THE WESTMINSTER COMMISSION ON AUTISM

A SPECTRUM OF OBSTACLES

AN INQUIRY INTO ACCESS TO HEALTHCARE FOR AUTISTIC PEOPLE

NCG NATIONAL CHILDREN'S GROUP

It is critical to improve access to healthcare for autistic people of all ages.

This population have increased health risks and reduced life expectancy, yet face multiple obstacles to accessing the same healthcare that other population groups enjoy.

The knock-on effect of poor access to healthcare on physical and mental health, on employment and the economy, on quality of life and mortality, leads us to **request positive action now.**

July 2016

The Westminster Commission on Autism has been financed by the National Children's Group. The National Children's Group has been set up by the National Children's Centre to run initiatives such as this Commission. These initiatives seek to bring organisations together and find solutions to issues affecting the welfare of individuals and families. Historically a children's charity, the National Children's Centre now champions the welfare of children, families and older people. The Westminster Commission on Autism is interested in autism across all age groups.

This report follows a seven-month inquiry chaired by Barry Sheerman MP.

The report has been written by Emily Christou, National Strategy Coordinator, National Children's Group with help from the Commission Members.

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Terminology

- **Autism** is used in this report as a term encompassing all Autistic Spectrum Conditions (including Asperger's Syndrome). Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them[1].

- This report will refer to '**autistic people'**. The decision to use this phrase as opposed to 'people with autism' or 'people on the autistic spectrum' was taken following research which demonstrates that autistic people generally prefer this term[2].

- **Health** is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity[3].

- **Health care** refers to services provided to individuals or communities by health service providers for the purpose of promoting, maintaining, monitoring or restoring health[4].

- **Neuro-typical** refers to those with normative neuro-development. I.e. those who do not have neurodevelopmental condition such as autism.

- **Obstacles** refer to problems or difficulties that prevent progress.

- **The Westminster Commission on Autism** is an independent, cross-party, cross-sector coalition of autistic individuals, parent-advocates, Parliamentarians and leaders from the autism 'sector'. The members have a commonality of purpose; to see the world become a more autism-friendly place.

[1] Autism.org.uk. (2016). What is autism? - NAS. [online] Available at: http://www.autism.org.uk/about/what-is.aspx [Accessed 17 May 2016].
[2] Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. Autism. Available at: http://crae.ioe.ac.uk/post/130542870298/is-a-person-autistic-do-they-have-autism-or
[3] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.
[4] who.int. (2004). A Glossary of Terms for Community Health Care and Services for Older People. [online] Available at: http://www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf [Accessed 17 May 2016].

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Foreword

"Over the course of this inquiry, it has become clear to me that getting healthcare right for people on the autistic spectrum is critical."

- Critical for equality; why should neuro-typical people have a wonderful NHS freely accessible to them but those on the spectrum have such a fight for the same quality service?
- Critical for living long lives; I was shocked to hear that a large, high-quality, Swedish study has shown that people on the autistic spectrum die an average of sixteen years prematurely. Getting healthcare right must be the first step to rectifying this inequality. The same study showed that those with autism and a learning disability have a life expectancy of 39. Such inequalities need to be mapped here in the UK and could show a similar pattern. If so, this has got to change.
- Critical for quality of life; autism is a complex condition with many associated co-occurring conditions. If we do not understand how to treat these co-occurring conditions, many may be left in poor health, unable to work and isolated from the society they so want to be a part of.
- Critical for employment; autism is estimated to cost the UK economy £32billion per annum[5]. This is more than cancer, stroke and heart disease combined. Much of this cost is due to loss of earnings yet many autistic people want to work and cannot find suitable employment. Some autistic people are living in poor physical or mental health and cannot work. If autistic people receive good physical and mental health care, have timely access to low level preventative support, are supported into employment and are embraced by the neuro-typical population, they can thrive.

This is not a critique of the NHS. This report seeks to highlight what good quality, person-centred healthcare, tailored to the needs of those on the autistic spectrum, can achieve. It is a call for ensuring equal access to quality healthcare for all on the autistic spectrum and to make this widespread and institutionalised.

If we fail to take immediate, sensible steps to improve access to healthcare for autistic people we may lose many more to unemployment, mental health issues, poor quality of life and even premature death.

This Commission has undertaken a thorough investigation of the issues and potential solutions. It has made six key recommendations approved by this strong coalition. We ask the Government to continue their commendable work in improving services for autistic people. We also ask them to listen to the autistic people, their families and the professionals who have voiced their ideas through this report and make changes to see lives improved.

Barry Sheerman MP

[5] Knapp, M., Romeo, R. and Beecham, J. (2009). Economic cost of autism in the UK. Autism, 13(3), pp.317-336.

Easy Read Summary of Our Report

We want to make sure that autistic people live long and healthy lives.

Many autistic people live long lives but some do not.

The Government knows that they need to help autistic people live long and healthy lives. In 2009, a law was passed called the 'Autism Act'. Because of this law, the Government now has an 'autism strategy'.

The strategy is a very good start to meeting the needs of autistic people.

We think that health services still need to get better for autistic people. The Government should make some changes.

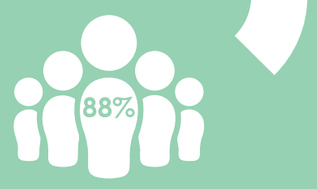
This is what we did and what we found out:

We have heard from lots of autistic people, families and carers, and autism professionals.

Some spoke to us on the telephone, others by email, some wrote to us and others filled in a survey.

This is what people told us:

Autistic people feel that health professionals do not always understand autism.



88% of the autistic people we spoke to said that they do not think health professionals understand their needs as an autistic person.

Autistic people do not always have people to help them access health services.

Doctors do not always keep a record of the autistic people using health services.

We think it is hard for professionals to understand autism because:

Every person on the autistic spectrum is different.

Autistic people often have sensitivity to lights, sounds, smells, tastes and touch. This means they can find it difficult to concentrate in hospitals or doctors surgeries.

Autistic people can find it very hard to tell the doctor what is wrong.

Autistic people do not always have someone to remind them to get help with their health.

There are some other things that make it difficult:

Autistic people often have other conditions such as ADHD or epilepsy. Doctors do not always understand these different conditions in autistic people.

Lots of autistic people also have a mental health condition. Health professionals do not always understand how to help an autistic person who has a mental health condition.

We have suggested 6 changes so that all autistic people can live long and healthy lives.

Things we think should change:

1

We think that the Care Quality Commission should make sure that health professionals are doing a good job for autistic people.

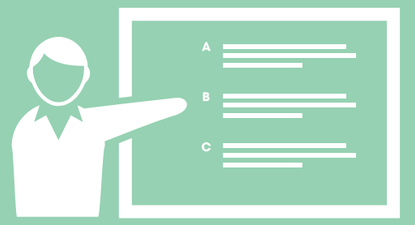
2

We think doctors should make a note on the computer for autistic patients.

This means that your doctor would know you are autistic and should make changes to meet your needs.

3

We think all autistic people should be offered to go to their doctor every year to have a health check.



4

We think that all health professionals should have autism training. NHS England should help to make training possible.

5

We think that the Government should make some money available. This money should be used to help autistic people understand what will happen at the doctor or hospital.

6

We think that NHS England should have an Autism Champion to lead on making changes for autistic people. We think that this would improve services for autistic people.

Executive Summary

According to our survey, 74% (n=497) of autistic, parent-advocate and professional respondents feel that autistic people receive 'worse' or 'much worse' healthcare than non-autistic people. Autistic people face significant risks to their health and can die unacceptably early[6]. But it does not have to be this way.

The passing of the Autism Act 2009[7] was an historic moment for the autistic community and has led to more focused attention on the issues affecting autistic people.

Following the Act, the Government has recognised the need to reduce the health gap for autistic people and included this in the 'Mandate to the NHS'. The Commission welcomes the Government's commitment to this issue. We have conducted a thorough investigation of the issues and consulted with over 900 autistic people, families and professionals. Our findings should be useful tools to help those trying to close the health gap.

Our evidence-gathering process has revealed a number of obstacles that autistic people encounter when accessing healthcare. These obstacles can be helped to be reduced by the implementation of our six recommendations.

The obstacles include (but are not limited to):

- Lack of training for health professionals and lack of strong accountability to ensure that health services meet the specific needs of the autistic population. 70% (n= 473) of our survey respondents chose training for healthcare professionals as the priority which would most improve access to healthcare for autistic people
- The lack of training leads to perceived poor understanding of autism and the feeling among autistic people that their health treatment is unsatisfactory
- Statistically, autism is largely 'invisible' in the health system as data collection is sparse. 76% (n= 241) of autistic people and parent-advocates told us that their General Practitioner (GP) does not make any reasonable adjustments for them or their autistic child. This is an indication that health professionals may not consistently identify autistic people and make accommodations for their needs
- Autistic people told us that they can struggle to identify changes in their health needs and seek appropriate help. This could be countered by monitoring the mental and physical health needs of the autistic population more closely. This could be achieved through Annual Health Checks
- Improvements in healthcare for autistic people can be complicated to make and this is exacerbated by a lack of leadership; NHS England does not have a National Clinical Director for autism nor a lead member of staff for autism
- Some autistic people may need assistance to access healthcare but many are socially isolated and lack support networks

This inquiry is timely but we have already seen too many autistic people living with poor physical and mental health and lost to premature death. This should spur us on to making important improvements now.

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[6] If you have concerns about the statement that autistic people IN Sweden have decreased life expectancy, please visit this website which gives an explanation. Many autistic people live long and healthy lives. http://www.autismeastmidlands.org.uk/information-about-report-autistica#

[7] Legislation.gov.uk. (2016). Autism Act 2009. [online] Available at: http://www.legislation.gov.uk/ukpga/2009/15/contents [Accessed 13 May 2016].

A large study, conducted in Sweden, has shown that on average autistic people die 16 years prematurely[8]. Research from other countries has also suggested that autistic people may be at risk of dying earlier. Yet in this country, the lack of data and research in this area means that we simply do not know the mortality risks of autistic people in England.

The timely use of appropriate, high-quality and person-centred healthcare can help ensure quality health for autistic people. However, we found that 74% (n=497) of all survey respondents think autistic people receive 'worse' or 'much worse' healthcare and 65% (n=440) think that health professionals 'rarely' or 'never' understand autism and how it affects someone's physical and mental health.

The statutory guidance associated with the Autism Act states that autism-awareness has to be included in all equality and diversity training for health and social care staff and ensure that both general awareness and specialist autism training is provided on an ongoing basis[9]. However, in the most recent self-assessment of progress against the strategy, only 29% of local areas rated themselves as 'green', meaning that training was available to all staff[10 11]. This suggests that many local areas are failing to comply fully with the Autism Act.

In addition, there is nothing in any of the NHS outcomes frameworks to measure outcomes for autistic people specifically. This is likely to mean that training in autism is not the priority it should be.

Even when healthcare staff have been trained, they still may be unable to identify autistic patients. This is, in part, due to inconsistent data collection and management. As a result, healthcare staff may not implement their training and reasonably adjust their services.

95% (n=302) of autistic survey respondents want GPs to have a note on their computer screen to tell them that the patient they are seeing is autistic and 94% (n=297) would be happy to be added to an anonymous database of autistic patients.

If services could consistently identify autistic patients, they may have a better chance at tailoring services to the needs of autistic patients and begin to reduce some of the risks to their health. This could be achieved through offering annual health checks to all autistic patients. Such checks have worked well for people with a learning disability in identifying unrecognised but treatable conditions[12]. Introduction of such checks for autistic people would need to be based on research evidence and be developed in consultation with the autistic community to ensure that they are effective.

