The Strategy Unit.

863: Autism population health needs assessment: rapid evidence scan

Richard Ward

NHS
Midlands and Lancashire
Commissioning Support Unit

Table of contents

Introduction

This rapid evidence scan was commissioned by Black Country and West-Birmingham (BCWB) Sustainability and Transformation Partnership (STP) to inform a forthcoming population health needs assessment for autistic people of all ages within the BCWB.

While the impact of COVID-19 on autistic people and their families is outside the remit of this review, it is likely that COVID-19 has worsened health inequities and disparities in access for autistic people, particularly the most vulnerable.

This evidence scan summarises available evidence from the international and UK published academic (primary and secondary research) and grey literature on each of these topics, highlighting gaps in the literature and potential areas of unmet need that may usefully inform local commissioning. This scan also includes a focus on the wider determinants of health, where they pertain to variations in care and outcomes (e.g. employment, criminal justice system; education).

This report covers five main areas relating to:

a) **population characteristics** of autistic people (including prevalence, demographics and comorbidities);

b) **health behaviours** in autistic people;

c) **variation in outcomes and wider determinants of health** (to understand what inequities are faced by autistic people);

d) **Access to health and care services**; and,

e) **current policy**, **recommendations** and **planned changes** to policy.

It is important to acknowledge and reflect upon the wider debate concerning the language used to describe autism in research. Covered in detail elsewhere (Botha et al., 2021), this debate concerns the use of 'person-first' versus 'condition-first' language to describe autism. While the intention of using 'person-first' language ('people with autism') is to position the individual, their 'personhood' and humanity above their condition, many autistic individuals, advocacy groups, and charities favour 'condition-first' language (Botha et al., 2021), to emphasise that autism is a part of the identity or make-up of that individual. This review uses condition first language (i.e. 'autistic people') in acknowledgement of this).

This review focuses on **autistic people who do not have a learning disability**, as local data collection and strategic efforts to enhance service provision for those with learning disability are further progressed.

Executive summary

Population characteristics

Prevalence and demographics

- UK prevalence estimates converge to suggest that autism occurs in around 0.6 to 1.7% of the general population (Russell et al., 2021; Roman-Urrestarazu et al., 2021; Rydzewska et al., 2018, Rydzewska et al., 2019); though there is considerable variation in how this data is collected and reported.
- And, these figures do not give a sense for the proportion of individuals who were diagnosed with autism later in life, and the proportion who may remain undiagnosed (Russell et al., 2021).
- There is variation in how local prevalence rates are collected and reported, which make it difficult to undertake robust comparisons.
- Gaps in existing literature and local intelligence sources preclude a reliable view of how sociodemographic characteristics are distributed among potentially more vulnerable autistic populations (Roman-Urrestarazu et al., 2021).
- Further research with detailed and consistent demographic data-collection is needed.

Population characteristics

Common comorbidities

- Autistic children, young people and adults are considerably more likely to have a physical or mental health condition than those who are not autistic (Harper et al., 2019; Harper et al., 2019).
- Notably, no source examined health conditions in autistic older adults, this constitutes a major gap in the evidence, given that the burden of many health problems and need for support both increase with age.
- While not exhaustive, this review identified several groups of conditions which have been confirmed to co-occur with autism across independent studies, including:
    - **physical health conditions** (tooth decay and gum disease; epilepsy; hypertension and high blood cholesterol; allergies; reproductive system diagnoses);
    - **mental health or other neurodevelopmental conditions** (anxiety, depression, ADHD, alexithymia, eating disorders).
- Evidence of potential gender disparities in the risk for certain health conditions may be an area for consideration when planning and commissioning preventive health services (Green et al., 2019).

Executive summary

Population characteristics

Common comorbidities

- Autistic women and girls may have a higher rate of endocrine and reproductive system diagnoses (7.8%), highlighting the importance of adopting a gender-informed lens when considering autism health inequalities (Kassee et al., 2020; Simantov et al., 2021).
- UK cross-sectional evidence (Simantov et al., 2021) points to an increased rate of pre-diabetes symptoms and reproductive system diagnoses (e.g. PCOS) in autistic women. Though, autistic women were found to have lower rates of vascular and metabolic conditions.
- Evidence of a higher rate of the following health conditions should be interpreted with caution, given methodological limitations: Bipolar-affective disorder; non-affective psychotic disorders (De Giorgi et al., 2019; Skokauskas & Frodl, 2015).
- It should also be noted that a scoping review by Kassee et al. (2020) highlights the preliminary and inconsistent nature of findings regarding potentially higher rates of gastrointestinal, metabolic, nutritional and immunological conditions in autistic adults.

Population characteristics

Common comorbidities

- Known associations between autism and specific health conditions identified may serve as a basis for strategic planning, such as informing areas of prevention (e.g. annual health checks).
- Particularly concerning is the considerable burden of mental health conditions faced by autistic people, and high rates of suicide relative to the general population (Lai et al., 2019).
- Even more so when coupled with findings from elsewhere in this review, which indicate substantial disparities in access to health and care services (particularly for mental health services), and a lack of support after diagnosis (Harper et al., 2019; Hood et al., 2021).
- Themes around a lack of access to mental healthcare, the ability of mental health services to tailor to autism needs, and a lack of post-diagnostic support services were consistent across published academic, grey literature, and local intelligence sources.

Executive summary

Health behaviours

A limited volume of evidence was identified concerning the health behaviours of autistic people.

Physical activity

- Several sources highlighted mixed findings regarding physical activity and related outcomes (Reinders et al., 2019) - some studies suggested lower physical activity levels in children, whereas others contradicted this. Though there was more consistent evidence of lower physical activity level for older autistic children, and higher levels of obesity in autistic adults (Curtin et al., 2014; Sedgewick et al., 2019).

Help-seeking

- Qualitative evidence suggests that autistic young adults may be reluctant to seek help for mental health difficulties (Coleman-Fountain et al., 2020).

Adverse childhood experiences, suicide and self-harm

- Concerningly, robust evidence also suggests a considerably higher rate of suicide and self-harm in autistic people (Hirvikoski et al., 2016; Steenfeldt-Kristensen et al., 2020).
- One US source also points to an elevated rate of adverse childhood experiences and potentially traumatic experiences in autistic children; autistic children were twice as likely to report four or more adverse experiences (Berg et al., 2016).

Health behaviours

Substance use

- UK evidence also highlights interesting trends related to substance use in autistic adults. Findings suggest lower rates of regular alcohol consumption, binge drinking, smoking and drug use in autistic people compared to the non-autistic people (Weir et al., 2021).
    - Autistic people who reported substance use were more likely to report doing so to manage behaviour or mental health (Weir et al., 2021); this is supported by earlier qualitative evidence from the Netherlands (Kronenberg et al., 2014).

Camouflaging and masking

- The emerging literature on camouflaging or masking behaviours (i.e. strategies to mask the symptoms of autism in social situations) has potential implications for how autism is understood and recognised within health and care settings (Hull et al., 2020).
- While empirical studies on the health risks of camouflaging have not yet been conducted, qualitative literature has explored the consequences, including physical and emotional exhaustion as reported by autistic interviewees (Hull et al., 2020; Green et al., 2019).

Executive summary

Variation in outcomes

Quality of life

- Systematic and narrative reviews shows that autistic adults may experience lower scores on quality of life (QoL) measures (Ayres et al., 2017; Green et al., 2019; Kapp, 2018).
- Widespread use of QoL measures that have not been validated for autistic adults may give 'misleadingly low or high scores' (Ayres et al., 2017). Highlighting a crucial need to develop appropriate measures to understand what matters to autistic people regarding QoL.

General health and mortality

- Population studies show poorer general health and health status in autistic children and young people; and there is limited research which directly assesses autistic adults' physical health (Cashin et al., 2018; Dillenburger et al., 2015; Powell et al., 2021).
- Evidence from more recent cohort studies shows higher mortality levels in autistic people (DaWalt et al., 2019; Hirvikoski et al., 2016).

Family, carer and sibling outcomes

- Evidence shows lower QoL (subjective mental and physical health) for parent, carers and siblings of autistic children (Koukouriki & Soulis 2020; Vasilopulou & Nisbet, 2016; Watson et al., 2021).

Variation in wider determinants of health (WDoH)

Employment and education

- There is considerable evidence of disparities in education and employment outcomes for autistic adults (by gender, socioeconomic status and ethnicity; Eilenberg et al., 2019).
- Several grey literature sources show poorer post-secondary education outcomes, and high un-and-underemployment for UK autistic graduates (Allen & Coney, 2021; All Party Parliamentary Group on Autism, 2017).
- International evidence mirrors this, though there is limited empirical evidence to indicate 'what works' in easing barriers and challenges to entering and sustaining employment that is fulfilling, particularly for a UK context (Chen et al., 2015; Harmuth et al., 2018; National Autistic Society 2016).
- UK surveys indicate unmet needs concerning autism-specific SEND provision and wider education provision (All Party Parliamentary Group on Autism, 2017).
- There are also gaps in the literature to understanding what kinds of outcomes matter to diverse groups of autistic people themselves (Scott et al., 2018).
- There is limited high-quality research with which to inform gender-specific employment policy for autistic women, despite emerging literature on the challenges faced by later diagnosed women in the workplace (Hayward et al., 2018).

