good quality information can play in helping us to better understand and evidence the needs of people with autism. Autism data plays an important role in determining service redesign and supports evidence based policy decision making.

We have seen some improvement in service delivery and data collection, however waiting times for autism assessment have remained high and access to services vary across Scotland. At the same time there has been a sustained rise in demand. In response to this and as part of 'Strategic Outcome one' the Scottish Government have funded an Improvement Programme to reduce waiting times for assessment by improving diagnostic services and increasing diagnostic capacity across child and adult services. In order to support the improvement programme and achieve effective and sustainable service change, good quality information is key to understanding demand, activity and capacity of autism services in Scotland.

You can download a copy of the outcomes approach at www.autismstrategyscotland.org.uk



Who's Who?

Professor Chris Gilberg

Professor of child and adolescent psychiatry



Describe yourself in three words

This is really for other people to do, but if you have to have my own assessment of myself I would have to use more than three words, and they would be:

Energetic

Aloof (but a loner and net-worker all at once)

Kind (if not back-stabbed)

Vicious (when misunderstood or whenever needed)

Loyal (but will only tolerate so much, cannot stomach tolerance of intolerance)

Hot-tempered

Disappointed

Observant and attentive to detail

Easily disturbed by everyday things going wrong

Aesthetic

Could you tell us a bit about your current role?

I am a professor of child and adolescent psychiatry first and foremost at Gothenburg and Glasgow. I am also visiting or honorary at many other universities in the UK, France and Japan. I have always worked both in the clinic and in research, and I consider it to be a big problem that so many people in our field of research are not clinicians or clinically active.

Why did you want to work in this area?

I am not sure I ever wanted to work in this area, but I was drawn to it for the simplest of reasons: the clinic where I had to do my psychiatry/child psychiatry internship was just across the road from where I was living at the time, and so it was easier for me to go there (child psychiatry) than to the clinic one hour's tram and bus ride away (adult psychiatry). And it was my mother, not me, who wanted me to go into medicine. I wanted to become a film director, but I was too young after graduation from high school to go into drama school, and in the meantime I went along with mother's wish.

What do you think the priorities for autism research should be and what excites you about the future of autism research?

Autism research needs to be seen in the context of neurodevelopment more generally, and people have to stop treating it as one disorder. It has to be turned upside down, looking at what we know about the individual and the biopsychosocial background in that case and then figure out the best personalised medicine approach for that patient. This is a challenge for research design, but I think it is clear that we have hit a wall when it comes to the insistence on collecting hundreds and thousands of "autism cases" (who are all different from each other anyway) and looking for "the cause and the treatment". Stop spending money on idiotic ideas like this. Lynn Waterhouse, Eric London and I have just written a long position paper where we make the point that as much as autism clinically will be relevant and around for years to come, in research the paradigm has to be shifted so that "the full phenotype" (which is always not just autism) be properly investigated in all cases, and that "the full biopsychosocial background" be covered at the same time and in the same study.

What has been the most rewarding aspect of your work?

The most rewarding aspect in my professional life has been working with individual families and seeing that the research we have performed has led to results that have actually helped them enormously in their everyday struggles.

How do you achieve a work/life balance?

I don't know that I have achieved an optimal balance as regards work/life. Carina, my wife, is also a child psychiatrist and researcher and I think that has helped rather than being a problem (as some people would have it is). Work is part of life. I paint, read a lot of novels, engage in public debate, watch films (and TV-series such as Breaking Bad, The Bridge, Arvingerne, Downton Abbey, The Wire, Suits and Modern Family) and even socialize with family and friends (Carina and I have five kids and two grandchildren, and we have some very good friends, and, of course, through work, a very large network of work-pals). One thing we have learnt together over the years; do not do clinical work or research with people you do not like. You may have to for a brief period of time, but never (if at all possible) spend too much time (life is too short) trying to fix a working relationship that you feel you do not really want to be in anyway. – Perhaps I should say that I do not sleep long hours (and that I don't know if that's good or bad for me or for anybody else).