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[8] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo lte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238. Available at: http://www.ncbi.nlm.nih.gov/pubmed/26541693

[9] Legislation.gov.uk. (2016). Autism Act 2009. [online] Available at: http://www.legislation.gov.uk/ukpga/2009/15/contents [Accessed 13 May 2016].

[10] Legislation.gov.uk. (2016). Autism Act 2009. [online] Available at: http://www.legislation.gov.uk/ukpga/2009/15/contents [Accessed 13 May 2016].

[11] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

[12] Robertson, J., Roberts, H. and Emerson, E. (2010). Health Checks for People with Learning Disabilities: A Systematic Review of Evidence. [online] improvinghealthandlives.org.uk. Available at: https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf [Accessed 15 May 2016].

An additional interlinked obstacle is the lack of leadership on autism within the health sector. There is no National Clinical Director for autism within NHS England. In contrast, there are National Clinical Directors for learning disability, dementia and mental health. There is an autism-lead in the Department of Health but there is no counterpart autism-lead at NHS England. It is challenging to drive real improvements for autistic people in the health sector without professionals who take responsibility for the issues and lead change. There are examples of committed individual healthcare professionals doing excellent work in the autism field. However, this is not the norm and is usually self-initiated.

The Care Quality Commission (CQC) do not ask autism specific questions in their healthcare inspections; 97% (n=748) of our survey respondents think that they should. Training for health professionals is not embedded and data on training take-up is not routinely collected. NHS England and other NHS bodies do not have titled autism-leaders. The 'accountability' mechanism for implementing the Autism Act is a Self-Assessment Framework (SAF) which is a useful tool. However, local authorities are responsible for the SAF and the main accountability mechanisms that the NHS pay attention to (e.g. NHS Outcomes Framework) do not have any measures on autism. This series of obstacles may hinder autistic people's healthcare.

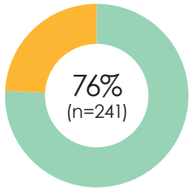
We have made six achievable and important recommendations to help the NHS fulfil the Government's call to reduce the health gap for this population and reduce the obstacles.

It should be noted that as health and social care are devolved to the Welsh Government, Scottish Government and Northern Ireland Executive, this report and its recommendations are concerned with England.

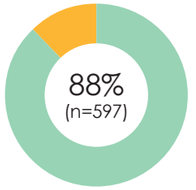
Summary of Recommendations

Recommendation One – Training:

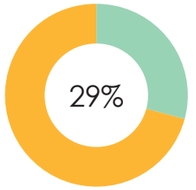
NHS England should issue a resource pack to assist Clinical Commissioning Groups (CCGs) in making sure training of all healthcare staff is embedded and data is collected on take-up; Secretary of State for Health to issue a letter instructing CCGs that they are obliged under the Autism Act's statutory guidance, to follow the requirements on training; those in control of clinical curricula, including Health Education England, should ensure all commissioned undergraduate and postgraduate training includes autism-awareness.



of autistic and parent-advocate survey respondents said **their doctor does not make any changes to meet their (or their child's) needs as an autistic person**;



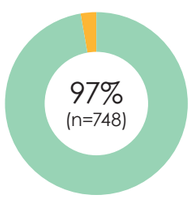
of all survey respondents **do not feel that health professionals understand the conditions which co-occur alongside autism**;



the Self-Assessment Framework shows only 29% **of local areas rated themselves 'green' for having training available to all staff**; a decrease on statistics from 2013 when 38% rated themselves green[13].

Recommendation Two - Inspection:

The Care Quality Commission should implement five autism-specific questions into their inspection framework, include autism in a Key Line of Enquiry and produce training brief guides on autism for inspectors.

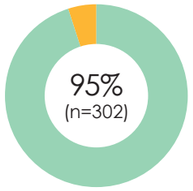


of all respondents to our survey **think the CQC should check that health services are meeting the specific needs of autistic people**.

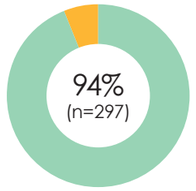
[13] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

Recommendation Three – Data:

An anonymous national primary care register for autism should be created, based on a single diagnostic-code in GP records, to be introduced in consultation with a broad cross-section of the autistic and wider autism community. The Learning Disability Mortality Review should be extended to include a new Autism Mortality Review to learn about the premature mortality of autistic people in England.



of autistic respondents **want doctors to have a note on their computer screen to tell them that the patient is autistic**;



of autistic respondents would be **happy to be added to an anonymous database of autistic people to help improve services**.

Recommendation Four – Annual Health Checks:

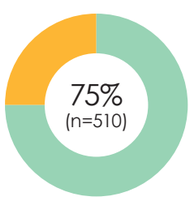
Once an anonymous national primary care register is in place, NHS England should use it to guide its work to reduce health inequalities for autistic people as outlined in the Government's Mandate. NHS England should consult with autistic people regarding the introduction of annual health checks to ensure that their unmet health needs are detected and treated and that they have a Health Action Plan in place. Such checks should be introduced if research evidence suggests they would be effective.

Recommendation Five – Leadership:

NHS England to appoint a National Clinical Director for autism and a senior lead member of staff for autism as well as ensuring additional capacity such that autism is considered across all NHS England work-streams, from Mandate to Business Plan, to make reduced health inequality a reality. Other health related bodies should follow suit.

Recommendation Six – Resources:

The Department of Health should launch a time-limited Autism and Health Innovation Fund for applications from Royal Colleges, professional bodies, third sector organisations and others to develop resources/aids/mentoring programmes to help autistic people access healthcare. Projects which are user-led should be the gold standard. Research funders should consider funding studies into preventing poor health in autistic people. Such research may prove a useful tool in indicating which resources/aids/mentoring programmes autistic people would benefit from.



of autistic and self-advocate and family-advocate respondents say they **would like help to understand what will happen when they go to the doctor or hospital**.

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*also a parent-advocate

PART ONE
BACKGROUND

1.1 Autism: The Basics

Autism is used in this report as a term encompassing all Autistic Spectrum Conditions (including Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified/PDD-NOS). Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them. It's estimated that over 1% of the UK's population are autistic[14 15], with 700,000 autistic people living in the UK today and 2.8m lives touched by autism daily[16].

Due to the variable influence of autism on an individual's life, autism is conceived of as a spectrum condition.

Autism is not a mental health condition but according to one study, 70% of autistic children meet the criteria for a co-occurring mental health condition, and 40% meet the criteria for two[17]. Autism is not a learning disability but a significant proportion of autistic people have a learning disability (prevalence estimates vary but are often quoted to be approximately 50%)[18].

Awareness of autism is generally good and 99% of the general population have heard of autism[19] but understanding of the complexity of autism spectrum conditions and the ways in which these conditions affect communication, sensory experience and behaviour is not so good. Too many myths still exist which cloud true understanding and acceptance of autism, such as the belief autistic people lack all empathy or that everyone with autism is the same.

The 'hidden' nature of autism means that making reasonable adjustments for autistic people can be difficult. Often the adjustment will need to be made to communication techniques i.e. avoiding open-ended questions or providing easy-read information. Making reasonable adjustments for autistic people is perceived to be more complex than for someone with a visible disability for example.

There are a range of related co-occurring conditions associated with autism including ADHD and epilepsy.

People often misconceive autism as a childhood condition. Autism is a lifelong condition. People also stereotypically think of autism as a 'male' condition and the typical autistic person as a male child. It is true to say that there are more men diagnosed with autism than women. However, this may be due to a misunderstanding of the manifestation of autism in women as well as a possible male bias in diagnostic tools[20].

Despite the efforts of many to improve understanding and break down barriers, the autistic community all-too-often struggle with navigating a world attuned to the needs of neuro-typical people. Misunderstanding and resultant anxiety can characterise many autistic people's lives. Too many have to fight for the same opportunities and liberties that the neuro-typical population take for granted.

This report depicts the struggles that many have with accessing quality healthcare and living healthy and long lives.

[14] Baird G, Simonoff E, Pickles A, et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). The Lancet 368: 210–215.
[15] Brugha TS, McManus S, Bankart J, et al. (2011) Epidemiology of autism spectrum disorders in adults in the community in England. Archives of General Psychiatry 68: 459–465.
[16] Autism.org.uk. (2016). Autism facts and history - NAS. [online] Available at: http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx [Accessed 14 May 2016].
[17] Simonoff E, e. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. - PubMed - NCBI. [online] Ncbi.nlm.nih.gov. Available at: http://www.ncbi.nlm.nih.gov/pubmed/18645422 [Accessed 13 May 2016].
[18] Autism.org.uk. (2016). Autism facts and history - NAS. [online] Available at: http://www.autism.org.uk/about/what-is/myths-facts-stats.aspx [Accessed 14 May 2016].
[19] YouGov: What the world thinks. (2015). YouGov | More people in the UK are aware of autism. [online] Available at: https://yougov.co.uk/news/2015/04/13/more-people-uk-are-aware-autism/ [Accessed 14 May 2016].
[20] Lai, M., Lombardo, M., Auyeung, B., Chakrabarti, B. and Baron-Cohen, S. (2015). Sex/Gender Differences and Autism: Setting the Scene for Future Research. Journal of the American Academy of Child & Adolescent Psychiatry, 54(1), pp.11-24.

1.2 What we already know: The Good and The Bad

Most autistic people should live long and healthy lives. However, a recent, large and high-quality Swedish study shows that autistic people that have a co-occurring learning disability see their life expectancy decreased by an average of 30 years and even those without a learning disability still have an average of 12 years deducted from their life expectancy[21]. We do not have reliable mortality figures for autistic people in the UK, but there is no evidence to suggest that our healthcare system is working better for autistic people than the Swedish system.

The Autism Act 2009 was a landmark in the battle to improve services for autistic people. The Act, associated 'Think Autism' Strategy and statutory guidance has done much to embed autism into local commissioning. Its focus has been predominantly on social care. However, the Government has included the need to reduce the health gap between autistic people and the general population in its mandate to the NHS.

The mandate cites prevention, early intervention and improved access to integrated services as necessary steps to begin to close the health gap and aims to achieve parity by 2020; an ambitious target. The Government has also supported the Autism Clinical Priority programme at the Royal College of General Practitioners (RCGP). Further, steps have already been taken by the Government to improve health outcomes for autistic people, particularly those with a learning disability. The Commission welcomes the world's first Learning Disability Mortality Review commissioned by NHS England. It is hoped that such a review will lead to improvements in services[22].

However, this mortality review does not address the possible loss of many years of life for those autistic people who do not have a learning disability as seen in Sweden. Furthermore, as this report will argue, there are autism-specific considerations to be made when addressing premature mortality. For example, the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that the leading causes of death was heart and circulatory disorders (22%)[23]. In contrast, the Swedish study has shown that the leading cause of premature death for people with both a learning disability and autism is epilepsy[24].

It cannot be assumed that the health gap for autistic people can be closed via initiatives primarily tailored for people with a learning disability.

The Government recognises that "When professionals do understand autism, the positive impact on the lives of adults with autism can be immense"[25]. The Autism Act enshrines the importance of autism-awareness training in health and social care settings and the statutory guidance makes it clear that staff across health and care should receive autism training. The Equality Act 2010 enshrines anticipatory reasonable adjustments in law.[26]

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[21] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo Ite, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.
[22] Theyworkforyou.com. (2016). TheyWorkForYou. [online] Available at: http://www.theyworkforyou.com/wrans/?id=2016-03-22.32130.h&s=autism [Accessed 14 May 2016].
[23] bris.ac.uk. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). [online] Available at: http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/finalreportexecsum.pdf [Accessed 19 May 2016].
[24] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo Ite, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.
[25] Gov.uk. (2016) Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, Department of Health (2015) Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf [Accessed 13 May 2016].
[26] Legislation.gov.uk. (2016). Equality Act 2010. [online] Available at: http://www.legislation.gov.uk/ukpga/2010/15/section/20 [Accessed 13 May 2016].