Executive summary

Variation in wider determinants of health (WDoH)

Criminal justice system (CJS) and related settings

- Conflicting findings were identified across sources as to whether autistic people are over-represented within the CJS; though, autistic people are overrepresented in secure psychiatric settings (Alley, 2018; King & Murphy, 2014; Rutten et al., 2017). There is also a lack of gender-sensitive autism screening tools for identifying autism in CJS.
- UK-based surveys (Crane et al., 2016) highlight discrepancies in experiences of autistic people, carers and policing professionals in levels of satisfaction reported.
- Qualitative evidence examining the contributory factors reported by autistic people leading up to their arrest points to the *"accumulation of un-manageable stress, and a lack of understanding and access to wider support"* (Helverschou et al., 2017).

Independent living and social participation

- Few secondary, primary or grey literature sources were identified around independent living, and social care.
- Autistic young adults from low income and ethnic minority backgrounds were more likely to live with parents or carers after secondary education; with reflected similar disparities in relation to driving and participating in wider social activities (Elienberg et al., 2019).

Access to health and care services

Barriers and facilitators

Several common barriers to access to health and care services (including diagnostic services) were identified (Calleja et al., 2020; Mason et al., 2019), including: sensory sensitivities; communication difficulties; lack of autism knowledge; waiting times.

Quality of care

- Quality and experience of care is also an area of concern identified by a high proportion autistic people who felt they had received worse healthcare (Christou, 2016).

Access

- There is considerable evidence that autistic people experience disparities in to access health and care services (Calleja et al., 2020; Christou, 2016; Eilenberg et al., 2019; Harper et al., 2019; Smith et al., 2020).
- Several sources describe disparities in access to transition-related services, and diagnosis and support services by ethnicity and socioeconomic status (BMA, 2019; Eilenberg et al., 2019; Healthwatch, 2017; Stahmer et al., 2019).
- Access to mental health services appropriately tailored to autistic peoples' needs emerged as a major area of concern for both CYP and adults (Harper et al., 2019; Harper et al., 2019; Hood et al., 2021).

Executive summary

Access to health and care services

Autism diagnostic services

- A recent systematic review highlights *"The evidence supporting racial, ethnic, and economic disparities in ASD diagnosis and service access is strong and has been replicated across multiple studies."* (Smith et al., 2020).
- Wider qualitative research has also highlighted the need to tailor diagnostic services to be more culturally and linguistically sensitive, in light of barriers to access (Legg & Tickle, 2019; Stahmer et al., 2019).

Post-diagnostic support services

- Available evidence points to a lack of post-diagnostic support services internationally and within the UK (Huang et al., 2020; Scattoni et al., 2021).
- Limited evidence exists concerning this topic; existing research largely includes white autistic men, signifying a need to co-produce research to understand the needs of more diverse groups of autistic adults (Shattuck et al., 2020).
- A recent NIHR study (Beresford et al., 2020) evaluated 18 Specialist Autism Teams. Key findings include: increasing referral rates year-on-year, with no increase in funding; extended psychoeducation provided appears to have some positive benefits in prevention deterioration post-diagnosis. The authors regard this as a crucial element of provision.

Current and planned changes to autism policy

Policy overview

The focus of national policy related to autism is fairly consistent across the last decade (Parkin et al., 2020), with several priority areas related to:

- Increasing societal and professional understanding of autism;
- Developing consistent local diagnostic and wider support; pathways;
- Developing the local and national governance required for policy implementation and monitoring;
- Moving care from hospital settings to the community;
- Reducing inequities in health outcomes and access to services; and,
- Improving the consistency of local and national data collection.

The most recent national strategy (Department of Health and Social Care, 2021), which extends provision of previous policies to children and young people, states three core enablers related to: improving research and innovation; improving data collection and reporting; and strengthening governance, leadership and accountability.

Executive summary

Current and planned changes to autism policy

While a limited number of sources assess the impact of policy changes, the available evidence suggested that national policy may be slow to positively impact most autistic people and their families (Lemmi et al., 2017; Marshall-Tate 2019; National Autistic Society & APPGA, 2019). Further research is required to fully assess the impacts of national policy upon autistic people and their families.

Learning from lives and deaths; and annual health checks

Inclusion of autistic people in learning from mortality reviews, and possible provision of annual health checks for autistic people are potentially positive developments which may reduce health inequities (Harper et al, 2019; NHS England, 2021). Evidence and guidance for local systems to anticipate how they might respond to these priorities is yet forthcoming.

Policy recommendations

Recommendations from national sources (Lemmi et al., 2017; NAS & APPGA,2019) and other relevant organisations were synthesised across the following topic areas:

- Understanding, training and awareness; Governance leadership and accountability; and, enhancing service provision and understanding autistic peoples' journey through services.
- Access to diagnosis and the diagnostic process; gender disparities; social care, and mental health.

Cross-cutting themes

Whilst this review is not intended to be comprehensive nor exhaustive given time constraints, there was a notable paucity of published and grey literature in some areas. Whereas, for other areas, the volume of literature identified was considerable (e.g. for areas such as employment and common comorbidities, multiple secondary sources or reviews were identified).

Only one secondary source was identified with relevance to independent living and social participation.

Regarding the grey literature, while some think-tanks had press-releases covering projects related to autism, it is notable that no previous publications or reports related directly or solely to autism. The bulk of information here came from grey-literature sources in the charitable and voluntary sector, from organisations who are themselves providers of information and services for autistic people.

This review identified a major gap in the existing evidence with respect to autistic older adults. As the literature on autistic adults has focused on younger adults and those approaching middle-age. Specifically, only a handful of papers identified mentioned autism in older adulthood.

Useful resources identified

This slide signposts to useful resources identified that might be useful in relation to using the information within this evidence scan, and any additional information collected as part of wider efforts.

Three resources were identified relevant to commissioning services, created by Skills for Care, National Development Team for Inclusion and the National Autistic Society:

- A framework diagram showing the diagnostic and support services that should be locally accessible to autistic people and those in their lives.

- *"Commissioning services for autistic people. A cross-system framework for commissioning social care, health and children's services for autistic people"* (Department of Health and Social Care, 2021) may be useful in informing what action may be taken around the insights presented here (including gaps in provision, local prevalence rates, and the need to collect more detailed and consistent demographic data).

Population calculator for autistic people (2020-2035) produced by the Skills for Care Workforce

Microsoft Excel Worksheet

- This tool gives estimated projections for the number of autistic between 2020-2035 (based on ONS population projections), with options to break this down by local authority and region.
- This requires the user to enter the known population or number of autistic people locally or regionally.
- Both options give estimated population figures for five year increments between 2020-2035, broken down by gender and age.

Population characteristics

What is autism?

Autism and demography

Common comorbidities

Population characteristics: what is autism and how common is it?

What is ASD/ASC/ Autism

Autism or autistic spectrum conditions are a spectrum or continuum of conditions which affect brain development.

Autism diagnostic criteria include three core symptoms: differences in social communication and interaction; highly focused interests or behaviours that appear to others as repetitive or restricted; and, challenges with sensory hyper-or-hypo-sensitivity (Frith & Happé, 2020).

The way that the features of autism present in an individual, and the impact of these features on daily functioning and support needs is highly variable.

This is why autism is referred to as a spectrum or continuum of conditions, as two individuals may be diagnosed with similar features of autism, yet may experience, relate to and manage the impact of these traits in their day to day life very differently to one another (Frith & Happé, 2020).

How common is autism- international and UK prevalence

Previous systematic reviews have attempted to synthesise global autism prevalence research, with an average prevalence rate of 91.92 per 10,000 populations (aged 2-17 years) across 27 largely US and European studies (0.91%) (Adak & Halder, 2017).

However, this estimate is unlikely to be robust, as prevalence estimates of individual studies varied considerably, in line with variation in the tools, methods and contexts in which prevalence was assessed.

More robust estimates have recently become available from large scale population-based studies in the UK (Russell et al., 2021; Rydzewska et al., 2018; Rydzewska et al., 2019) and internationally (Cawthorpe, 2017; Magen-Molho et al., 2020).