Health of people with autism in Scotland: A whole country study.

Dr Ewelina Rydzewska

Why is this project important?



Scotland's Census is the official estimate of people and households in Scotland. The information about the Scottish population is collected every 10 years. For the first time in 2011, the Census questionnaire also included a question on autism. Little is known about the characteristics and health status of the total population of people with autism living in Scotland.

We analysed the Scotland's Census 2011 data for people with self-reported autism, and compared it to the information on the population without autism. Amongst a variety of factors, we investigated age, gender, and self-rated health.

What have we found?

People with autism (n=31,712) comprised 0.6% of the total population of Scotland (n=5,295,403). There were more males (n=24,490; 77.2%) than females (n=7,222; 22.8%) with autism, and more children aged 0-15 (n=17,348; 54.7%) than adults aged 16 and over (n=14,364; 45.3%).

The prevalence of autism was 0.8% for girls and 3.0% for boys in the 0-15 age group; 0.5% for women and 1.9% for men in the 16-24 age group. Prevalence rates fell progressively with each subsequent older age group. This decline is reflective of increased awareness in availability of diagnostic services for autism over the last two decades.

Very good or good health was described for 78.1% of children and 64.7% of adults with autism, and for 98.1% of children and 79.0% of adults without autism. (Figure 1) 13.6% of children and 23.3% of adults with autism also had learning disabilities compared with 0.3% of children and 0.4% adults without autism. 7.6% of children and 23.6% of adults with autism stated they had an additional mental health condition compared with 0.2% of children and 5.2% of adults without autism. Other disabilities, such as visual impairment, were also more common in people with autism. 41.9% of people with autism said their day-to-day activities were limited a lot due to health problems compared with 9.4% of people without autism. 13.7% had three or more conditions compared with 2.4% of people without autism.

How might this project benefit people with autism?

This project will increase our understanding of the health inequalities experienced by people with autism in Scotland. Our work with the Census information is still in progress, and we intend to investigate whether and how individual and household characteristics impact on health of the population with autism.

Where did this information come from?

This section presents findings from analysis of Scotland's Census 2011 data. If you have an enquiry that specifically relates to Scotland's Census 2011, please contact National Records of Scotland (NRS) Customer Services

at customer@gro-scotland.gsi.gov.uk
or visit www.scotlandcensus.gov.uk.

For more information, please contact Ewelina at ewelina.rydzewska@glasgow.ac.uk
or visit www.sldo.ac.uk