However, the requirement for NHS staff to be trained is hard to enforce and the 2014 self-assessment framework responses indicate that there is more to be done to monitor such training. Autism is not included in the different accountability mechanisms used for the NHS (e.g. the NHS Outcomes framework) and so NHS bodies are not incentivised in the same way as they are for learning disability and dementia to ensure that training is in place. Furthermore, there is no audit of reasonable adjustments to ensure that services routinely meet the needs of autistic people.

While there is mention of the need to close the health gap for autistic people in the Government's mandate to the NHS, there is no mention of autism in the NHS Business Plan nor in Public Health England's Remit Letter.

There is much to be commended in the Autism Act, Strategy and guidance. The Commission particularly welcomes the commitment to meet the asks of autistic people including:

"I want staff in health and social care services to understand that I have autism and how this affects me"
"I want services and commissioners to understand how my autism affects me differently through my life."[27]

The process for monitoring the implementation of the Autism Strategy is through the Autism Self-Assessment Framework managed by Public Health England on behalf of the Department of Health. This Self-Assessment framework is a useful tool. However, responsibility for the SAF falls on local authorities and the NHS is not properly held to account for the services it provides for autistic people.

While the Autism Act and strategy set out a clear direction of travel, the implementation is variable and not as fast as many respondents would like.

In securing access to quality healthcare, it is important that CCGs are involved in the planning and implementation of the autism strategy. The Government's statutory guidance recognises this.

However, some local areas are performing worse now than when self-assessed in 2013. In 2014/15, 39% of local authorities reported that CCGs, primary and secondary care practitioners are involved in planning and implementation. Action is needed to ensure that more CCGs are involved in multi-agency training plans in coming years.

There has been commendable progress made in improving services for autistic people. This should be used as a springboard to solve the access to healthcare issues autistic people are facing.

[27] Gov.uk. (2016) Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy, Department of Health (2015) Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf [Accessed 13 May 2016].
[28] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

1.3 The need for this inquiry

"What autism really is, is an enormous population of men and women with tremendous potential who are being denied what everyone deserves: the chance to live a happy, healthy, safe, secure and productive life. Viewed in this light, autistic people are one of the largest disenfranchised minorities in the world."

Steve Silberman at the UN April 1st 2016[29]

Autistic people are at a significant but little understood disadvantage when trying to access healthcare. According to the Swedish study on premature mortality, autistic people, on average, have 12 years deducted from their life expectancy and on average, those that have a co-occurring learning disability die 30 years prematurely[30].

Why might autistic people die prematurely?

This is not yet well-understood. However, Autistica, the UK's largest autism research charity, explains that autistic people "…Experience depression, anxiety and sensory overload… Can face significant issues in accessing healthcare…" and argue that "As we see in the general population, these factors may increase the likelihood of suicide and death from other causes. Further research is required to more accurately understand the multiple factors which can lead to early death in autism."[31]

The Royal College of General Practitioners (RCGP) recognised the health inequalities experienced by autistic people and the statistical 'invisibility' of autism in the health system. Led by Dr Carole Buckley, the RCGP have made autism a clinical priority from 2014-2017. The RCGP is the professional membership body and guardian of standards for 50,000 family doctors. The clinical priority programmes have the power to influence change but the RCGP does not have statutory power over its members[32].

It is not just the RCGP who have recognised the health gap suffered by autistic people. The Commission is delighted that the Government has included the need to reduce the health gap in its mandate to the NHS. The Commission welcomes the Government's ambitious target to close the health gap by 2020[33]. It is our hope that the recommendations made here will help to make this a reality.

"We truly feel like the forgotten members of society where no one really gives a damn about us as long as we don't make too much of a fuss or noise. Its driven me to depression thinking about how my child will be cared for by society when I am not longer around to fight his corner"

(Ravi Patel, Parent Advocate)

[29] Silberman, S. (2016). Autistic people are not failed versions of "normal.". [online] ideas.ted.com. Available at: http://ideas.ted.com/autistic-people-are-not-failed-versions-of-normal-theyre-different-not-less/ [Accessed 15 May 2016].
[30] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo Ite, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.
[21] Cusack, J., Spiers, J., Shaw, S. and Sterry, R. (2016). Personal tragedies, public crisis. 1st ed. [ebook] Available at: https://www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf [Accessed 15 May 2016].
[32] http://www.rcgp.org.uk/membership.aspx
[33] Gov.uk. (2016). The Government's Mandate to NHS England for 2016-17. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/494485/NHSE_mandate_16-17_22_Jan.pdf [Accessed 15 May 2016].

1.4 Methodology and Participation

The Commission Members were clear from the outset that all work done by the Commission should be informed by the authentic voices of autistic people and their families.

Autistic people have contributed to the inquiry at every stage; as Commission Members, through written evidence submissions, presenting oral evidence at Commission meetings, through our survey and in the writing of this report. The Commission is deeply grateful to over 900 autistic people, family-advocates and professionals who contributed to this inquiry.

The Commission gathered evidence through:

- Four oral evidence sessions held in the Houses of Parliament. The list of contributors to these sessions is listed on page 25.
- Written submissions of evidence from autistic people and parent-advocates. The opportunity to contribute written evidence was advertised via social media and contributors used a framework of questions to structure their submission. An easy-read framework of questions was also available.
- Some contributors chose to input via a telephone interview. The same framework of questions was used.
- 863 autistic people, family-advocates and professionals contributed via our survey (697 complete responses – 81%). The survey pathways varied according to the respondent's connection to autism. Some respondents had multiple connections to autism. For example, they might have been a parent, an autistic person and an academic. There were 1133 total connections to autism. In some cases, questions were only asked if the respondent was autistic or a parent-advocate. In other cases the question was asked regardless of the respondent's connection to autism. Therefore, the percentages in this report are accompanied by a note as to which respondents were asked the relevant question.

Our 'Access to Healthcare' survey was constructed and managed by Craig Kennady, an autistic self-advocate, parent-advocate and campaigner. Craig used 'Survey Monkey' to build the survey and wrote the questions with some input from other members.

The survey sought both open-ended and quantitative responses. Permission to share responses in this report was granted by respondents however all names have been changed to ensure confidentiality. The survey was open from 22nd April 2016 to 9th May 2016.

Survey respondents were recruited using convenience sampling methods and internet snowballing methods through social media. Commission Members shared the survey in their networks. This means that the respondents are a self-selecting group and there are limitations associated with the survey results.

These results are not representative of the autistic population at large but give an indication of the feelings and experiences of this population.

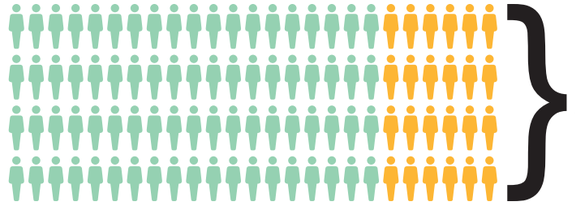
PART TWO
OUR FINDINGS

2.1 Obstacle One: Lack of Understanding

One of the most commonly reported obstacles faced by autistic survey respondents, in accessing the healthcare they need, is the perceived lack of autism understanding among health professionals. The Commission does not seek to criticise hard-working, well-intentioned and compassionate professionals of whom there are many but not enough doing good work in this field. However, it does seek to expose the limited quality, advocate-led, autism training for health professionals and the lack of understanding among health professionals perceived by our consultation respondents.

Few health professionals have any quality autism training as a part of their initial qualification or their Continuous Professional Development (CPD) training. In a recent survey, 40% (n=304) of GP respondents reported receiving **no autism training** in either their degree qualification or during their training or practice as a GP[34]. The same survey found that GPs reported low confidence in consulting with and managing autistic patients. 65% (n=440) of our survey respondents think that healthcare professionals 'rarely' or 'never' understand the physical and mental health needs of autistic people. Health services are expected to make reasonable adjustments under the Equality Act 2010[35].

According to the National Audit Office, 80% of GPs feel that they need additional guidance and training to identify and manage patients with ASD more effectively[36]. This may be related to lack of confidence due to unclear referral pathways and lack of support services[37]. If GPs do not have the resources to appropriately manage their autistic patients, patients may perceive their GP to lack understanding. More research would be needed to make a conclusion on this.



74% (n=497) of all survey respondents **felt that autistic people receive a 'worse' or 'much worse' heath service than their non-autistic counterparts.**

75% (n=440) of all survey respondents **felt that healthcare professionals 'rarely' or 'never' understand autism and how it affects someone's physical and mental health.**

We have heard a number of examples of health professionals suggesting that medical treatment, ranging from dental braces to a kidney transplant, should be withheld due to the patient's autism. We have also received many stories of autistic people subjected to pain, illness and prolonged suffering because their health care professionals did not understand, or could not manage, their needs and behaviours.

[34] Ibid.
[35] Legislation.gov.uk. (2010). Equality Act 2010. [online] Available at: http://www.legislation.gov.uk/ukpga/2010/15/contents [Accessed 17 May 2016].
[36] Survey of General Practitioners in England on the subject of autism, Report prepared for The National Audit Office 2008 Available at: https://www.nao.org.uk/wp-content/uploads/2009/06/0809556_gp.pdf [Accessed 13 May 2016]
[37] Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. GPs' perceived self-efficacy in the recognition and management of their autistic patients. Manuscript in preparation.

"I had gallstones which were super painful for 10 months. I told dr it was 10/10 pain but because I didn't scream they didn't believe me. They didn't know autistic people may not scream when in pain.

I had a scan. Dr stopped scan and sent me for operation as he said pain would be equivalent to child birth. I did tell them it hurt. They didn't listen"

Jonny Kingsley,
Autistic Self-Advocate

"We had to go to hospital for a minor op. It was probably the worse experience of my life. They had no understanding at all. My poor son was so deeply traumatised. He was terrified. He and myself came home bleeding. He ripped the needle out of his hand. Hurt himself. When i asked had they ever experienced a child with Autism they said yes but not that bad. We had more help from the other parents because they could see how bad it was."

Janice Ip,
Parent-Advocate

"… last time I had to attend hospital for a emergency op they wouldn't take my needs into consideration and I refused to stay and went untreated"

Brenda Crosby,
Autistic Self-Advocate

"Personally, I don't like talking.
I don't know how to estimate my pain.
I don't know what questions I will be asked, and so when the questions come as a surprise I find it hard to figure out what the answer is. I have to revise what my symptoms and problems are beforehand, but I still find it really hard to recall them when surprised with questions. I saw a psychiatrist once who refused to read the notes I had written out beforehand on how I would like him to approach our session.
I couldn't verbalise them either."

K,
Autistic Self-Advocate

"…it would have been so, so good if the GPs I have seen over the years had enough training to spot the signs proactively – then I could have been diagnosed years ago, and lived a richer life"

Nathan Ramsbotham,
Autistic Self-Advocate

"GPs have little understanding of autism and how it may affect those with an ASD… Sensory issues and time to process information are often not acknowledged…
The unusual reaction to pain is also not recognised by many GPs until it is pointed out to them"

Sandra Kirsty,
Parent-Advocate

2.2 Obstacle Two: Autism and Co-occurring Conditions

Historically, it has been assumed that the physical health needs of autistic people are the same as the neuro-typical population. It is fast becoming apparent that this is not true.

The physical health needs of the autistic population are complex and need specialist consideration. However, very few healthcare interventions have ever been scientifically validated to determine whether they are autism-appropriate. There is a need for research to address this gap.