- Whole-country population studies (Rydzewska et al., 2018; Rydzewska et al., 2019) conducted via Scotland's 2011 Census data (consisting of n= 5,295, 403 records) show prevalence rates of 1.9% for children (17,348/916,331). For young people aged 16-24, this estimate was 1.2% (7,715/632,488). The overall point prevalence rate of autism in this study was 1.6%.
- These figures dovetail with previous UK prevalence estimates of 1.7% in children (238/ 14,043) derived from the Millennium Cohort Study (Russell et al., 2013). This converges with evidence from the largest UK cohort study on autism to date. Which used national-level education data (n=7,047,238) to show autism prevalence as around 1.76% (Roman-Urrestarazu et al., 2021).

Population characteristics: what is autism and how common is it?

How common is autism- international and UK prevalence (cont.)

A recent population-based cohort study, using linked primary care data (Clinical Practice Research Datalink [CRPD] database; Russell et al., 2021) reported 65,665 individuals (0.6%) with an autism diagnosis recorded within their primary care record in 2018 (n= 9,594,598 patient records).

Lower or comparable prevalence rates have been demonstrated in large international prevalence studies.

- One Israeli whole-population study in children shows dissimilar results, with a prevalence rate of 0.65% (11,699/ 1,786,194) (Magen-Molho et al., 2020).
- One US based study shows a rate of 1.45% in children (14.5 cases per 1,000 population), using an active surveillance network across 11 counties (n=346,978 children) (Christensen et al., 2017).

While UK point prevalence estimates converge to suggest that autism occurs in around 0.6 to 1.76% of the general population, these estimates vary. These estimates are derived from cases that have been diagnosed in childhood and adolescence, which vary in ascertainment method (i.e. by self-report/ proxy, or reported by a medical professional). These figures therefore do not give a sense for the proportion of individuals who were diagnosed with autism later in life.

Population characteristics: autism and demography

Demographic characteristics

These slides aim to give an overview of what is known in relation to the distribution of different demographic characteristics among populations of autistic people, highlighting any gaps in the evidence base for particular demographic characteristics.

Age

Autism can be diagnosed reliably from the age of 2-3. Though making diagnoses before this age is challenging. Autism is most commonly diagnosed in young children, though recent evidence indicates a considerable increase in the incidence of autism in adults, reflecting changes in policy and service provision for adult diagnostic services (Frith & Happé, 2020; Russell et al., 2021).

The most recent evidence relating to trends in age and autism diagnosis comes from a large UK population-based cohort study, using linked primary care data (Clinical Practice Research Datalink [CRPD] database; Russell et al., 2021).

- Data from 9,594,598 patient records indicates that of the 65,665 individuals with an autism diagnosis, a minority received their diagnosis in adulthood (16.17%), with over 80% of cases being diagnosed under the age of 19.

Given this, most data relating to autism are collected in populations of children and young people, and comprehensive population-based data on the prevalence and presentation of autism in middle and older age is limited.

Though, UK based evidence drawn from the adult psychiatric morbidity survey (APMS 2007) points to prevalence rates of 1.1.% in 14 to 44 year olds, 0.9% in 45 to 75 year olds, and 0.8% for those aged over 75 (Brugha et al., 2011). Overall, lower proportions of autism in over 45s and older adult age categories likely reflect under-diagnosis and under-recognition of autism in this group (Huang et al., 2020).

Gender

Whilst autism is known to impact both males and females, girls and women are disproportionately less likely to receive a diagnosis, and are considerably more likely to receive a ‘late diagnosis’, even in the presence of symptoms of equal severity (Green et al., 2019; Hull et al., 2020). Current UK and international evidence outlined below reflects that the rate of males diagnosed with autism is three to five times higher than for females:

- Of 25,063 individuals with a recorded autism diagnosis, only around than 20% of those were female (Rydzewska et al., 2018)- follow-up analyses also reflect a 3:1 male to female ratio in prevalence rates at ages 10 and 11 (4.4% for boys vs 1.1% for girls) (Rydzewska et al., 2019).

Population characteristics: autism and demography

Gender (cont.)

Other large international prevalence studies in child and adults populations reflect similar disparities in the proportions of males and females diagnosed:

- Of 11,699 children in Israel with an autism diagnosis in Magen-Molho et al. (2020), 83.5% were boys compared to 16.5% girls.
- Similarly, US research by Christensen et al. (2017) reports prevalence was significantly higher in boys than girls aged 8 (n=346,978 children; 2.3% boys vs. 0.5% girls).
- Using Canadian health service registry data, Cawthorpe (2017) reported that across sixteen years, the population prevalence of autism reflects a rate of 0.90% for males and 0.21% for females. Interestingly, age at diagnosis differed considerably between girls (average=29; median= 19) and boys (average= 14; median= 11)

Rather than reflecting elevated incidence of autism in men relative to women (i.e. that autism is more common in men than women), it is thought that the signs of autism in women and girls may be under-recognised and therefore under-diagnosed (Huang et al., 2020).

Gender identity and sexual orientation

Available evidence indicates that there is currently no reliable estimate of the relative proportion of autistic individuals who identify as LGBTQ+ (Hillier et al., 2019; Warrier et al., 2020). This is because this kind of data is seldom collected in a way that enables robust comparisons, as many large population-based studies do not collect information on autism and gender identity, or sexual orientation (Warrier et al., 2020).

While this area of research is emergent, an earlier systematic review covering articles published between 1966 and 2015 (n= 19 articles included) indicates that autism may be more prevalent in children and adolescents experiencing gender dysphoria compared to the general population (Glidden et al., 2016). Though, there is limited research concerning adults (Glidden et al.).

More recently, researchers at the Autism Research Centre in Cambridge (Warrier et al., 2020) have conducted the largest analysis to date concerning gender identity and autism (across five UK based cross-sectional datasets; n= 641,860).

- Compared to those who identity as cisgender, people who identify as transgender or gender-diverse are between three-and-six-times as likely to be autistic.

Population characteristics: autism and demography

Gender identity and sexual orientation (cont.)

- Exploratory analyses undertaken by the authors also highlighted that transgender and gender-diverse participants were more likely to report *"that they suspected they had undiagnosed autism."*
- The authors highlight further that *"[Our] analyses indicate that transgender and gender-diverse individuals are more likely to be autistic compared to cisgender individuals, and further that undiagnosed autism may also be higher in transgender and gender-diverse individuals."*

Regarding sexual orientation, while there is some evidence that autistic people may identify as non-heterosexual at a higher rate than those who are not autistic, this has not been explored or confirmed in large-scale or population-based studies.

- An early systematic review and meta-analysis concerning sexuality in 'high-functioning autism' highlights higher rates of being individuals identifying as gay, bisexual or asexual, compared to typically developing adolescents and adults, across several studies (Percora et al., 2016).
  - Though, it should be noted that these studies were examined as part of qualitative synthesis of findings, and so the rate at which autistic individuals identify as gay, bisexual or asexual, relative to non-autistic individuals is unclear.

Ethnicity

While evidence on the association between ethnic background or ethnicity and autism prevalence is somewhat conflicting, it appears that across the international evidence base, there are differences in the prevalence of autism between ethnic groups.

Specifically, some studies indicate that non-white children are less likely to receive an autism diagnosis, which may indicate disparities in access to diagnostic service or under-identification. In the UK and globally, there is also a paucity of research concerning the experiences of ethnically diverse populations who are autistic.

Findings from several population-based studies point to differences in how prevalent autism is among different ethnic groups:

- One study conducted in Scotland, found that children and young people with autism were more likely to be of Caucasian ethnicity (Rydzewska et al., 2018; Rydzewska et al., 2019).
- US-based work by Christensen et al. (2017) also highlighted lower autism prevalence in children from a Black or Hispanic ethnic background.
- Magen-Molho et al. (2020) identified strong associations between ethnicity and autism prevalence, specifically autism prevalence was around three times lower in those whose ethnic background was Arab or non-Israeli.

Population characteristics: autism and demography

Ethnicity (cont.)

Findings from the largest case-control cohort study concerning autism and ethnicity to date, (using data from Spring School Census, National Pupil Database) shows consistent differences in prevalence rates across ethnic groups (Roman-Urrestarazu et al., 2021). Specifically, in a large sample of children and young people (5 to 19 years old; n= 7,047,238) two ethnic groups were identified as being more likely to have an autism diagnosis recorded in the educational system, compared to white pupils:

- Black pupils were 26% more likely to be recorded as having an autism diagnosis (aPR= 1.26 [95%CI, 1.23-1.29] and had the highest prevalence rate overall (2.11%).
- Chinese pupils were 38% more likely to be recorded as having an autism diagnosis (aPR= 1.38 [95%CI,1.26-1.50]) (prevalence= 1.59%).

Several groups were also indicated to have lower prevalence of autism, or being less likely to have an autism diagnosis recorded:

- Roma/Irish Traveller pupils were around 60% less likely to be recorded as having an autism diagnosis (aPR=0.42 [95%CI, 0.36-0.48]), and had the lowest prevalence rates of autism overall (0.85).
- Asian pupils (aPR= 0.83 [95%CI, 0.81-0.85]), and pupils from any other ethnic group (aPR= 0.92 [95%CI, 0.87-0.97]) were less likely to have autism compared to White pupils.