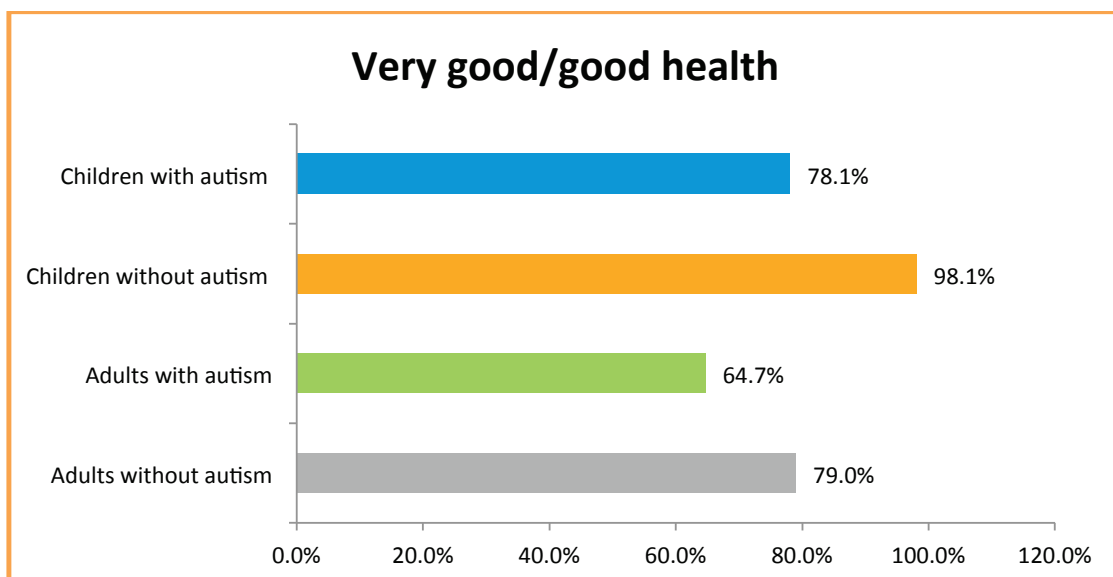


Figure 1. Reported very good or good health' to the bottom of the graph.

Children and young people with autism in Scottish schools

Dr Lisa O’Leary

Why is this project important?



Children and young people with autism experience significant health inequalities across the life span. There is a need for better information about the lives of children and young people with autism, so that their educational opportunities, health, and economic opportunities can be improved. Analysing routinely collected data can be an effective way to

address significant gaps in our understanding of the lives of people with autism. The Scottish Pupil census provides an important source of information that can help to address the gaps in our knowledge.

Where did this information come from?

The Scottish Pupil Census is conducted annually, and collects information from all publicly funded primary, secondary, and special schools. Changes in how additional support needs are recorded have taken place over time. Since 2008, all schools have recorded all types of additional support needs a child has. We have reviewed data from 2008 to 2015 for pupils aged between 4.5 and 18 years of age.

What have we found?

The number of pupils recorded to have autism in Scotland has increased from 4,900 in 2008 to 11,722 in 2015 (Figure 1). This is equivalent to 0.7% of pupils in 2008 and 1.7% in 2015, representing an increase of 139.2%. The increases were highest between 2009 to 2010 and from 2010 to 2011 with increases of 23.8% and 19.9% respectively.

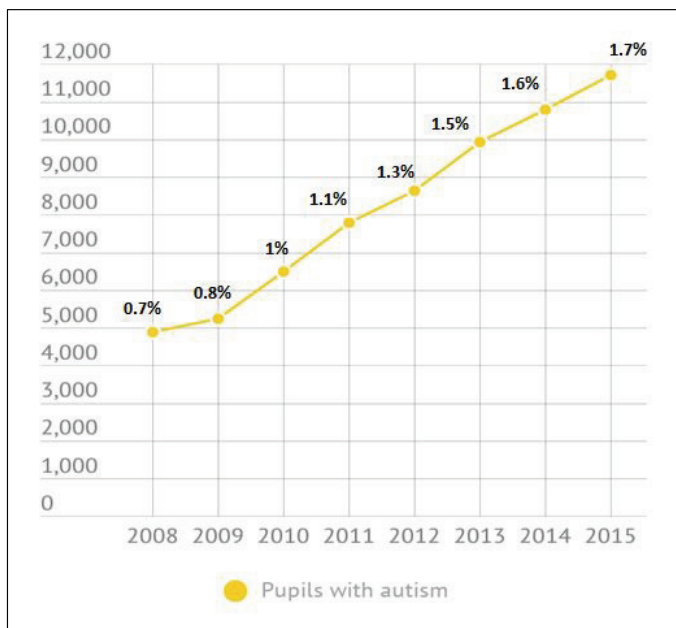


Figure 1: Reported proportion of pupils with autism out of all pupils in schools over time

Figure 2 demonstrates that the reported number of pupils with autism increased across all schools from 2008-2015. The graph also demonstrates that this increase was greatest in secondary schools, and was lowest in special schools. This may reflect the increased reporting of children with autism in mainstream schools across this timeframe.

How might this project benefit people with autism?

This project will provide us with information about the lives of children and young people with autism in schools in Scotland. It is important to know this information, so that suitable planning can be made to offer support where needed.