Autism rarely presents with core symptoms alone. There are a huge range of co-occurring conditions which can accompany autism. The associated condition (or co-occurring condition) can significantly change the physical health needs of an autistic person. But health practitioners may not always understand these conditions:

(n=597)

of all survey respondents told us that they **feel health professionals do not understand the conditions which co-occur alongside autism**.

Research is needed to establish the confidence of healthcare professionals in managing autistic patients with co-occurring conditions.

Healthcare professionals may not know and understand the core symptoms of autism and the interplay with co-occurring conditions. Those professionals who have some awareness of autism may be more likely to look out for co-occurring conditions.

There have been limited studies into the interplay between physical co-occurring conditions such as epilepsy, for example, and autism. This is a concern and should be a priority for research. Epilepsy has a prevalence of 0.97% in the general population[38] but has an incidence of more than 20% in the autistic population[39]. It is becoming increasingly clear that the combination of epilepsy and autism needs to be understood. A large, quality Swedish study shows that autistic people who also have a learning disability die an average of 30 years prematurely[40]. The leading cause of death is epilepsy. Yet we do not have a good understanding of the relationship between these two conditions nor do we have specialists or specialised treatment to tackle this.

But it is not just epilepsy that autistic people are more susceptible to. The same Swedish study found that autistic people die prematurely in almost all cause-of death categories. Cancer, cardiovascular disease, congenital malformations and almost all other diseases are causes of premature death in this autistic group. But reducing the obstacles to accessing healthcare can improve the detection and treatment of these diseases and improve life expectancy.

Other studies have found that autistic patients appear to be more susceptible to stroke, Parkinson's disease, gastrointestinal and sleep disorders, diabetes and immune conditions[41].

Without a holistic understanding of the autistic person's physical health needs and without a person-centred approach to this, the health needs of autistic people may go unmet.

[38] epilepsyscotland.org.uk. (2011). Epilepsy prevalence, incidence and other statistics. [online] Available at: http://www.epilepsyscotland.org.uk/pdf/Joint_Epilepsy_Council_Prevalence_and_Incidence_September_11_(3).pdf [Accessed 15 May 2016].
[39] Bolton, P., Carcani-Rathwell, I., Hutton, J., Goode, S., Howlin, P. and Rutter, M. (2011). Epilepsy in autism: features and correlates. The British Journal of Psychiatry, 198(4), pp.289-294.
[40] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo lte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.
[41] Croen, L., Zerbo, O., Qian, Y., Massolo, M., Rich, S., Sidney, S. and Kripke, C. (2015). The health status of adults on the autism spectrum. Autism, 19(7), pp.814-823.

2.3 Obstacle Three: Co-occurring Mental Health Issues

Autism is not a mental health condition. However, in addition to experiencing physical co-occurring conditions, up to 70% of autistic children have at least one co-occurring mental health condition[42]. Further studies indicate significantly increased suicidal thoughts among autistic people[43]. Unfortunately, all-too-often when autistic people do develop mental health problems, the NHS is not always able to help them effectively.

"Mental health services openly, and unashamedly, tell me that they know very little about autism and certainly the services they offer are tarnished by this inability to recognise autism - e.g. emphasis has been on encouraging general socialising without knowing ASD limitations and/or have use of metaphors in their programmes."
Sam Hall, Autistic Self-Advocate

The Mental Health Taskforce was a welcome step towards improving mental health services for all users. The Taskforce's report 'The Five Year Forward View for Mental Health' did note that "People of all ages…who have multiple needs such as a learning disability or autism are also at higher risk."[44]

"Autism is of growing interest to mental health services and is a condition that deserves special attention. If mental health staff are not trained to deal appropriately with autistic people, they will not meet the needs of this population group. We cannot tolerate autistic people having their mental health needs unmet; particularly as the suicide risk can be higher among autistic people."
Steven Michael OBE, Ex-Chair of the NHS Confederation Mental Health Network

Our evidence suggests that mental health staff are not well-trained in autism. The Commission heard of multiple cases of misdiagnosis and missed diagnosis of mental health issues among autistic people. Some people do not receive a secondary diagnosis of a mental health issue because their symptoms are dismissed as being 'part of autism'. Others are diagnosed with a mental health condition and are not referred on for an autism diagnosis.

Mind have recently been involved in this area, having produced a toolkit in 2015 entitled 'Supporting people living with autism spectrum disorder and mental health problems'[45]. Mind found that mental health services tended to either ignore peoples' autism or overlook their mental health issues instead, and sometimes try to 'treat' autism itself as though it were a mental health condition.

One person with Asperger's and bipolar highlighted in the booklet, Lucy, said: "I am just me – a whole person with my own unique personality, rather than a set of symptoms which can be easily recognised to one of my 'conditions'".

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[42] Simonoff E, e. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. - PubMed - NCBI. [online] Ncbi.nlm.nih.gov. Available at: http://www.ncbi.nlm.nih.gov/pubmed/18645422 [Accessed 13 May 2016]. *Also a Self-Advocate and a Parent-Advocate
[43] Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M. and Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. The Lancet Psychiatry, 1(2), pp.142-147.
[44] england.nhs.uk. (2016). The Five Year Forward View for Mental Health. [online] Available at: https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf [Accessed 15 May 2016].
[45] mind.org.uk. (2015). Supporting people living with autism spectrum disorder and mental health problems. [online] Available at: https://www.mind.org.uk/media/3120340/autism-guide-web-version.pdf [Accessed 15 May 2016].

The recent Swedish finding that those autistic people without a learning disability die an average of 12 years prematurely is unacceptable but the finding that suicide is a leading cause-of-death is saddening.

As a result of the work of the Mental Health Taskforce, a new 'autism pathway' will be developed within the NHS. It is vital that the specific mental health needs of autistic people are looked at as the pathway is developed and that those on the spectrum who have experience of mental health services are involved in the pathway development.

In addition to the Swedish finding, a study conducted in the UK also found significant suicidal thoughts among the autistic population[46]. We need a better understanding of the suicide risks in this population. This could be achieved through a new Autism Mortality Review.

[46] Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M. and Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. The Lancet Psychiatry, 1(2), pp.142-147.

2.4 Obstacle Four: Diagnostic Overshadowing

Autistic people repeatedly told us that they have their health concerns dismissed as being 'just a part of their autism'. It is possible that a lack of understanding among health professionals leads to co-occurring conditions being mistakenly seen to be part of the autistic spectrum condition. This is certainly the perception of those who contributed to our inquiry.

The autism label can overshadow other possible physical or mental health diagnoses and sometimes other diagnoses may overshadow a possible autism diagnosis. Some autistic people and parent-advocates feel that health professionals have lower expectations for the health of an autistic person. This may be due to health professionals not receiving good-quality training on what is, and what is not, a core aspect of autism.

One mother told us that her autistic son's epilepsy was uncontrolled. He was having an average of three seizures per year and each of these would have significant consequences to his health; he was a 6-foot-tall, 17-year-old who would crash to the floor with each epileptic episode. The doctor felt that this level of control was satisfactory. But his mother felt that if he had been a non-autistic 17-year-old, three seizures a year would not have been considered acceptable; he would be wanting to drive and be independent and every effort would be made to make this possible and control his epilepsy accordingly.

Autistic people often feel that they have to fight harder than non-autistic people to have due attention given to their physical and mental health needs.

Autistic people should not have to accept poor physical or mental health. Non-autistic people do not expect to live with substandard physical or mental health and nor should autistic people. But in order for autistic people to have their health concerns taken seriously, health professionals need to understand what exactly is and is not a core symptom of autism and what can be treated. This requires them to receive quality training developed and delivered by autistic people.

"It seems difficult for medical staff to get beyond people's autism and accept they may also have a co-occurring medical issue"

Sandra Kirsty, Parent-Advocate

2.5 Obstacle Five: Sensory Processing and Communication

Autistic people can experience severe sensory processing abnormalities[47]. Respondents told us that when someone experiences too much sensory input, they can meltdown or become agitated, anxious and upset. Many autistic people and parent-advocates wrote to the Commission to tell us that one of the biggest barriers to accessing healthcare services is the sensory experience of the environments.

Respondents told the Commission that waiting in loud, busy and brightly-lit waiting rooms that smell of disinfectant and feature a bombardment of posters on the walls, can induce sensory overload in autistic people. Once the overload takes place, it is difficult for the individual to re-regulate their senses. It is extremely difficult for the autistic person to communicate their health needs to a professional when experiencing sensory overload.

Not only does sensory overload cause upset, it can cause physical symptoms. "sensory overload caused by bright lights, fluorescent lights, colours, and patterns makes the body react as if being attacked or bombarded, resulting in such physical symptoms as headaches, anxiety, panic attacks or aggression'"[48]

There is a relevant interplay of an intolerance of uncertainty, sensory sensitivities and anxiety in autistic people which may be exacerbated in healthcare environments[49]. Healthcare environments are, for most people, attended irregularly and carry a degree of uncertainty with them.

Such uncertainty can be intolerable for autistic individuals, the sensory experience of a healthcare environment unbearable and the anxiety induced insufferable.

"It's the not knowing what will happen, how long it will all take, will I have to take my clothes off, how many people will I have to interact with, will I have to stay overnight. All these unknowns mean that you end up torturing yourself about what might happen from the moment you make the appointment until the moment you are released."

Adam Fredrick, Autistic Self-Advocate

There is an inevitable knock-on effect of such experiences on the healthcare provision possible. One mother told the Commission "... my autistic son had a seizure and was taken to the children A&E. Despite the Dr saying they had experience of autistic people it became apparent quite quickly they lacked the experience to converse in a way that my son understood. He was extremely stressed as he came around from his seizure in a different place, a noisy environment, one which caused a sensory overload so he sat on the bed underneath his hoodie and rocking for comfort. The Dr asked if he could hear voices - his reply was yes. They then started talking about a psychiatrist assessment. When I reworded the question to what voice can you hear he responded with yours and the Doctors. This was a completely different interpretation by my son and one that I was able to help him with."

...>

[47] Crane, L., Goddard, L. and Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. Autism, 13(3), pp.215-228.
[48] Williams, D. (1994). Somebody somewhere. New York: Doubleday. P.43
[49] Neil, L., Olsson, N and Pellicano, E. (2016) The Relationship Between Intolerance of Uncertainty, Sensory Sensitivities, and Anxiety in Autistic and Typically Developing Children. J Autism Dev Disord.

This is an episode of sensory overload and distress that resulted in a problematic breakdown in communication between a healthcare professional and an autistic patient.

Some autistic people reported to us that communicating needs to a health professional can also be impaired by 'Autism Fatigue'[50]. There is a lot of anecdotal evidence to suggest that autistic people have to expel huge amounts of energy to cope in a world attuned to the needs of neuro-typical people. Countering sensory overload and navigating social situations can cause exhaustion to become entrenched. Jonathan Andrews presented to the Commission on this concept and explained that some people can appear externally to be coping but they burn a lot of energy in keeping up appearances. When experiencing such fatigue, it can become challenging to communicate health needs to a professional.

It is, therefore, unsurprising that so many autistic people told us that they feel that consultations with healthcare professionals are all-too-often unsatisfactory. There is much more to be done to ensure that autistic people can confidently and easily access healthcare environments and benefit from quality consultations that are commonplace for non-autistic patients.

...Many autistic people and parent-advocates wrote to the Commission to tell us that one of the biggest barriers to accessing healthcare services is the sensory experience of the environments...

[50] Andrews, J. (2016) "Autism: Sorting Fact from Fiction". https://www.thersa.org/discover/publications-and-articles/rsa-comment/2016/01/autism-sorting-fact-from-fiction. Royal Society of Arts. Includes links to several blogs which discuss personal experiences of autistic fatigue.