This conflicts with US and international evidence indicating lower prevalence rates of autism in Black and other minority ethnic groups.

Population characteristics: autism and demography

Socioeconomic status

Concerning socioeconomic status, autism and related demographic characteristics, the evidence from the published academic literature is mixed.

- Using Scottish Census data, Rydzewska et al. (2018) demonstrated that autistic children and young people were more likely to live in the most socioeconomically deprived areas, compared to non-autistic children and young people.

Conflicting findings from similar international studies appear to suggest higher prevalence where higher socioeconomic status is concerned, though the literature also highlights a paucity of studies which measure socioeconomic status in relation to autism:

- Magen-Molho et al. (2020) found that higher socioeconomic status was associated with a higher prevalence of autism (prevalence rate ratio= 2.01, 95% CI: 1.83–2.19).
- Notably, a large US-based study (n=346,978) in which data were gathered in 2012 by an active surveillance network, did not collect or report data on measures related to socioeconomic status (Christensen et al., 2017).
- This was also true of the largest UK study to date by Russell et al. (2021), who do not present a breakdown of prevalence rate by deprivation or socioeconomic status.
    - They acknowledge that further research in England is needed to examine wider demographic factors, including ethnicity, socioeconomic status and rurality, which may impact diagnosis and prevalence rates.

An earlier systematic review (Adak & Halder, 2017) summarises available evidence from 22 studies (n=7 UK studies; 2005-2015) regarding associations between autism prevalence, gender and socioeconomic status. Key findings including conflicting evidence in context to a limited volume of literature:

- A handful of studies reported socioeconomic status (n=6) for autistic children, with mixed findings. Half of these studies demonstrated positive associations between autism and socioeconomic status, whereas the remainder demonstrated no association.

It is notable that an earlier UK study reported by the authors found no association between parental income as a measure of socioeconomic status and autism in children (Brugha et al., 2011). It is also notable that only around a quarter of papers identified by the authors reported on socioeconomic status.

Population characteristics: physical health comorbidities

These slides will give an overview of what is known concerning the physical and mental health conditions which commonly co-occur with autism.

Highlighting sociodemographic differences where this information is available, this will draw attention to the potential implications of high comorbidity for certain sub-populations, while reflecting any recommendations from the literature.

Physical health conditions and disabilities

Children

Available evidence highlights a higher burden of physical disabilities, sensory conditions and physical health conditions in autistic children and young people (CYP) compared to non-autistic CYP (Rydzewska et al., 2018; Rydzewska et al., 2019).

For example, a whole country population observational study conducted in Scotland found that compared to the general population, conditions such as deafness/ partial hearing loss, and blindness/ partial sight loss and other physical disabilities were between 5 and 16 times more prevalent in autistic children; mental health conditions were 16 times more prevalent in autistic children and young people (Rydzewska et al., 2018).

Adults

Several secondary sources highlight a lack of literature related to the physical health of autistic adults. A scoping review by Cashin et al. (2016) outlines that very few primary research studies assess the health status and physical health of autistic adults. Kassee et al, (2020) also reflects this, as the first scoping review to examine the physical health of autistic women and girls.

Multiple sources also point to a clear need to conduct further research to understand how physical health changes across the lifespan for autistic adults, particularly for older adults (Roestorf et al., 2019; Cashin et al., 2016; Kassee et al., 2020). Particularly, very few studies have conducted direct or comprehensive physical health assessments on representative populations of autistic adult (Cashin et al., 2016).

Population characteristics: physical health comorbidities

Reproductive, metabolic and endocrine conditions

Several sources point to an elevated level of reproductive and endocrine conditions in autistic women and girls.

A scoping review by Kassee et al. (2020) identified and thematically reviewed 40 relevant studies concerning autistic women and girls, who were found to experience a higher rate of physical health challenges compared to both non-autistic women and girls, and compared to autistic men and boys.

- A major theme that emerged from the literature was the higher burden of reproductive and endocrinal health challenges faced by autistic women (prevalence= 7.8%) and girls compared to non-autistic women and girls (3.5% in general population). These included hormonal conditions, ovarian cancer, and symptoms and challenges related to their menstrual cycle.
- However, the authors highlight this evidence as preliminary, as the consistency of these findings cannot be established due to studies using self-report measures rather than direct clinical assessment, small to moderate sample sizes and studies using different measures.

Two UK based primary cross-sectional studies (N= 1,230; n= 361 autistic women; age= 15-77) examined associations between autism symptoms in women, and symptoms of reproductive, metabolic and endocrine conditions (Simantov et al., 2021). Several diagnoses and pre-clinical symptoms were found to be more common in autistic women, compared to the general population, including:

- reproductive system diagnoses (OR= 1.03, $p<0.05$);
- pre-diabetes symptoms (OR= 1.31, $p<0.001$);
- atypical onset of puberty (OR= 1.45, $p<0.01$); and,
- irregularities in menstrual cycle length (OR= 1.36, $p<0.05$).

Interestingly, there was also evidence of lower rates of vascular and metabolic conditions in autistic women (OR=0.65, $p<0.05$). Most importantly, the authors highlight that healthcare providers should consider this evidence in relation to health checks and health screening programmes for autistic individuals (Simantov et al., 2021).

Population characteristics: physical health comorbidities

Oral health conditions

A systematic review and meta-analysis by da Silva et al. (2017) identified seven research studies relevant to the prevalence of oral health conditions in autistic children and young people.

- Meta-analysis identified the pooled prevalence of signs of tooth decay to be around 60.6% (95%CI= 44.0-75.1).
- Whereas for gum disease the pooled prevalence was around 69.4% (95%CI= 47.6-85.0).
- While studies included in this meta-analysis used highly variable methods, the finding that over half of autistic children and young people assessed within these studies had tooth decay or gum disease is concerning.

This dovetails with an international scoping review concerning autism and paediatric dentistry. Herrera-Moncada et al. (2019) outline a more recent systematic review with conflicting evidence.

Reviewing this in context to cross-sectional studies published since, they conclude that there is more supporting than conflicting evidence for higher rates of tooth decay and gum disease in autistic children and young people.

This highlights the need for policies to ensure better prevention of poor oral health in this group, particularly across the lifespan, as the prevalence of oral health conditions in autistic older adults is not known.

Population characteristics: physical health comorbidities

Cardiovascular, circulatory and respiratory conditions

Primary cross-sectional evidence from n= 255 US adults (aged 18-71 years) points to twice the rate of hypertension in autistic young adults (12.9%), compared to the general population (6.3%, p<0.05) (Fortuna et al., 2016).

- Compared to younger adults (aged 18-29 years), autistic adults aged 40 and over were almost three times as likely to have hypertension (Adjusted Odds Ratio [AOR]= 2.8, 95%CI= 1.3-6.1).
- Autistic adults over 40 were also around seven times more likely to have hyperlipidaemia or high blood cholesterol (AOR= 6.7, 95%CI= 3.0-15.1).

Neurological and immunological conditions

One source pointed to a higher rate of epilepsy compared the general population, even when accounting for the influence of learning disability as a variable in analysis, which may suggest that a high rate of epilepsy also affects autistic people without a learning disability.

A more recent scoping review by Kassee et al. (2020) highlights higher prevalence rates of epilepsy in autistic women and girls (7.0%), compared to both autistic men and boys (3.9%), and women and girls in the general population (0.69%).

- This also highlights the higher rate of epilepsy in autistic men and boys compared to the general population (3.9% vs. 0.73%).

Regarding immunological conditions, US cross-sectional research (Fortuna et al., 2016; n= 255) also points to autistic young adults being substantially more likely to have allergies (39.7%) compared to the general population (8.4%, p<.0.001).

Population characteristics: mental health comorbidities

Mental health conditions

A meta-analysis of 96 prevalence studies highlights that common mental health conditions are highly prevalent in the autistic people, more so than for the general population (Lai et al., 2019). Pooled prevalence rates from this study suggest the following mental health conditions commonly co-occur with autism. It should be noted that the sample sizes for each pooled prevalence estimate were not provided by the authors.

- ADHD (pooled prevalence= 28%, 95%CI= 25-32).
- Sleep disorders (13%, 95%CI= 9-17).
- Impulse control and conduct disorders (12%, 95%CI= 10-15%).
- Obsessive-compulsive disorder (9%, 95%CI= 7-10%).
- Bipolar disorders (5%, 95%CI= 3-6%).
- Schizophrenia spectrum disorders (4%, 95%CI= 3-5%).

Alexithymia

Autism has also been found to co-occur frequently with alexithymia (defined as difficulties in identifying, describing or expressing, and distinguishing between different emotions and internal or bodily sensations).

The first systematic review and meta-analysis to explore this identified 15 studies (Kinnaird et al., 2019), which compared autistic and neurotypical people on the '20-item Toronto Alexithymia Scale' (TAS; Berthoz & Hill, 2005, cited in Kinnaird et al., 2019).