What next?

Further analysis is being undertaken in order to identify the multiple factors that impact on the health and lives of children and young people with autism.

For more information, please contact Lisa at Lisa.O’Leary@glasgow.ac.uk or visit www.sldo.ac.uk

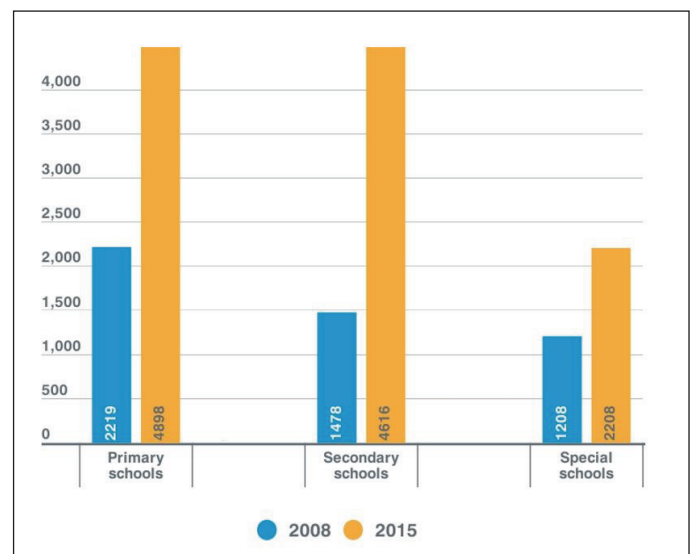


Figure 2: Reported number of people with autism in different schools in 2008 and 2015

Co-existing Health Conditions in People with Autism

Dr Ewelina Rydzewska

Why is this project important?



People with autism experience a wide range of additional health problems, some of which may be more common than for other people, and frequently more than one condition co-occurs. Many of these health problems can lead to emotional distress, physical discomfort, and reduced quality of life. Whilst evidence exists regarding

the prevalence of additional health needs, work is still underdeveloped and there is significant variation in reporting and quality between studies. We therefore aimed to synthesise the existing evidence to build a picture of what we do and do not know about the additional health needs experienced by autistic people.

Where did this information come from?

We systematically reviewed existing systematic reviews and meta-analyses in order to identify evidence on the physical and mental health needs of people with autism. We used PsycInfo, Scopus, CINAHL, Medline, and Cochrane databases to perform the search of publications between 2005 and 2015. We used the following search terms: ['autis*' OR 'pervasive developmental disorder' OR 'Asperger*' OR 'ASD'] AND ['systematic review' OR 'meta-analysis'].



What have we found?

Out of 3,072 search results, following screening of titles and abstracts, full texts of 243 articles were read. Ultimately, 19 articles (4 meta-analyses, 13 systematic and 2 narrative reviews) met our inclusion criteria for data extraction. These focused on mental (n=9) and physical (n=4) health problems, epilepsy (n=3), a range of long-term conditions (physical, mental, developmental, behavioural or emotional), life expectancy and causes of death (n=3). Additional health needs are common, but limitations of the studies included insufficient information on the definitions used of autism and the additional health needs, and of assessments made, which made comparison between studies difficult. Highly selected or non-representative samples, and lack of control groups also limited the generalisability of findings.

How might this project benefit people with autism?

We found gaps in the existing research on additional health needs of autistic people. This needs to be addressed, to avoid misleading assumptions and to further contribute to informing development of guidelines and training for improved detection and intervention. Such practice and policy developments are ultimately needed to improve the quality of life for people with autism, and are closely aligned to values placed at the core of the Keys to Life and Scottish Strategy for Autism recommendations.

For more information, please contact Ewelina at ewelina.rydzewska@glasgow.ac.uk or visit www.sldo.ac.uk

Health of people with a combination of autism spectrum disorder and learning disabilities in Scotland

Ms Kirsty Dunn

Why is this project important?