2.6 Obstacle Six: Leadership of Autism in the Health System

There seems to be widespread agreement that there are problems in getting healthcare right for autistic people. But who's problems are they?

Barriers to accessing healthcare can be put up by the very structure of the health system itself. There is no single group of health professionals who take responsibility for autism and own the issues associated. Thus, there are few who champion autism and fight for the best for autistic people within the health sector. Kate Bamforth, a Learning Disability Liaison Nurse, explained that her liaison team take ownership of the healthcare for people with a learning disability but are not commissioned to do the same for autistic people who have an IQ >70. However, it should be emphasised that many individual healthcare professionals make every effort to provide excellence to their autistic patients.

There is an autism-lead in the Department of Health but there is no counterpart autism-lead in NHS England. **NHS England does not have a National Clinical Director for autism. Identifying a lead-person can be a way of galvanising progress.** This has been demonstrated through the appointment of Dr Carole Buckley as the Clinical Champion for Autism at the RCGP.

CASE STUDY

A little leadership goes a long way!

The Royal College of GPs made autism a clinical priority from 2014-2017. They received £32,000 of Department of Health funding. This grant from the Department of Health has enabled the College to campaign for improved healthcare for autistic people:

- *Cascade training out to 8000 GP practices*
- *Four faculty conferences delivering the connect autism training*
- *Training components in training for non-clinical staff including receptionists*
- *Produced GP friendly materials with top-tip consultation skills*
- *Resources for patients and carers on how to get the most out of your consultation*
- *Autism Charter to be promoted in GP practices*
- *A closed Facebook page – supporting clinicians who are autistic, or parents or siblings of autistic family members*
- *The entire April 2016 edition of Clinical News dedicated to autism – read by 50,000 GP College members with top tips*
- *Production of a new e-learning module in May*
- *Curriculum for training new GPs under review*
- *Autism in the CPD for GPs*
- *Three articles in Innovate – the GP's in training magazine*
- *Produced a GP Toolkit which is a 'one stop shop' for autism resources*

2.7 Obstacle Seven: Isolation, Avoidance, Inertia and Neglect

Despite having significant risks to their health, autistic people told us that they avoid healthcare environments and their health can suffer as a result.

Autistic Commission Member, Helen Ellis, told the Commission that some autistic people do not recognise their symptoms as unusual or make the connection between poor health and the need to proactively seek help from a professional. However, many of those that do recognise their symptoms and understand the need for professional help told us that they avoid attending healthcare environments. More research is needed to understand avoidance behaviours in the autistic population and the possible impact on access to healthcare and health outcomes.

Many told us of the crippling fear and anxiety that healthcare environments and professionals induce. The anxiety can result in a total inability to communicate their needs with the professional and can result in unsatisfactory and upsetting consultations.

Dr Yo Dunn told the Commission that "A large proportion of autistic people 'struggle to do stuff' even when highly motivated to achieve the task and no matter how much information is provided. Many need prompting and other support in order to achieve everyday tasks including taking medication, making and attending appointments and other health-related tasks."

Numerous advocates reiterated this point; that autistic people can struggle to complete tasks and can forget to do essential health-related tasks.

In addition, parent-advocates of autistic people told us many times of healthcare needs going unmet due to behaviour that challenges and poor understanding among healthcare professionals. One parent-advocate told us:

> "There is absolutely no chance of me getting him to take medicine. I don't know what we would do if he was ever very ill. I daren't even think about it"
>
> **Malachi Akram, Parent-Advocate**

Heather Tanner (a Parent-Advocate) told the Commission that her son John is eligible for an NHS Annual Check because he has a learning disability (he is also autistic). Sadly, John's health-check detected major kidney failure. Heather recounted her concerns when the hospital questioned whether John should be put onto dialysis treatment due to his mental capacity to cope with the procedures. Similarly, when discussing a kidney transplant, the hospital suggested that John might not be able to cope with surgery.

John needed blood tests three-times a week after his transplant. To do this, John was repeatedly restrained by four of five healthcare staff in corridors (he was too frightened to enter the room). Heather explained that she felt that resorting to restraint was unnecessary and asked for a community nurse to draw blood in John's home. This was refused. Heather now takes John's blood herself.

John's story is one of many stories which show a lack of training, skill or confidence in caring for autistic people. 74% (n=497) of respondents felt that autistic people receive worse or much worse healthcare than non-autistic people.

If John's mother had not stepped in to meet his needs, they may have gone unmet.

Making healthcare accessible to autistic people inextricably involves social care. Without an advocate, many contributors told us that they would end up not accessing healthcare services at all.

"Dentists – my tooth fell apart. Dentist was going to refer me. But they didn't. Will go dentist again when friends less busy. My teeth hurt every day"

Jonny Kingsley, Autistic Self-Advocate

"I can't actually get to the doctors currently as my support has gone – so am getting more ill physically- sores due to no support, not following medications properly and little things like sinus infections (since christmas) and breathlessness (for months now) are just collecting and not getting sorted"

Toby Adeyemo, Autistic Self-Advocate

"I found that Andrew could easily have been completely excluded from the Doctors because he forgot to attend"

Angela James, Parent-Advocate

Avoidance behaviours in a population who have increased health risks is an undesirable combination. More research is needed to establish such behaviours in the autistic population.

If health services are failing to meet the needs of others like John, it is possible that some autistic people may 'give up' on services which could lead to neglect of health needs. This could be particularly pronounced among those that do not have a strong and supportive advocate like Heather to insist on them having their needs met. As in the general population, social isolation will play into this lack of a support network and the possible resultant neglect. Autistic people are frequently socially isolated, yet often need someone else to assist them with their health needs.

"I avoid both [the GP and the hospital] unless I am in agony. Going out to either requires hours or usually days of psyching myself up/mentally preparing. I have 3 as yet undiagnosed health problems/worries that I can't sum up the courage to make the trip to the doctor's for. I'd rather suffer at home than talk to strangers (don't even like talking about it with family). If you want to see your own doctor you have to wait weeks for an appointment if you need to see someone sooner you have to take pot luck with a locum or another doctor you've never seen before."
Adam Fredrick-Hamilton, Autistic Self-Advocate

2.8 Training for Excellence

Health Education England was established as a Special Health Authority in 2012 and became a Non-Departmental Public Body on 1 April 2015, under the provisions of the Care Act 2014. Its role is to "…support the delivery of excellent healthcare and health improvement to the patients and public of England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place."[51]

Responsible for training staff for the NHS and developing those already working within healthcare, Health Education England works to ensure that undergraduate, postgraduate and Continuous Professional Development courses train and equip staff appropriately.

Health Education England has developed online autism awareness training resources available through 'eLearning for Health' and 'MindEd' on the Health Education England website and lists quality assured training available from other organisations[52]. These resources are free to use and available to everyone working in health and social care and beyond. Health Education England monitors who is accessing them. Health and social care service provider organisations are responsible for ensuring that their workforce is benefitting from these resources and developing the right skills, values and behaviours to deliver care excellence. All training resources should include autistic people in their production and delivery.

There is no national mechanism to ensure that the health workforce is benefitting from any available resources and developing the right skills, values and behaviours to deliver excellent healthcare and health improvement.

The statutory guidance that accompanies the Autism Act stipulates states that autism-awareness has to be included in all equality and diversity training for health and social care staff and that CCGs have to ensure that both general awareness and specialist autism training is provided on an ongoing basis.

Only 29% of local areas have made autism-training available to all health and social care staff[53].

The strongest piece of evidence to come out of our inquiry is the vital need for ensuring that all healthcare professionals are accessing quality training. Autistic people are the experts in their condition and training is the message repeated time and time again. If NHS England is going to close the health gap for autistic people, all staff must be well-trained. Design and delivery of training should include autistic people.

Dr Yo Dunn, Independent Consultant and Trainer, told the Commission that financial incentives and/or strong specific statutory duties would be required to actually achieve significant change in current practices in positive rather than negative directions.

@W_Autism_Comm major improvement would be if GP's and mental health workers had quality autism awareness training. Could be transformative

[51] Health Education England. (2015). Health Education England. [online] Available at: https://hee.nhs.uk/ [Accessed 17 May 2016].
[52] Health Education England. (2015). Autism. [online] Available at: https://hee.nhs.uk/our-work/hospitals-primary-community-care/mental-health-learning-disability/learning-disability/autism [Accessed 17 May 2016].
[53] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

2.9 Commissioning for Excellence

"Commissioning is seen as a key means of helping achieve a wide range of policy objectives in the NHS, including improving the safety and quality of services; creating better value for money and wider patient choice; and reducing inequalities in health."[54]

Clinical Commissioning Groups have statutory responsibility to commission most NHS services that the CCG deem to be necessary to meet reasonable local needs.[55] Clinical Commissioning Groups may struggle to meet the needs of autistic people if they do not have an understanding of autism, lack data on their local autistic population and do not have strong partnerships with local Autism Partnership Boards.

The inclusion of the autism health gap in the NHS mandate is a significant step in a positive direction. However, the NHS Business Plan for 2016/17 does not mention reducing inequalities in health for autistic people.[56] Statutory guidance does note that "Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families"[57] This commitment by the Government is welcome.

In his evidence to the Commission, Dr Phil Moore (Deputy Chair of Kingston CCG and Board Member of the NHS Clinical Commissioners) mentioned the need for training for commissioners to ensure that they commission local services with autism in mind. Health Education England should seek to ensure that Commissioners receive quality, self-advocate led, autism-training.

The local needs can also be communicated to CCGs through local Healthwatch branches. Healthwatch Cheshire East shared an example of their work with the Commission which led to improved diagnostic services for autistic people. Healthwatch England should encourage all local branches to consult their local populations on autism related issues and take these to CCGs to see changes made.

In order for services to meet the health needs of autistic people, commissioners need to understand autism and be made aware of the local needs of autistic people. This requires commissioners to receive quality training and have access to data regarding the health needs of local autistic people.

[54] Researchbriefings.parliament.uk. (2016). Research Briefings - The structure of the NHS in England. [online] Available at: http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7206#fullreport [Accessed 15 May 2016].
[55] ibid
[56] england.nhs.uk. (2016). Our 2016/17 Business Plan. [online] Available at: https://www.england.nhs.uk/wp-content/uploads/2016/03/bus-plan-16.pdf [Accessed 15 May 2016].
[57] gov.uk. (2015). Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf [Accessed 15 May 2016].

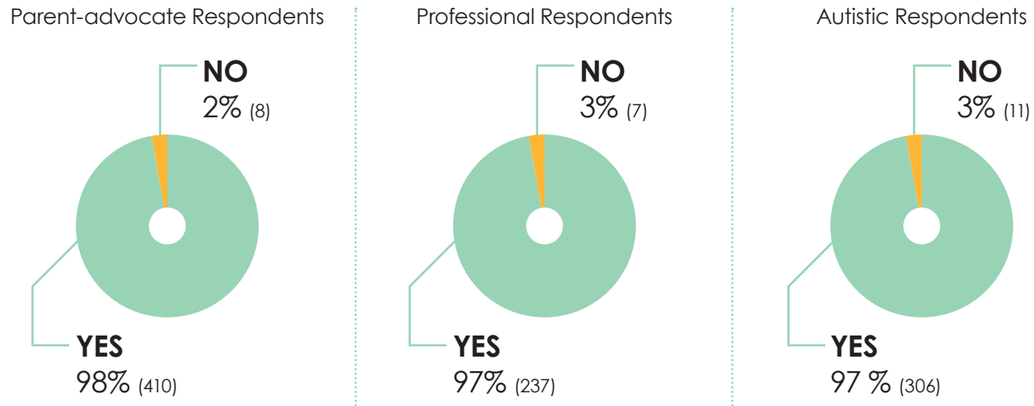
2.10 Inspecting for Excellence

The Care Quality Commission is the independent regulator of health and adult social care in England. Inspections of health and social care providers are structured around five key questions:

- Are they safe?
- Are they effective?
- Are they caring?
- Are they responsive to people's needs?
- Are they well-led?