- The mean weighted prevalence of alexithymia was considerably higher in autistic people (n=366; 49.93%) than for neurotypical group (n=348; 4.89%).
- Random effects meta-analysis showed that the overall risk scoring above the clinical cut-off for alexithymia was 6.5 times higher for autistic people (95%CI= 3.26-12.93, $p<0.001$) compared to the neurotypical group.

Population characteristics: mental health comorbidities

Depression

Several published academic secondary sources indicate considerably elevated prevalence rates of depressive disorders, and symptoms of depression, in autistic adults and young people (Green et al., 2019; Lai et al., 2019; Smith et al., 2021).

- These sources indicate that depression is one of the most common secondary conditions or comorbidities faced by autistic people.
- The evidence shows elevated prevalence rates in childhood, with these increasing considerably in adulthood; a common challenge which can result in unmet needs, is where professionals with a lack of knowledge of both autism and depression may struggle to recognise symptoms such as low mood in autistic people.
- Specifically, Smith et al. (2021) conducted a systematic review to understand the determinants of depression in this population, they found that while prevalence estimates varied widely (9% to 75% across 24 studies), the majority of studies (n=16) indicated prevalence rates between 25 and 50%.
  - Notably, all studies comparing autistic individuals to the general population found significantly higher levels of depressive symptoms in autistic individuals.
- A narrative review by Green et al. (2019) points to a considerable volume of evidence that autistic females experience higher rates of internalising disorders (namely, depression, anxiety and eating disorders) that autistic males.
  - It is also important to note that the age at which females receive a diagnosis may influence symptom severity- this is concerning given evidence of under-diagnosis in females.
- A US-based narrative review (Pezzimenti et al., 2019) gives an overview of the prevalence, presentation, risk factors and impact of depression in autistic CYP.
  - Notably, they highlight prevalence rates of 7.7% in samples of CYP, and 40.2% in autistic adults- with lifetime prevalence of depression being around four times higher for autistic people across the life span, compared to the general population.
  - This source highlights the importance of noting the variability in the way that symptoms of depression can present in autistic people. As some symptom presentations may be consistent with ‘prototypical depression’, whereas other symptoms may be more specific.

Population characteristics: mental health comorbidities

Anxiety

Several sources suggest a higher rate of anxiety disorders in autistic children, young people and adults.

- Specifically, Autistica point to previous research to suggest that anxiety is one of the most common mental health issues, affecting four of every ten autistic children (Simonoff et al., 2008, cited in Harper et al., 2019).
- A more recent meta-analysis by Lai et al. (2019) shows the pooled prevalence of anxiety disorders in autistic adults at around 20% (across 96 studies; 95%CI= 17.0-23.0).

The prevalence rate of anxiety disorders in autistic people is concerning, as co-occurring anxiety may reportedly worsen or exacerbate core autism symptoms such as social challenges and sensory sensitivity (Smith et al., 2021).

Bipolar Affective Disorder (BPAD)

A systematic literature search and narrative review (Skokauskas & Frodl, 2015) concerning the overlap between autism and BPAD identified 20 studies (n=530) across the US, Europe and Asia, showing that around 7% of autistic people across included studies also had BPAD.

- This finding should be interpreted with caution, as prevalence rates varied considerably among the included studies (from 0 to around 57%), given variable methods and study designs employed.

Non-affective psychotic disorders

A recent systematic review identified 14 studies (n=1,708; De Giorgi et al., 2019) related to autism and psychosis-related mental health conditions, finding that the weighted pooled prevalence of these disorders in autistic people is around 9.5% (95%CI= 2.60-16.00).

- However, the authors note that this figure should be interpreted cautiously, as prevalence rates in included studies varied considerably, ranging from 0 to 61.50%; sub-group analyses also revealed a mean prevalence of 19.6% in studies with n= <100, whereas large studies showed a smaller prevalence rate (6.3%).

The Strategy Unit.

Health and health-risk behaviour in autistic people

Physical activity and related outcomes; mental wellbeing (help-seeking; adverse childhood experiences)

Substance use; suicidality and self-harm; masking and camouflaging behaviour.

Health behaviour: physical activity and related outcomes

Physical activity and related outcomes

An international scoping review identified 40 primary research studies (n=20 US studies between 2014-2017; average sample size n=23 [range=1 to 103]; 86% males) relevant to physical activity levels of autistic people (Reinders et al., 2019). This highlights conflicting evidence concerning physical activity levels. With some studies showing that autistic nursery children are more physically active than non-autistic children, and some contradicting this.

While it is unclear whether autistic children engage in an equal or reduced amount of physical activity relative to non-autistic children, the authors conclude that older autistic children may engage in more sedentary behaviours.

Reinders et al. (2019) highlight several barriers and facilitators to participation in physical activity and exercise for autistic children (enjoyment and interest, bullying, parental worry).

A narrative review by Curtin et al. (2014) outlines available evidence on levels of obesity in autistic children, and obesity-related risk factors experienced by this population. Key findings include:

- International studies show that autistic children experience at least the same or higher rates of obesity than children in the general population.
- Some medications are known to induce rapid weight-gain and metabolic changes; with the authors reporting that *"clinical and nationally representative populations of children, […], report that approximately 30% - 60% of children with ASD are prescribed at least one psychotropic medication […] and antipsychotics are among the most commonly prescribed. [32]".*
- While lower levels of physical activity have been reported in autistic children, the authors state that further research is needed to understand the degree to which physical activity levels are related to weight status and obesity in autism.

A large UK-based online survey (Sedgewick et al., 2019) compared weight and body mass index (BMI) outcomes of n=335 autistic and n=335 age-matched non-autistic people. Key findings related to weight outcomes and BMI include:

- Average BMI was significantly higher in autistic people compared to non-autistic people ($t[664]= -4.03$, $p<0.001$).
- A categorial regression with weight category as the outcome also showed autistic people were significantly more likely to be: a) underweight ($t= -14.20$, $p<0.001$) b) overweight ($t= 3.26$, $p<0.001$) or c) obese ($t= 11.72$, $p<0.001$) compared to non-autistic people. Finally, autistic people had a 58.84% higher likelihood of being overweight or obese.

Health behaviour: mental wellbeing and related factors

Help-seeking

A UK-based qualitative cross-sectional study (Coleman-Fountain et al., 2020; n=19 [17 males]; n= 18 white-British; aged 23-24 years) explored how autistic young adults understood and managed mental health issues.

- This found that many autistic young adults interviewed preferred self-management as a way of managing their mental health difficulties; notably, few saw asking for help (or accepting help) for emotional distress as *"something they would do without hesitancy or difficulty*".
- The authors conclude that this preference may limit autistic young adults' help-seeking behaviour, contributing to worsening symptoms in a population with a considerably higher burden of mental health difficulties.

Adverse childhood experiences or trauma

One source suggests autistic people may experience a higher rate of stressful life events, as well as increased vulnerability from adverse childhood experiences and trauma. Examples given in the literature include experiencing bullying and stigma.

- A US population-based study using data from the National Survey of Child Health (Berg et al., 2016; n=116,534. n= 1,611 with autism; 3 – 17 years old) found that the prevalence of adverse childhood experiences (ACEs) was considerably higher among autistic children than for non-autistic children.
- Specifically, children with autism were significantly more likely to report experiencing one to three ACEs (adjusted relative risk ratio [aRRR]= 1.53, 95%CI= 1.16-2.0, p<0.01).
- Autistic children were also around twice as likely as non-autistic children to experience four or more ACEs (aRRR= 1.99; 95%CI= 1.35-2.91, p<0.01).
- Importantly, the authors note *"[…] exposure to four or more ACEs appears to exceed a clinical threshold, exerting a substantially greater impact on probability of poor outcomes.[5]"*.

Health risk behaviour: suicidality and self-harm

Suicidality

An action briefing on suicide prevention by Autistica (Harper et al., 2019) cites preliminary findings from ongoing research to suggest that as many as 11% of deaths by suicide are comprised of autistic people.

This is supported by a Swedish cohort study (Hirvikoski et al., 2016) showing suicide as a leading cause of death in a population-based cohort of autistic people (n=27,122) compared to general population controls matched by age, gender and country (n=2,672,185).

Concerningly, Autistica also note that many of the factors that are known to increase suicide risk, are also more prevalent in autistic people (e.g. unemployment; self-harm; mental health difficulties).

Self-harm

Regarding self-harm or self-injurious behaviour, a UK-based meta-analysis (k=37; n= 14,379) by Steenfeldt-Kristensen et al. (2020) showed that the weighted prevalence of self-injurious behaviour in autistic people is around 42% (95%CI= 0.38-0.47). This suggests autistic people face a considerably higher risk of self-injurious behaviour.