Autism and learning disabilities commonly coexist. However, little is known about demographic factors and self-rated health status of people with this combination.

Where did this information come from?

We analysed Scotland's Census 2011 data to find out about the health of people with autism and learning disabilities, compared with other people.

What have we found?

Out of Scotland's population of 31,712 people known to have autism, 5,709 (18%) also have learning disabilities; 3,769 (66%) males and 1,940 (34%) females. Very good or good health was described for only 2,863 (50.1%) with autism and learning disabilities, compared with 22,832 (72%) with just autism, and 4,330,647 (82.3%) of the people not recorded as having autism.

How might this project benefit people with autism and learning disabilities?

Health is poorer for people with a combination of autism and learning disabilities than for other people. It is important to know these differences, so that suitable planning can be made to offer the best support.

The Scottish Learning Disabilities Observatory is investigating this further, including gaining a better understanding of mental health problems and other disabilities.

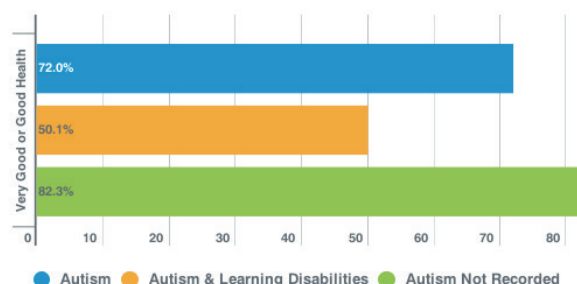


Figure 1. Reported very good or good health

For more information, please contact Kirsty at Kirsty.Dunn@glasgow.ac.uk or visit www.sldo.ac.uk

Book Review

By Kabie Brook

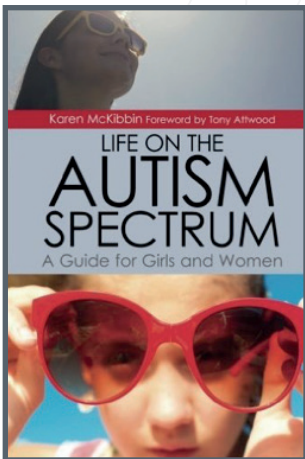
Kabie is the chairperson of Autism Rights Group Highland (ARGH) which is an independent collective advocacy, lobbying and campaigning group of autistic adults in Highland. They work together and with others to try to improve the lives of autistic people across Scotland and beyond.

Life on the Autism Spectrum: A Guide for Girls and Women (2016) by Karen McKibbin, Jessica Kingsley Publishers



This book promises a lot, not only to give insight into why autistic women and girls are so misunderstood but also to explain the day to day challenges that we face and to offer tools and strategies to help overcome these challenges.

The author, Karen McKibbin is a clinical psychologist who uses her experience to guide us through the life course of 'Alison', drawing on this fictional character as a technique, to highlight experiences and life stages that are particularly troublesome or significant. The book also uses testimony from other unnamed autistic women to give a feel of listening to what autistic people are saying themselves rather than to merely describe experience from an outsider viewpoint.



We follow Alison's life through a series of chapters: the social world and communication, bullying, food selectivity and sensory issues, special interests, abilities, routines and rituals, gender labelling and puberty and menopause.

Initially I couldn't help being struck by the choice of language in this book; throughout the author has chosen to use terms such as 'High functioning', 'Aspie' and 'with autism' as opposed to a more inclusive identity positive language. It was also disappointing to read yet another book that so clearly decides to categorise autistic women by functioning label and to not address issues which it (possibly) feels relate only to autistic women who would not be classified as having the right functioning label by the author.

The use of the 'NT' label to mean nonautistic implies that there is a neurological binary: NT or autistic, rather than taking a neurodiversity approach recognising the wide variation of human neurology.