There is currently no autism-specific question included in any CQC healthcare inspection framework. There are two references to autism within a Learning Disability question but only in reference to LD wards in a mental health service or community mental health services.

Do you think that the Care Quality Commission should check that health services are meeting the specific needs of autistic patients?



"We are satisfied that we look actively for services meeting the needs of people with autism in LD wards. We are less likely within mental health and even more less likely in acute hospital settings and in primary care."

Dr John Devapriam, CQC

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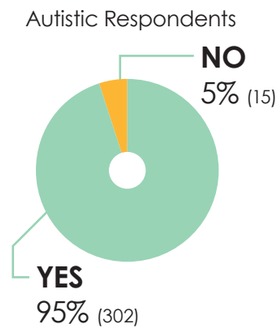
Inspections carried out by the CQC are structured around Key Lines of Enquiry (KLOE). The framework accompanying the KLOE R2 "Do services take account of the needs of different people, including those in vulnerable circumstances?" mentions dementia and LD but does not mention autism.

The five questions used to inspect healthcare provision for patients with a learning disability could easily be extended for autism. There is a video clip and brief guide available to train inspectors on LD issues but there is nothing for autism. Autistic people are not routinely used in inspections as Experts by Experience.

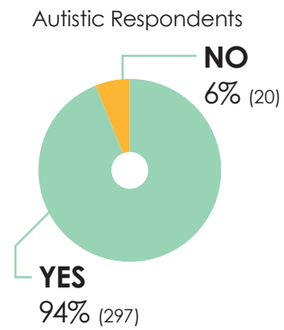
The CQC do not ask any autism specific questions in their healthcare inspections. 97% (n=748) of survey respondents felt that the CQC should ensure that health services are meeting the specific needs of autistic people.

2.11 Collecting Data for Excellence: The Statistical 'Invisibility' of Autism in the Health System

Would you like your doctor to have a note on their computer to tell them that you are autistic?



Would you be happy for your GP/ doctor to add you to an anonymous database of autistic people to help improve services?



There have been some positive developments in terms of data collection including the new premature mortality review on LD which will review every death of people with a learning disability wherever they are in the health service. Similarly, autism is now part of the Mental Health Minimum Data Set (MHMDS). Both the LD mortality review and the MHMDS will begin to provide the necessary data to make positive changes for autistic people.

However, there are concerns that data on autism is all-too-often fractured according to additional conditions such as LD or mental health and therefore the specific data on autism is patchy. The new premature mortality review for LD does not account for those autistic people who do not have a learning disability but may still die prematurely. The Commission met with Public Health England, NHS England, Dr Yo Dunn and Professor Gillberg to discuss the role that data collection plays in improving healthcare.

Commission Members were displeased to see the incompleteness and lack of data available to Public Health England. Hospital admissions data is inconsistently collected such that it appears to show that most autistic people never go into hospital. Furthermore, we know that the Swedish study shows that suicide rates are nine-times higher for autistic people[58]. Such deaths are investigated by a coroner in this country but autism is very rarely mentioned on death certificates. Death certificate data shows no increased prevalence of suicide in autistic people; it is incomplete, inconsistent and unusable.

How will commissioners and healthcare professionals meet the needs of autistic people if their needs are not monitored?

NHS England told the Commission that currently there is inconsistent identification of autistic patients; something which frustrates many of those who sent written submissions to the Commission. Our survey respondents have made it clear that they would like their GP to have a flag on a computer screen to tell them that they are autistic. 95% (n=302) of autistic people would like their doctor to have a note on their computer screen to tell them that the patient is autistic.

It is clear that a range of professionals believe that we need to start recording autistic people's use of health services and that the first step in doing so would be to have a consistent diagnostic-code for autism and an anonymous National Primary Care Register for autism.

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[58] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo lte, S. (2015). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), pp.232-238.

"We have inconsistent identification and flagging systems…For healthcare professionals it is really helpful to have a flag either on a register, or on a system or on a record. Such that we know we have got to do something different…to make a reasonable adjustment...to change the way we provide the service… From a purely NHS point of view, it [a flag] is really helpful such that we can start to know how well, or otherwise, we are doing"

Hazel Watson, NHS England

"Currently there isn't a register for people with autism [in the QOF]…if that changes, it would substantially enhance the chances in the beginning to get some data. We have recently had successes in getting a lot of data about the primary healthcare of people with learning disabilities…by getting anonymised extracts …which has been very effective... If we had QOF registers for autism we would be able to do the same for people with autism."

Professor Gyles Glover, Public Health England

"Having a diagnostic code recorded in primary care data systems for autism... is the sine qua non for improvements in outcomes."

Professor Christopher Gillberg, University of Gothenburg, Sweden.

However, it is extremely important that data collection always considers the concerns of the autistic population.

Dr Yo Dunn explained to the Commission "Concerns have been expressed by a significant number of autistic people about 'registers' or any information collection which potentially allows the identification of individual patients. **Statistical information which cannot be used to identify individuals raises far fewer ethical concerns and would clearly be of benefit in tracking progress on healthcare outcomes.** I think many people would like to see improvement in the collection of data on the whole autistic population (without the fracturing of the autistic population and/or merging with other groups e.g. learning disabilities/ mental health etc.)"

The concern about the use of a register collected which could identify individual autistic people has been raised by others including Helen Ellis, Commission Member:

"I understand from a research point of view why data is very important. The minute you start talking about a register my mind is screaming - You haven't convinced me why I should be on it! You haven't told me what you are going to want from me, what you're going to do with it, where it is going to be stored. I don't want to go on a list that in 20 years-time, a social worker is going to pull out and go 'yeah [you're autistic]...you can't have your kids anymore' it's a terrifying thing for a lot of people and there's not a lot of trust re keeping data secure"

It is clear that there is an incredibly strong mandate for the introduction of a diagnostic-code for autism and an anonymous National Primary Care Register for autism included in the Quality and Outcomes Framework (QOF) for GPs. However, it is also imperative that this is done is partnership with the autistic community, allaying their fears and promoting the benefits.

2.12 Learning from Sweden

The premature mortality statistics quoted in this report come from a Swedish study. Such a study is impossible in the UK because *we simply do not have the data available to conduct large-scale investigations of the health service use of autistic people.*

NHS Choices have acknowledged the Swedish study as highlighting a real need for a better understanding of premature mortality here in England[59].

There are limitations with using Swedish data to speak about healthcare issues in England. Our healthcare system is different, the training of our healthcare professionals is different and the management of autistic patients is different.

Autistic people in Sweden receive very early diagnosis. In Sweden, children are screened for autism at age two-and-a-half or three[60]. All diagnosed patients are recorded on the National Patient Register in Sweden. The result of early diagnosis alongside a National Patient Register is a large resource of data that can be used to monitor autistic people's healthcare and seek improvements.

The Commission welcomes the Government's commitment to launch the world's first Mortality Review for people with a learning disability. Learning about causes of premature death will help to prevent such deaths in the future. The Commission considers this to be a positive step and one which should be extended to include the premature deaths of autistic people.

A new Autism Mortality Review would begin to give a clearer picture of the mortality issues associated with autism. Without this, we remain reliant on Swedish data to speak about premature mortality and autism.

[59] Nhs.uk. (2016). People with autism are 'dying younger,' warns study - Health News - NHS Choices. [online] Available at: http://www.nhs.uk/news/2016/03March/Pages/People-with-autism-are-dying-younger-warns-study.aspx [Accessed 17 May 2016].

[60] It should be noted that Professor Gillberg advocated for such a screening programme and argued that it ensures much earlier diagnosis. Screening for autism has been reviewed in the UK and has not been recommended. If this were to be reviewed, attention to the Swedish screening method may be helpful.

2.13 Learning from Dementia

Three key lines of our inquiry have been training, data and inspection. Strong efforts have been made to improve dementia services through training, data, inspection, awareness-raising and more. The comparison table below highlights just how far we have got to come to achieve parity for autistic people.

This comparison particularly highlights the need for investment in research. A research-spend of £4m on autism is an incongruity when the cost to the economy is £32bn[61].

	AUTISM	DEMENTIA
PREVALENCE[62]	700,000+	850,000
COST TO ECONOMY[63]	£32 billion+ (based on 600,000 diagnosed)	£23 billion
TOTAL RESEARCH SPEND[64]	£4m	£50m
RESEARCH SPEND PER PERSON	£4.26[65] – £6.60[66]	£61[67]
DATA	No Autism Profile No Indicator in QCF No National Audit	Dementia Profile Indicator in QCF National Audit of Dementia
INSPECTION	No autism-specific work undertaken by CQC	Dementia specific questions included in inspection framework
LEADERSHIP	No National Clinical Director	National Clinical Director for Dementia
PUBLIC AWARENESS	£325,000[68]	Prime Minister David Cameron launched 'Challenge Dementia' with a spend of £2.3m[69]

...>

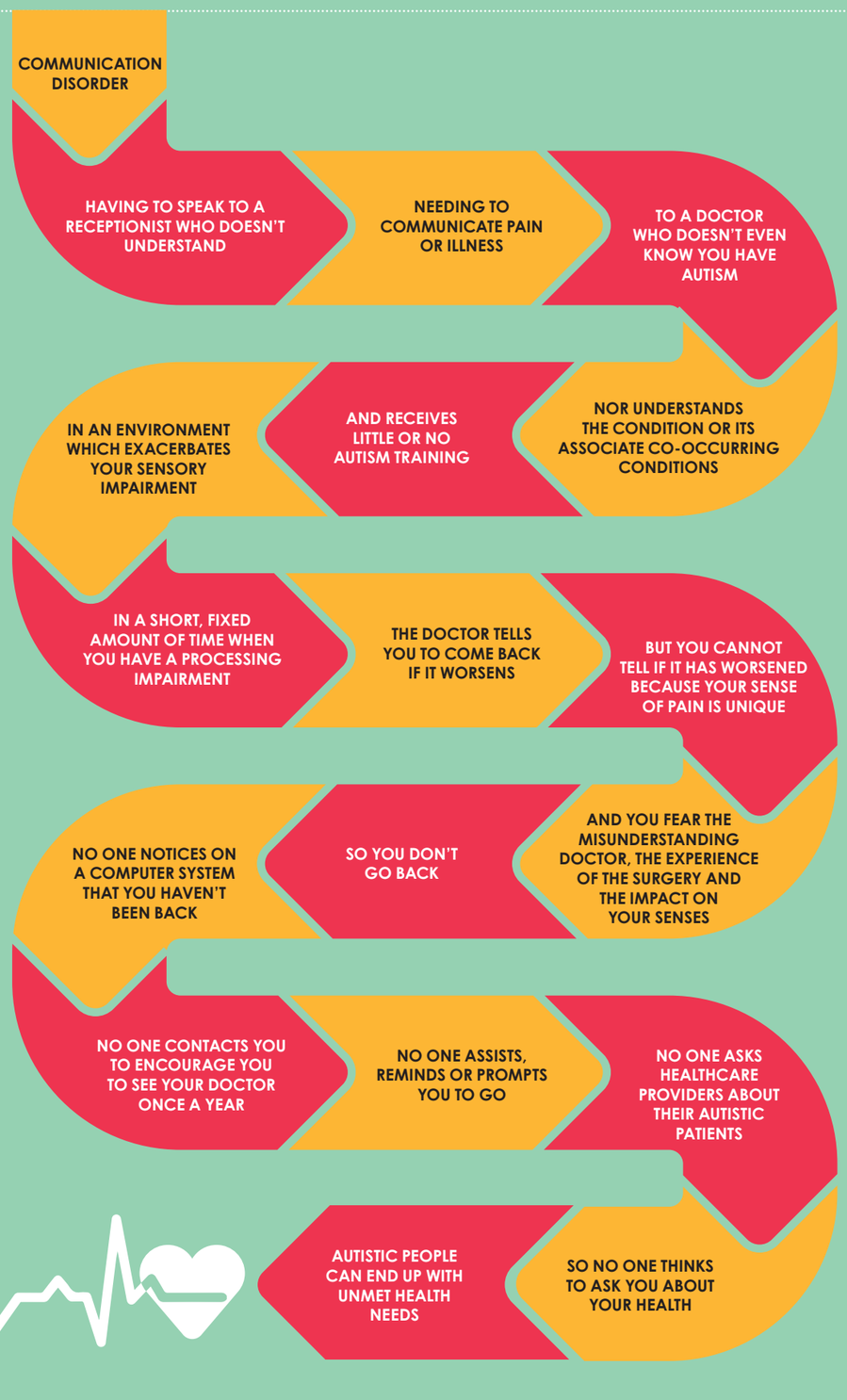
[61] Knapp, M., Romeo, R. and Beecham, J. (2009). Economic cost of autism in the UK. Autism, 13(3), pp.317-336.
[62] ibid
[63] ibid
[64] ibid
[65] Pellicano, E., Charman, T. and Dinsmore, A. (2013). A Future Made Together. [online] newsletters.ioe.ac.uk. Available at: http://newsletters.ioe.ac.uk/A_Future_Made_Together_2013.pdf [Accessed 17 May 2016].
[66] Knapp, M., Romeo, R. and Beecham, J. (2009). Economic cost of autism in the UK. Autism, 13(3), pp.317-336.
[67] ibid
[68] UK Parliament. (2016). Autism:Written question - 36142. [online] Available at: http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2016-04-29/36142 [Accessed 15 May 2016].
[69] Theyworkforyou.com. (2016). World Autism Awareness Week - Backbench Business. [online] Available at: http://www.theyworkforyou.com/debates/?id=2016-04-28a.1573.0 [Accessed 15 May 2016].