- The authors performed sub-group analyses, finding that the presence learning disability in the sample, and age were not associated with the overall rate of self-injurious behaviour in the included studies (p=0.240, p=0.961, respectively).
- Sub-group analyses also revealed significantly higher prevalence rates for females than males (z= -2.46, p=0.013, 95%CI= - 0.011- -0.001).

Health risk behaviour: substance use

Substance use

UK mixed-methods survey-based research (quantitative n=2,386; qualitative n= 919) by Weir et al. (2021) highlight several findings concerning autistic adults and substance use behaviour:

- Autistic people reported less regular consumption of alcohol, and were less likely to consume alcohol regularly compared to non-autistic people (16% vs. 22.2%, adjusted OR [aOR]= 0.69, 95%CI= 0.55-0.86, p=0.002).
- Autistic people were also less likely to engage in binge drinking compared to non-autistic people (3.8% vs. 8.2%, aOR= 0.38, 95%CI= 0.26-0.56, p<0.0001).
- Autistic males were less likely to report ever having smoked (50.8% vs. 64.6%, aOR= 0.50, 95%CI= 0.32-0.76, p<0.002), or having used drugs (35.4% vs. 52.7, aOR= 0.53, 95%CI= 0.35-0.80, p<0.002).
    - Of those who reported a motivation for substance use, autistic people were around nine times more likely to report substance use to manage behaviour (OR= 8.89, 95%CI= 2.05-81.12, p=0.001).
    - Autistic people were also three-times more likely to report recreational substance use to manage symptoms of ill mental health (OR= 3.08, 95%CI= 1.18-9.08, p=0.032).

A Netherlands-based qualitative study (Kronenberg et al., 2014) used in-depth interviews and descriptive phenomenology to examine everyday motivations for substance use in n=12 autistic people with a substance use disorder. Key themes described include:

- **A jumble of thoughts and emotions,** leading to a cycle of negative thinking and emotions was described by many interviewees.
- **Managing sensory overload,** and getting out of the cycle of negative thoughts was described as the basis for substance use for many.
- The authors also note that *"To our knowledge, the treatment of co-occurring SUD + ASD has not yet been studied."*

Health risk behaviour: camouflaging or 'masking'

Camouflaging or 'masking'

There is an emerging body of evidence concerning autistic adults' (particularly females) use of conscious or unconscious strategies to minimise the appearance autistic traits within social settings- or 'camouflaging' (Hull et al., 2020).

Examples of these "behavioural coping strategies to conceal symptoms" (Green et al., 2019) given by a recent narrative review include mirroring facial expressions or other non-verbal gestures in conversation. This concept has been proposed as one candidate explanation for lower rates of diagnosis in autistic women and girls (Frith & Happé, 2020).

A narrative review by Hull et al. (2020) outlines that this area of research is emergent; key themes explored include developing methods to measure this concept, and qualitative investigations of camouflaging behaviour among autistic women and girls.

There is also an emerging body of qualitative evidence around the potential physical and emotional consequences of maintaining this camouflage.

- Summarising available research Hull et al. notes that *"Consequences […] included physical and emotional exhaustion, often requiring time alone to recover; issues around identity and authenticity […] and difficulty accessing support and diagnosis."*

Variation in outcomes

Quality of life; Health status; Mortality; Family, carer and sibling outcomes

Variation in outcomes: quality of life

Quality of life

Ayres et al. (2017) systematically reviewed available evidence concerning quality of life of autistic adults. They identified 14 relevant studies (n =959; 18- 59 years) comparing QoL of autistic adults to non-autistic adults (n= 2 randomised studies; n=10 cross-sectional studies; n= 2 intervention studies) across seven different QoL measures which used either self-report, proxy or both.

- Synthesis of findings across these studies showed that autistic adults may be likely to report lower QoL scores than non-autistic adults, particularly for QoL domains related to social inclusion.
- However, without an understanding of what aspects of QoL matter to autistic people, the authors state that it is difficult to make sense of this information.
- Most studies used well-validated and reliable measures for QoL (n=13), though these measures have not been validated in autistic populations.
- Notably, the authors state *"[…] widespread use of tools without established reliability and validity […] in autistic adults is an important finding of this review because this practice may lead to misleadingly low or high scores."*

A narrative review by Green et al. (2019) also summarises available literature concerning autistic adults' quality of life.

- This highlights gaps in the literature concerning potential differences between quality of life of autistic men compared to women.
- Specifically, the authors highlight a lack of studies examining both social support and quality of life in autistic adults. Reviewing one of the largest QoL studies in the available literature, which found lower QoL in autistic adults, they also identify that female gender predicted lower QoL.

Finally, a wider UK-based narrative review (Kapp, 2018) concerning social support and wellbeing highlights a similar gap in the evidence regarding autism-specific measures of QoL, and the importance of conducting further research to understand what outcomes are important and meaningful to autistic people themselves.

- Specifically, the authors note that *"the literature reveals the importance of autistic individuals' unique perspectives on their own lives and the need for research on how to help them from an early age to holistically understand their strengths, differences, and needs in an affirmative way that empowers them to constructively face their challenge".*

Variation in outcomes: general health and health status

General health and health status

A scoping review examining available evidence concerning the physical health of autistic adults concludes that there is a lack of research which directly assesses health status, stating that there is a lack of understanding of the general health status of autistic adults (Cashin et al., 2018).

Several primary sources from the published academic literature highlight poorer general health or health status in autistic children and young people:

- A US-based multi-site study (Powell et al., 2021) analysed follow-up data from participants originally survey between 2 and 5 years old.
- Follow-up data obtained from parents of adolescents (n= 146 autism group; n= 249 control; age range= 12-16) showed that:
    - Autistic adolescents were 90% more likely to have physical difficulties (21.2% vs. 1.6%; adjusted prevalence ratio [aPR]= 11.6 95%CI= 4.2-31.9); and,
    - Multiple mental health conditions (>1 condition: 63% vs. 28.9%; aPR= 1.9, 95%CI= 1.5-2.5) compared to the control group.
- A whole country population study (Rydzewska et al., 2019) of children and young people (CYP; n= 1,548,819; children 0-15; n= 916,331; young people 16-24; n= 632,488) in Scotland also found that autistic children (22%) and young people (25.5%) reported significantly poorer health compared to children (2.0%) and young people (4.4%) in the general population (children: $\chi 2$= 29, 365.6; $p<0.001$; young people: $\chi 2$=7652.1, $p<0.001$).
    - The authors highlight that after adjusting for age and gender, autism had an odds ratio of 11.33 (95%CI= 10.98-11.70) in predicting poorer health in a logistic regression model.
- Dillenburger et al (2015) analysed five datasets from the longitudinal Millennium Cohort Study; n= 18,522- five data sweeps from 9 months to 11 years old).
    - This showed a greater level of reported health concerns for children later identified as autistic (16%) compared to non-autistic children (8%); a higher rate of health concerns was also reported at birth (34% vs. 25%).

Variation in outcomes: mortality

Mortality

The scoping review by Cashin et al., 2018) notes that while there is uncertainty in the evidence base concerning life-expectancy statistics, these largely reflect a higher rate of mortality for autistic adults.

A US community-based cohort study by DaWalt et al. (2019) examined mortality in autistic adolescents and adults over 20 years (n= 405) to address the gap in the literature concerning mortality risk in this population.

- The authors report several key findings, including a mortality rate of 6.4% over 20 years (from 1998 to 2018; mean age= 38.5).
- While it should be noted that the majority of the sample had a learning disability, the authors state that "*For every one year older age at the start of the study period, the individual had a 7% greater risk of dying over the next 20 years. Sex and ID [sic. Learning disability] status were not predictive of mortality.*"

A Swedish matched case cohort study (Hirvikoski et al., 2016) examined all-cause and cause-specific mortality for a population-based cohort of autistic people (n=27,122) compared to general population controls matched by age, gender and country (n=2, 672, 185).

- Over the observation period, 2.6% (n=706) of autistic people deceased, compared to 0.91% (n= 24,358) of population controls (OR= 2.56, 95%CI= 2.38-2.76).
- Analyses also divided the autistic cohort into those with and without learning disability, showing that all-cause mortality was higher in both groups (OR=5.78 [95%CI=4.94-6.75] and OR=2.18 [95%CI= 2.00-2.38], respectively) compared to the general population.
- The most common cause of death for the cohort of autistic people without a learning disability was suicide (OR=9.40, 95%CI=7.43-11.90).