However, the introduction to the book does make some good points about diagnostic assessment being skewed towards a very rigid gender normative and male stereotypical presentation in autistic people. For me this is the crux of where, for autistic people who don't meet the diagnosticians rigid thinking of what it is to be autistic, things can go wrong and this is ultimately why a gender based analysis of the experience of autism is so important.

Books like this are a reminder that autistic people aren't only male and that there are many variations within the autistic community. Generalisations at times create what could be unhelpful stereotypes that may confuse autistic female readers that don't identify with them, or men /others that do.

There are many parts of the book that offer an insightful and thoughtful input into autistic people's lives, the problem for me is that much of it relates to and rings true for all genders. At some points in the book it is pointed out that certain things may apply to men also but the feel and language used in the book counteracts this message.

There were many good points that I was delighted the author included; throughout the book there is a thread of acceptance and the need to support us as whole autistic people rather than broken non autistic people.

There was also mention of self-advocacy and the importance of teaching self-advocacy skills.

Post Traumatic Stress Disorder was referred to in the chapter on bullying, something often not addressed. This chapter also gave a good 'feel' of autistic reality at school and work where we can be targeted by bullies with devastating results.

I was also pleased to see in the "menopause tools and support section" advice that autistic women may benefit from talking to others to share and get support from people who truly know about autistic experience. (Menopause is the topic of a book currently being written by autistic people to be published by ARGH, a book that will hope to share experience and coping tips in a way that will benefit others within the autistic community and those who support us).

The tools and strategies sections were somewhat disappointing to me and lacking in all but the most basic advice, for example there are very few practical tips in puberty section which instead focused heavily on explanations of psychological difficulty without solutions.

Overall this is a useful short read giving an insight into a small sample of life experience for autistic women.

For someone wishing to start thinking about these areas this could be a start towards further understanding and investigation.

News and reviews

Below are some events that you may be interested in.



Seminar on 2 June 2016, Motor Disruption in Autism:

Venue: University of Strathclyde, Glasgow

Insights for Practice, Intervention, and Research, aims to improve practical health understanding of the role of movement in autism spectrum disorder, with genuine dialogue between research and practice. New evidence shows movements are fundamentally disrupted, and a possible aetiological origin of autism. This seminar, funded by the Scottish Government's Innovation in Autism, brings to Scotland the world's best research, psychiatric expertise, and practical experience, shedding light on the motor disorder in autism, with new insights for improved practice.



Autism and sensory processing

Date: 16 June 2016

Venue: The Angel Hotel, Cardiff

A one day conference featuring the latest research in sensory processing as well as useful coping strategies for autistic individuals and the professionals who support them.



XI Autism-Europe International Congress

Date: 16-18 September 2016

Venue: Edinburgh

We are delighted to invite you to the 11th Autism-Europe International Congress, organised by The National Autistic Society.

Autism-Europe's international congresses are dedicated to sharing advances in practical and scientific knowledge about autism to as wide an audience as possible, including researchers, professionals, parents and self-advocates.



Gillberg Neuropsychiatry Centre
Sahlgrenska Academy

Registration is free, but places are limited.

6th Birgit Olsson Lecture 16th November 2016

On the 16th of November 2016 at 2 pm

Professor Fred R Volkmar will give the sixth Birgit Olsson lecture entitled "The changing face of autism" at the Wallenberg hall in Gothenburg.



Welcome

We would like to welcome the newest member of the team. Mrs Sandra Auchterlonie joined us in May and is our new Administrative Assistant.

A short message from Sandra:

"I am very excited to join the Scottish Learning Disabilities Observatory as a part-time administrator where I will be the first point of contact for the Observatory. I will be arranging all of our meetings and events, and through various social media platforms will be keeping everyone up to date on our projects and sharing all our exciting news. In my spare time I enjoy walking in our lovely countryside and I am very lucky to live on the banks of Loch Lomond."



Congratulations!

We would also like to congratulate our team member Dr Phillippa Wiseman, Research assistant, who recently gave birth to a beautiful baby boy named Noah Wiseman on 20th April 2016.

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