The steps taken to improve diagnosis and support of patients with dementia have been welcome. The UK's 850,000 people with dementia deserve to have their healthcare held accountable through CQC inspections and thorough data collection. They also deserve to live in dementia-friendly communities; educated through the Challenge Dementia project. They deserve to have their condition researched with a healthy budget. They deserve to be treated by health professionals who are trained.

This inquiry has demonstrated the need for parity for autism. With significant risks posed to the health of autistic people and to their life expectancy, getting healthcare right for this population group is essential. Just like patients with dementia, autistic people deserve to have the CQC ensure that healthcare providers meet their needs. Autistic people deserve to have data collected on their condition so as to improve services, to live in understanding communities and to have their condition researched with a sensible budget. Critically, they deserve to be treated by healthcare professionals who are well-trained in their condition.

The Government's 'Challenge Dementia' programme has been transformative for patients with dementia. Steps are also being taken for autistic people but progress is slower. Our six recommendations may substantially enhance access to healthcare for autistic people.

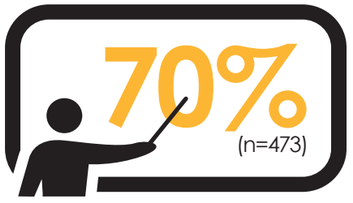
A True Obstacle Course



PART THREE
RECOMMENDATIONS

3.1 Recommendation One: Training

NHS England, in partnership with autistic people, to produce a resource pack for CCGs on training; Secretary of State for Health to write to CCGS; Department of Health to strengthen Autism Self-Assessment Framework; those who control clinical curricula to ensure the embedding of autism-training.



of all survey respondents **cited training as the priority which would most improve access to healthcare for autistic people**.

The introduction of the Autism Act was a momentous achievement for the autistic community. It is the first piece of condition-specific legislation and stipulates that all healthcare staff should be trained in autism. Only 29% (down from 38% in 2013) of respondents to the autism self-assessment framework rated themselves 'green' for having training available to all[70]. There is no central collection of data on the take up of this training.

The self-assessment framework does not currently collect data on the take up of training. HEE makes training available but does not monitor the individual healthcare professionals benefitting from it. The CQC does not ask about autism training in healthcare inspections. Autism is not included in the different accountability mechanisms used for the NHS (e.g. the NHS Outcomes framework) and so NHS bodies are not incentivised in the same way as they are for learning disability and dementia to ensure that training is in place. If NHS England is going to close the health gap for autistic people, our evidence suggests it is critical that all healthcare staff are trained.

Therefore, we are calling on:

1. NHS England to produce a resource pack for CCGs with examples of best practice and advice on increasing training of all health care staff
2. Secretary of State for Health to write to all CCGs to reiterate that they are obliged to make training available as stated in the statutory guidance and instruct them to prioritise take-up of training
3. Department of Health to support existing question 19 in the Autism Self-Assessment Framework with a request for local authorities to submit data on take-up of training
4. Those in control of clinical curricula, including Health Education England, to ensure that they only commission undergraduate and postgraduate training which includes autism-awareness

Contributions made to this inquiry by autistic people and their families are clear; training, designed and delivered by autistic people, is utterly essential if access to healthcare is to be improved.

NHS England, the Department of Health, the CQC and Public Health England all must play their part in ensuring healthcare staff meet the needs of autistic people.

[70] Improvinghealthandlives.org.uk. (2016). Autism self-assessment 2014 :: Public Health England - Improving Health and Lives. [online] Available at: http://www.improvinghealthandlives.org.uk/publications/313914/Autism_self-assessment_2014 [Accessed 14 May 2016].

3.2 Recommendation Two: Inspection

The CQC to implement five autism-specific questions into hospital and primary care inspection frameworks; include autism in Key Line of Enquiry R2; develop training guides for inspectors.

1. The CQC to include the questions on the following in their inspections framework for hospitals:
   a. What reasonable adjustments do you routinely implement to meet the healthcare needs of autistic patients?
   b. Which/How many members of staff have received (a) autism awareness-training and (b) specialist autism training?
   c. Do you have a flag for autistic patients? If so, can you show us where they are currently?
   d. Do you have an autism lead member of staff?
   e. Can you show us some outcomes from the care and treatment of autistic patients?

These questions mirror existing questions for patients with a learning disability[71].

2. Key Line of Enquiry (KLOE) R2 is embedded in each inspection framework. It asks, "Do services take account of the needs of different people, including those in vulnerable circumstances?" This KLOE currently references dementia and learning disability as examples. It should be extended to mention autism.

3. A brief guide and video clip should be developed to train inspectors in an understanding of autism so that they can appropriately assess autistic people's healthcare. Health Education England should assist with this. The training should include advice on routinely including autistic people as Experts by Experience. Trainers should be equipped with an evidence table with prompts on autism. All training should be developed with autistic people and family-advocates.

[71] improvinghealthandlives.org.uk. (2015). CQC inspection reports of NHS trusts How do they address the needs of people with learning disabilities? [online] Available at: http://www.improvinghealthandlives.org.uk/securefiles/160515_1643//IHaL%20CQC%20inspections%20LD%20FINAL.pdf [Accessed 15 May 2016].

3.3 Recommendation Three: Data Collection

GP indicator for autism in the Quality and Outcomes Framework (QOF) leading to a National Primary Care Register to end the statistical 'invisibility' of autism in the healthcare system; extension of the Learning Disability Mortality Review to include a new Autism Mortality Review.

The Commission calls for consistent diagnostic-coding to be used in GP practices so that there is consistency in flagging autistic patients. This code should be used to form an anonymous National Primary Care Register to be used to improve services, overcoming the current lack of data available. This should be introduced as part of the QOF which incentivises GPs to utilise a code and maintain a register.

95% (n=302) of autistic survey respondents **want their doctor to have a computer flag for autism**.

96% (n=297) of autistic survey respondents **would be happy to be added to an anonymous database of autistic people to help improve services**.

76% (n=241) of autistic and parent-advocate survey respondents **reported that their GP does not make changes to their or their child's services to meet their needs as an autistic service-user**.

As we do not have a clear picture of the mortality of autistic people here in the UK, we are calling for the Learning Disability Mortality Review to be extended to include an Autism Mortality Review.

An Autism Mortality Review would allow the gathering of important data into the mortality risks associated with autism. We do not currently have an accurate picture of the mortality of autistic people and as such, cannot tailor services to ensure good health outcomes.

The Commission's recommendations on data come with an intrinsically linked recommendation; discussions around the introduction of an anonymous GP register within the QOF must be had with autistic individuals and family-advocates fully involved.

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Some autistic people have expressed concerns about the way in which data from a GP register could be used. NICE, the British Medical Association and other involved bodies have a responsibility to work with the autistic community to ensure that their concerns are addressed and to make the benefits of such a register clear. A truly anonymous register carries far fewer concerns than one in which an individual could be identified.

We are calling for the NICE Indicator Advisory Committee to develop a GP indicator and anonymous National Primary Care register for autistic patients as part of the QOF. Furthermore, the development of an indicator for the CCG Outcome Indicator Set should be considered. The Health and Social Care Centre should develop an indicator to monitor health outcomes for autistic people in the NHS Outcomes Framework.

The National Primary Care Register would be a useful research tool. The Swedish study on premature mortality was made possible by the use of a national patient register. Consideration should be given to the use of an anonymous National Primary Care Register for autism research.

"After all, we can only be sure to improve what we can actually measure."[72]

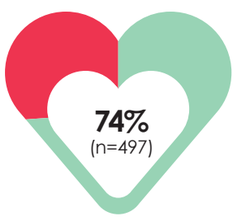
[72] gov.uk. (2008). High Quality Care For All. [online] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228836/7432.pdf [Accessed 15 May 2016].

3.4 Recommendation Four: Annual Health Checks

Following the introduction of an anonymous National Primary Care register for autism within the QOF, NHS England should look to implement annual health checks for autistic people.

On the basis of health inequalities suffered by those with a learning disability, annual health checks for people with a learning disability were introduced in 2008/09. Annual Health Checks are seen to be a reasonable adjustment.

According to the Swedish study, autistic people who do not have a learning disability die an average of 12 years prematurely yet we do not offer this population group an annual health check.

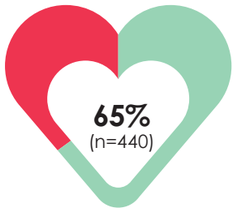


of all survey respondents **feel that autistic people received 'worse' or 'much worse' healthcare compared with non-autistic people**.

There is a good evidence to show that the introduction of health checks consistently leads to:

- "the detection of unmet, unrecognised and potentially treatable health needs (including serious and life threatening conditions such as cancer, heart disease and dementia)
- Targeted actions to address these health needs"[73]

The evidence gathered for this inquiry indicates that the whole autistic population may benefit from an annual health check.



of all survey respondents **felt that health professionals 'rarely' or 'never' understand autism and how it affects someone's physical and mental health**. A full health check is a reliable way of identifying and treating co-occurring conditions.[74]

Part of the reasoning for introducing annual health checks for people with a learning disability, was the recognition that people with learning disabilities often have "difficulty in recognising illness, communicating their needs and making timely use of primary health care services"[75]

...>

[73] Robertson, J., Roberts, H. and Emerson, E. (2010). Health Checks for People with Learning Disabilities: A Systematic Review of Evidence. [online] improvinghealthandlives.org.uk. Available at: https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf [Accessed 15 May 2016].
[74] ibid
[75] ibid

A core symptom of autism is difficulty in communication. Furthermore, autistic people do not experience pain and other symptoms in the same way as the neuro-typical population and their ability to make timely use of healthcare services may therefore be impaired. There is also a common theme from our consultation which shows autistic people avoiding healthcare settings and lacking the motivation, inertia and ability to make timely use of primary health care services. The co-occurring conditions of anxiety and sensory impairment exacerbate these problems.