Variation in outcomes: family, carer and sibling outcomes

Family, carer and sibling outcomes

Published academic literature- secondary sources

A systematic review featuring qualitative synthesis of 12 primary research studies showed poorer QoL among parents of autistic children, compared to non-autistic children (Vasilopulou & Nisbet et al., 2016). Key findings include:

- **All studies showed lower QoL scores for parents of autistic children** in at least one domain, compared to the general population; and,
- **Subjective physical and mental health were reportedly poorer in parents of autistic children (including poorer social functioning**)- though, physical health was rated consistently lower than mental health, with the authors highlighting that three studies showed only physical health QoL deficits.
- **Several sociodemographic variables were also shown to be associated with poorer QoL in parents of autistic children**:
    - Gender (75% of studies showed poorer maternal QoL than paternal QoL); and,
    - Socioeconomic status (80% of studies examining household income showed positive associations with higher parental QoL and household income).

Limitations of this review reduce the validity and generalisability of these findings, namely:

a) All studies included were cross-sectional, precluding causal inference;

b) Use of convenience samples means studied populations are not representative; and,

c) Lack of verification or confirmation of autism diagnosis.

A recent UK-based systematic review (Watson et al., 2021) thematically synthesised 15 studies (n=8 Europe; n=2 Australia; n=2 US; n=2 Asia; n=1 cross-cultural study [Taiwan and UK]) examining the experiences of n=164 siblings of autistic children.

- The authors conclude that having an autistic sibling impacts personal and self-development (for example, positive impacts were reported around increased empathy and ability to compromise; though, some reported a level of responsibility above their developmental stage).
- However, siblings reported potentially negative or maladaptive coping strategies such as “giving in” or isolating themselves from others to avoid household conflict, or a reluctance to disclose problems or distress to parents.

Variation in outcomes: family, carer and sibling outcomes

Family, carer and sibling outcomes

Published academic literature- primary sources

Findings from more recent primary academic sources highlight several key findings regarding the health and wellbeing of parents or carers and siblings of autistic people:

In a Greek cross-sectional study by Koukouriki & Soulis (2020), siblings of autistic children (n=118; SoA) were found to have higher levels of anxiety and poorer health-related quality of life (HRQoL), compared to siblings of non-autistic children in the control group (n=118; SnA).

- Significantly higher GHQ-Anxiety scores in SoA group (mean=14.42) compared to SnA group (mean=12.11) (t=-4.51, $p<0.001$).
- Significantly lower total scores on a HRQoL measure in the SoA group (mean=111.62) compared to the SnA group (mean=118.90) (t=4.83, $p<0.001$).

A case control study conducted in Spain (n=41 SoA; n= 37 SnA; age range=6-12; n=45 males) Garrido et al. (2020) found significantly lower scores on satisfaction with family quality of life ($p<0.001$), and social support scores ($p<0.001$), and higher autistic trait scores ($p=0.025$) in SoA compared to SnA.

Variation in wider determinants of health (WDoH)

Wider determinants of health: Education; Criminal justice system; Employment; Intendent living and social participation

Variation in wider determinants of health (WDoH): education

Education

Published academic literature- secondary sources

A systematic review by Eilenberg et al. (2019) identified 40 primary research studies related to disparities in transition outcomes for autistic adolescents and young adults. Of these, n=13 studies related to educational outcomes, with the majority conducted in the US. Key findings include:

- Three studies examined transition planning during high-school. Two of which showed that African-American autistic people were less likely to participate in transition planning meetings. Notably, the authors highlight that *"African American students on the autism spectrum were more likely than White students to endorse the goal of attending college, yet they were less likely to participate in college preparatory activities".*
- Ten studies examined post-secondary education outcomes related to participation. Eight of these examined associations between socioeconomic status and education participation; two studies found no association, whereas six papers using data from the US-based National Longitudinal Transition Study-2, showed that autistic young adults from lower income households were less likely to attend university or college.

Grey literature

The Association of Graduate Careers Advisory Services (Allen & Coney, 2021) reported on the outcomes of n=39,185 disabled graduates (n=265, 385 overall). Autistic graduates were the most likely to be unemployed across all categories of qualification.

The All Party Parliamentary Group on Autism (APPGA, 2017) conducted three online surveys (n=176 autistic young people; n=2,573 parents and carers; n=308 teachers) in England concerning autistic peoples' experience of the educations system. Key findings reveal several disparities and potential unmet needs:

- Around 52% of autistic children reported feeling that their teachers do not know how to support them (23% mostly disagree; 28% strongly disagree); similar proportions reported not getting enough help at school or college (19% mostly disagree; 32% strongly disagree).
- Around 42% of parents reported children being refused an SEN assessment at first request; many also reported that support was not timely enough (70% waiting >6 months for education support; 50% > 1 year).
- Under 50% of teachers surveyed felt confident about supporting autistic children.

Variation in wider determinants of health (WDoH): education

Education

Grey literature (cont.)

One UK report by Ambitious about Autism (Cooke, 2018) looked at school exclusions of autistic children and young people, with statistical evidence derived from a Freedom of Information request submitted to the Department of Education (Jan 2018). The data given in response related to numbers of autistic pupils (autism as primary need on EHCP) who were excluded permanently or for a fixed term. (2011 to 2015/16). A summary of key findings includes:

- In the five-year period studied, exclusions for children had increased by around 60%, with regional increases in exclusions across the whole of England being around 44%.
- This is considerably higher than the rate of increase (around four per cent) in exclusions in England overall.
- This report also notes that officially recorded statistics represent only part of the picture, as some pupils may be exclusions excluded 'informally' or 'unofficially', without this being recorded (the authors give the example of sending a pupil home to calm down), The authors note that this is unlawful.

The authors make several wider recommendations for the forthcoming School Exclusions Review (Cooke, 2018). These have been synthesised below:

Training, understanding and awareness. Ensure better training for school governors and those involved in the exclusion appeal process, as well as teachers and wider school staff..

Regulatory powers and accountability. Give regulatory organisations such as Ofsted the powers to investigate unlawful exclusions and take appropriate legal action; and, ensure education organisations and local government are accountable to support autistic children. The authors give the example of exploring incentives to make schools financially and academically responsible for pupil exclusions and securing alternative provision.

Reporting and governance. Establish clear and anonymous reporting procedures; responsible agencies reporting annually on autistic pupil exclusions; mandatory reporting of exclusions of pupils with an ECHP, and review of their EHCP following exclusion; financial penalties and dealing with unlawful exclusions and falsification of school registers as disciplinary matters for the responsible organisation's senior leadership.

Variation in WDoH: criminal justice system and related settings

Criminal justice system and related settings

Published academic literature- secondary sources.

Three secondary sources or review were identified in relation to autism prevalence in CJS settings, including secure psychiatric care settings, showing mixed findings.

Rutten et al. (2017) conducted a literature review of studies relating to prevalence of autism and offending behaviour (1990-2016). 12 studies were identified, five relating to the prevalence of delinquency in autistic populations, and seven relating to the prevalence of autism in forensic populations.

- The prevalence of offending behaviour in autistic people varied substantially (five studies; n=1,672 from UK, Austria, US and Denmark) across studies, ranging from 5 to 26%.
- Several studies comparing prevalence of criminal offences in autistic people to that of the general population found a lower likelihood of offences such as traffic offences, but a higher likelihood of other crimes such as arson. The authors state for most autistic people, there is no association between autism and offending behaviour.
- The prevalence of autism in forensic populations also varied substantially (from 2 to 18% across seven studies; n=4,107 from Netherlands, Sweden, Japan and the UK).

These are substantially higher than in the general population; suggesting autistic people may be over-represented in forensic criminal justice settings.

A UK systematic review (King & Murphy, 2014) notes mixed findings across seven studies (three Swedish, three UK, one Japanese), to suggest that while prevalence in included studies was higher than general population autism prevalence, comparisons across studies are limited by the use of variable methods. On this basis, the authors conclude that autism does not appear disproportionately prevalent in criminal justice settings.

A more recent systematic review (Alley, 2018) examined the existing literature on the prevalence of autism within secure psychiatric care settings, identifying 12 studies, three of which examined prevalence in UK settings.

- All three studies indicated a higher autism prevalence in secure psychiatric care settings (particularly high secure settings) compared to the general population, however, the influence of learning disability on autism prevalence rates could not be disentangled.
- There is also a lack of gender-specific autism screening tools for identifying autistic women who may require more support.

Variation in WDoH: criminal justice system and related settings

Criminal justice system and related settings

Published academic literature- primary sources.

Two primary sources were identified concerning autistic peoples' experiences of the CJS:

A qualitative study by Helverschou et al. (2017) (n=9; age range=21-50; eight men and one woman) of offenders with an autism diagnosis examined individual experiences with the criminal justice system (from arrest to life after prison). Several findings have importance for understanding autistic individuals' interactions, and potential vulnerability, within the CJS:

- Accumulation of un-manageable stress, lack of understanding and lack access to wider support, leading up to committing an offence.
- All but two participants reported having limited or no contact with family and limited social networks.
- Several participants reported confusion and uncertainty around the process of arrest and criminal trial proceedings.
- The majority of participants indicated the importance of support from a range of sources (family, professional, care staff), which the authors conclude may be crucial to prevent further offences.