It has also been noted that the learning disability annual health checks are beneficial because they are an 'introduction' to the GP and the surgery environment. This familiarisation process is critical for autistic people who appreciate predictability. Yet autistic people are not offered this introduction. Such an opportunity would decrease uncertainty which is a key driver of anxiety which in turn, may be a cause of avoidance behaviours.

The introduction of such checks should be done in consultation with the autistic community to ensure they are accessible, take-up is good and they are effective.

3.5 Recommendation Five: Leadership

NHS England to appoint a National Clinical Director for Autism and an autism-lead member of staff; health bodies to appoint autism-lead staff; Department of Health to include autism in Public Health England's Remit Letter.

Autism is not only statistically invisible within the health system but is also an underrepresented condition. There is no National Clinical Director for autism within NHS England nor an autism 'lead'. Furthermore, there is no autism lead in the Royal College of Nursing, Royal College of Paediatrics and Child Health or Royal College of Psychiatrists, nor in Public Health England, NHSCC, CQC, NICE or any other NHS or arms-length body that the Commission is aware of. There are no autism nurses on hospital wards and very few autism liaison staff in GP surgeries.

This lack of leadership leaves gaps in ensuring that health services meet the needs of autistic patients. Rarely is there an autism-specific approach which avoids this fragmentation.

This lack of leadership has been identified by professionals and autistic people alike. Hazel Watson, NHS England, explained that although there is a commitment in the NHS mandate to reduce health inequalities for autistic people, because implementation sits across a number of programmes, it is harder to follow a 'Golden Thread' to ensure delivery.

The Commission calls on the Department of Health to request NHS England to appoint a National Clinical Director for Autism and an autism-lead to work in partnership with the autism-lead in the Department of Health and to oversee:

- production of a 'Golden Thread' implementing work-streams from the NHS Mandate to NHS Business Plan
- appropriate introduction of an Autism Indicator in the QOF for GPs and a Primary Care Register for autism
- timely introduction of annual health checks in consultation with the autistic community
- production of a resource pack for CCGs, in partnership with autistic people, to ensure that autism-training becomes embedded
- the Government's call to reduce health inequalities
- liaison with bodies such as HEE and General Medical Council to ensure that the healthcare workforce can meet the physical and mental health needs of autistic people
- cessation of the hospitalisation of healthy autistic people
- cessation of inappropriate use of Assessment and Treatment Units.

The Department of Health's remit letter to Public Health England does not mention autism. The Remit Letter should reference the need to collaborate on closing the health gap for autistic people.

3.6 Recommendation Six: Resources

Department of Health to launch a time-limited Autism and Health Innovation Fund.

75% (n=510)
of autistic and parent-advocate survey respondents said that they **would like to receive help to understand what will happen when they go to the doctor or hospital**.

The Asperger Consultant Group explained in their submission to the Commission, the importance of their concept of the Triad of Understanding – 'others understanding me', 'me understanding myself' and 'me understanding others'. It is critical to train health professionals to understand autistic individuals. However, it is also critical that autistic people are able to understand themselves and others too. Autistic people may need to be helped understand their own symptoms, where to go for help, how to ask for help, what the process will be and what the outcomes might be.

The myVoice Youth Consultants, a group of young autistic people, have been reviewing local health services with a grant from the Department of Health. One of their key recommendations is that service providers should produce and distribute information to patients so they understand how to use the service in a step-by-step format.

The 'All About Me!' pilot project, funded by NHS England and produced by Autism-In-Mind, wrote to the Commission and told us "…we believe that if young people have greater self-awareness and a developed understanding of what their autism means to them; they will be better equipped to deal with life stressors…If you don't have a good understanding of self…then how can you go to the doctors with a healthcare need and be sure it is a healthcare need and not just related to your autism?"

- We are calling for the Department of Health to offer a time-limited Autism and Health Innovation Fund.
- Applications to be made by Royal Colleges, NHS bodies and third sector organisations.
- The scope of the fund is for the development and distribution of tools, aids and resources to help autistic people make the most out of healthcare experiences.
- Research funders should also consider studies into preventing poor health in autistic people. Such research may prove a useful tool in indicating which resources/aids/mentoring programmes autistic people would benefit from.

The National Autistic Society has developed a hospital passport which is currently undergoing review. Only 4% of our survey respondents use the hospital passport but 30% said they would like their GP to provide one to them. If the review concludes that this is a worthwhile tool, raising awareness of its availability and training healthcare professionals to use it, will be important.

Understanding is a two-way process. As professionals are trained, autistic people should be equipped with the resources to understand what will happen in healthcare environments.

"We have nothing, to help us, last time I had to attend hospital for a emergency op they wouldn't take my needs into consideration and I refused to stay and went untreated"
Mary Croos, Self-Advoate

[76] Robinson, J. (2016) 'Data analysis in participatory research with adults with Asperger's syndrome' in Hardwick, L, Smith, R. and Worsley, A. (eds.) Innovations in Social Work Research, Jessica Kingsley, pp. 241-258

These six, simple, inexpensive and achievable recommendations could substantially improve access to healthcare for autistic people. The recommendations could help to make steps towards closing the health gap suffered by autistic people and improve quality of life and life expectancy.

Training, inspection, data collection, annual health checks, leadership, resources and research are the tools to deconstruct the obstacle course.

Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
APPG	All Party Parliamentary Group
AS	Asperger Syndrome
ASC/ASD	Autistic Spectrum Conditions/Autistic Spectrum Disorders
CPD	Continuous Professional Development
CQC	Care Quality Commission
GP	General Practitioner
HEE	Health Education England
IQ	Intelligence Quotient
KLOE	Key Line of Enquiry
LA	Local Authority
LD	Learning Disability
LGBT	Lesbian, Gay, Bisexual and Transgender
MHMDS	Mental Health Minimum Data Set
NHS	National Health Service
NHSCC	NHS Clinical Commissioners
NICE	The National Institute for Health and Care Excellence
PHE	Public Health England
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCPCH	Royal Colleges of Paediatrics and Child Health
RCPsych	Royal College of Psychiatrists
SAF	Self-Assessment Framework

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Appendix One: A Note on Diagnosis

According to respondents in the ASPECT report, a national consultation of those with Asperger Syndrome, diagnosis was a key area of concern; 64% (n=154) of respondents said it was either very or somewhat problematic to get a diagnosis and 61% (n=145) find the route to diagnosis very difficult.

Autistica's 'One in a Hundred' report noted that families found getting a diagnosis a real challenge and did not feel that they received sufficient information and services .

While diagnosis is an issue of great concern to the autistic community and their families, the Commission recognised the existing work being done by the All Party Parliamentary Group on Autism in partnership with the National Autistic Society. The Commission welcomes the Government's commitment to measure the number of people diagnosed with autism in every area of England. In an effort to avoid replicating existing work, the Commission did not include a specific focus on diagnosis in the Terms of Reference for this inquiry.

However, it should be noted that the Commission sees diagnosis as a critical aspect of access to healthcare. The recommendations made here cannot be successfully implemented without due attention to the diagnosis crisis facing our country. More about the crisis can be seen at www.autism.org.uk/DiagnosisCrisis

[77] Beardon, L. and Edmonds, G. (2016). ASPECT Consultancy Report. [online] sheffield.ac.uk. Available at: https://sheffield.ac.uk/polopoly_fs/1.34791!/file/ASPECT_Consultancy_report.pdf [Accessed 14 May 2016].

[78] Wallace, S., Parr, J., and Hardy, A. (2013). One in a Hundred: putting families at the heart of autism research. [online] autistic.org.uk Available at: https://www.autistica.org.uk/wp-content/uploads/2014/10/One-in-a-Hundred-Autisticas-Report.pdf

Appendix Two: Inquiry Terms of Reference

The Westminster Commission on Autism

Access to Healthcare Inquiry - Terms of Reference

The Westminster Commission on Autism has been launched in recognition of the need to do more to work in strategic partnerships, taking action to improve quality of life for people with autism. All work carried out by the Commission will be driven by the authentic voices of those with autism and their families/advocates. The Commission will produce evidence based recommendations for policy and practice. The Commission will meet regularly in the Houses of Parliament and hold time-limited inquiries. These inquiries are intended to lead to positive improvements in policy and practice.

Following the Government's inclusion of tackling health inequalities and promoting "full, healthy and independent lives"[79] for people on the autism spectrum in the latest mandate to NHS England, the first inquiry will consider 'Access to Quality Healthcare' for people on the autism spectrum. The inquiry will make specific reference to recent studies indicating that people on the autism spectrum die prematurely in almost all 'cause-of-death' categories[80]. The Commission recognises timely access to healthcare, including preventative care, as an essential part of ensuring that autistic people live long and healthy lives. Further, the Commission holds that good autism practice is good practice for all.

Therefore, the 'Access to Quality Healthcare' inquiry will seek to answer the following key questions:

1. What barriers are present when people with autism access healthcare services?
2. In seeking to address the barriers, what is the role of training in finding solutions? This includes staff in healthcare environments as well as training for people with autism to equip them to make the most of their healthcare services.
3. In seeking to address the barriers and improve quality of life and life expectancy, what is the role of data collection, regulation and inspection?
4. What more can be done to improve implementation of existing measures/resources (i.e. NICE guidelines) which are aimed at addressing the barriers?

The Commission will call for evidence submissions from autistic people, their families, charities, service providers, academics, health professionals, statutory bodies and others. Themes drawn from this evidence will be used to produce recommendations in a written report for the attention of Government, NHS England, Clinical Commissioning Groups, Local Government and others. If it is felt that new measures/resources are required to address the issues uncovered, the Commission may choose to run a follow-up inquiry. All work carried out by the Commission is aimed at creating a more 'autism-friendly' world so as to improve quality of life for people with autism.

[79] Gov.uk. (2016). The Government's Mandate to NHS England for 2016-17. [online] Available at: https://www.gov.uk/gover ıent/uploads/s attachment_data/file/494485/NHSE_mandate_16-17_22_Jan.pdf [Accessed 15 May 2016].

[80] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bo lte, S. (2015). Premature mortality in aut spectrum disc Journal of Psychiatry, 208(3), pp.232-238.

The Surgery

She tries to hide her grimace with a smile
Sickly and feigned – but thinks I cannot tell –
And gestures, still confused, to velvet chairs.
"You'll need to sit and wait" she clarifies,
Her furrowed brow betraying silent hope
I pick the one that's furthest from her desk.

"So what's this all about?" His crocodile-
fanged mouth demands an answer briskly snapped.
I start composing thoughts; he chomps again,
Incisors devouring my blooming thoughts.
Too much light gnaws their weeds; the ceiling glares;
The muggy heat constricts my gasping throat.

I've never told him. But he's never asked;
"Physician, educate thyself", I say.
The nurses used to grasp it all, until
Cost-cutting saw them shunted out the door.
"There's not much I can do". He falsely smiles.
"Come back if it gets worse, that's what I'd do".

I still recall that day ten years ago.
Sometimes I wonder if I should go back –
But surely they would tell me if I should?

By Jonathan Andrews, Self-Advocate

autism alliance
autism plus
ADDING VALUE TO LIVES
RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE
IDENTIFICATION INTERVENTION INCLUSION
autism
west midlands
AUTISTICA
Building brighter futures through autism research
NCG NATIONAL CHILDREN'S GROUP
mind
for better mental health
The National Autistic Society
Ambitious about Autism
Hesley Group
north east
autism society