One UK based study used three online surveys (n=394 police officers; n=31 autistic adults; 49 parents of autistic adults) to examine the views of police officers regarding their experiences of working with autistic people, and to examine the views of autistic adults and parents concerning their experiences of the police (Crane et al., 2016). Key findings point to discrepancies between experiences of police officers, autistic people and their parents:

- Police officers reported moderate satisfaction (42%= largely satisfied) and being fairly knowledgeable (47%) in working with autistic people in the community.
- This differs considerably from autistic adults (69%) and parents (74%), who reported dissatisfaction with experiences, unmet needs and potential discrimination.
- Factors indicated here included sensory challenges due to inappropriate physical environment, lack support and sufficient explanation of the process (leading to emotional distress), and breakdowns in communication.

Variation in WDoH: employment and workplace outcomes

Employment and workplace outcomes

Published academic literature- secondary sources

An early narrative review (Chen et al., 2015) highlights several aspects of poorer employment outcomes, that are consistent with findings from international sources:

- **Unemployment.** High rates of unemployment indicated across several international studies (ranging from 40 – 80%).
- **Underemployment.** Autistic individuals who are employed tend to be paid less and may have limited weekly working hours, or work in part-time or voluntary roles. For example, a longitudinal study highlighted by the authors followed 66 autistic adults for ten years, finding that only six per cent of individuals had 'competitive jobs', while no adults worked in full-time roles. Other longitudinal research cited (n=68) mirrors this, with only two participants working on full-time salaries.
- '**High-functioning' and Asperger's syndrome employment outcomes.** Similar outcomes are reported in studies which look at diagnostic sub-groups of autism- with unemployment rates ranging from 44 – 89%.

Chen et al. (2015) report that while many studies reported participants finishing secondary and post-secondary-education, similar outcomes were reported in terms of underemployment (trouble staying in a job; low working hours; less pay).

Several limitations are highted by the authors:

a) Most studies provide general information about employment outcomes with small samples, rather than examining outcomes specific to different aspects of employment (e.g. interviewing and recruitment processes).

b) The use of unstandardised assessment tools also prevents robust comparison of employment outcomes.

Variation in WDoH: employment and workplace outcomes

Employment and workplace outcomes

Published academic literature- secondary sources

Key findings from Chen et al. (2015), and core limitations, appear to be mirrored in more recent research, including scoping and systematic reviews which highlights poor employment outcomes for autistic adults across the international evidence base:

Canadian researchers (Harmuth et al., 2018) conducted a scoping review of 161 articles (2000-2017) related to employment for autistic adults. The majority were conducted in the US and Canada, England, and Australia. While many articles point to fewer hours worked by autistic adults, with full-time employment described as 'rare', a breakdown of these outcomes and indicated studies was not provided. The authors point to several major gaps in the literature:

- Only 19% (31) of articles included used standardised outcome measures.
- This means it is difficult to form a robust view of variation in employment-related outcomes, beyond what is already known about high levels of under-and-un-employment in autistic adults.

No study examined the experiences of older autistic adults who may have received a later diagnosis- this as a substantial gap in the existing literature. Very few discussed the implications of mental health issues within the workplace or what adjustments might be made.

An internationally-based scoping review (Scott et al., 2018) performed a holistic synthesis of employment research in autistic adults. Identifying 134 studies, 98 related to employment outcomes and 36 related to employment programmes or interventions, most articles were from the US (n=87), UK (n=12), Australia (n=8) or Sweden (n=4). Summarising this review, several findings appear particularly relevant:

- Unstandardised employment outcome measures across this evidence base (which consists largely of descriptive observational studies) limit robust conclusions regarding the employment outcomes of autistic adults.
- This also highlights a need to conduct further research to understand how autistic adults themselves view 'successful' employment, and how this might vary across the spectrum of autism needs.

Variation in WDoH: employment and workplace outcomes

Employment and workplace outcomes

Published academic literature- secondary sources (cont.)

Findings from two, more recent, systematic reviews highlight potential disparities in employment outcomes based on gender, ethnicity and socioeconomic status.

A recent US-based systematic review by Eilenberg et al. (2019) identified 15 primary research studies which examined the employment outcomes of autistic young adults. While findings were mixed, this evidence points to disparities in employment outcomes based on socioeconomic status and ethnicity.

- The majority of studies used data from the NLTS2 study (n=7 studies), of which five studies pointed to poorer outcomes for autistic young adults from lower income households compared to autistic young adults from high income households, in being less likely to hold paid-employment.
- Five studies also suggested that autistic young adults from ethnically diverse backgrounds may be comparatively less likely to be employed than White autistic young adults.

A systematic review identified nine studies (n= 731; age= 18-70; n=279 females overall) relevant to the workplace and employment challenges of 'high functioning' autistic women and girls (Hayward et al., 2018). The most common outcomes reported in the available literature were underemployment, unemployment and trouble sustaining or staying in employment. Challenges related to these outcomes reported were:

- Challenges related to social relationships and interaction (11 studies).
- Communication difficulties- including trouble processing verbal information and implicit communication, misunderstanding in verbal communication (six studies).
- Physical and mental health challenges related to stress (five studies).
- Managing sensory issues (five studies).
- Need for structure and adapting to change (five studies).

Overall, this study highlights a lack of high-quality research with which to inform gender-specific employment policy and practice for autistic women.

Variation in WDoH: employment and workplace outcomes

Employment and workplace outcomes

Published academic literature- primary sources

One primary research study identified highlights several common findings or insights, providing more detail into potential variation in employment outcomes and experiences among autistic adults.

A nationwide Swedish cohort study (n= 814 autistic people; age range= 19-35 years; reference population n= 22,013) used linked datasets to identify unemployment trajectories between autistic and non-autistic young adults (Lallukka et al., 2020).

This study had two follow-up periods for unemployment (five years after initial cohort inclusion year) and disability pension (after unemployment follow-up, extending up to 2013). Three unemployment trajectories were identified using ‘group-based trajectory analysis’ over the two study follow-up periods:

1. Low probability of unemployment which sharply increases;
2. Low probability of unemployment that is stable over time; and,
3. High probability of unemployment which decreases slowly over time.

- Autistic people were more likely to be in the group with a low probability of unemployment which sharply increases over time (OR= 2.53, 95% CI= 2.02 – 3.18),
- Autistic people were also more likely to be in the group with a high probability unemployment which decreases slowly over time (OR=3.60, 95% CI= 3.08 - 4.19).
- Compared to the reference group (0.10%; 23/22,013), autistic people (9.34%; 76/814) were also around 93.4 times more likely to be granted disability pension.

Variation in WDoH: employment and workplace outcomes

Employment and workplace outcomes

Grey literature

Autistica (Harper et al., 2019) summarises research findings relevant to understanding the challenges faced by autistic people in relation to employment, and to framing the wider published and grey literature concerning the employment outcomes of autistic individuals:

- **Rates of unemployment and underemployment are very high among autistic people.** High proportions of autistic people struggle to find employment, those who find work tend to be overqualified for the role. Roles tend to be more likely to be non-full-time (part-time, casual and temporary roles).
- **Typical recruitment processes may selectively disadvantage autistic applicants,** compared to neurotypical applicants. Autistic people face further barriers to staying in a job and fulfilling their potential. Examples of recruitment processes, and additional workplace barriers, include 'competency-based' and 'situational' interview questions, the interview process itself, lack of structure in the day, and unsuitable sensory environments.
- **Being in fulfilling and stable employment may bolster quality of life and wellbeing** (and the negative impacts of unemployment on mental health and wellbeing), taken with higher rates of suicide and depression in this population, this creates an imperative to understand and improve the employment outcomes and workplace experiences of autistic people.

Variation in WDoH: employment and workplace outcomes

Employment and workplace outcomes

Grey literature

Findings from a series of focus groups and a UK survey (n=2,080 autistic adults or proxy responses), conducted as part of the National Autistic Society's (2016) work to understand the employment gap, suggest disparities in outcomes and experiences around:

- **Employment or getting a job.** Full-time employment rate for autistic people is around 16%; combined with the rate of part-time employment (16%) this shows that only 32% of adults in this large survey were employed. Around 40% of respondents reported having never worked. These figures are considerably lower than the rate of adults without disabilities in full-time employment (80%).
- **Getting a job that matches the person's skills and want to work.** Around 40% reported part-time employment and wanting to work more hours; around 51% of those in employment also reported being overqualified for the job they hold.
- **Employers assumed autistic people would want jobs that do not involve social interaction**, or that they favour jobs that require technical skills and attention to detail. This is not the case for all autistic people, as this survey showed that for 11% of respondents, their ideal industry to work in was the arts industry, 10% wanted to work in IT; whereas smaller proportions indicated administrative or office work (9%), research development or library (7%) or museum-based roles (7%).

Variation in WDoH: independent living and social participation

Independent living and social participation

Published academic literature- secondary sources

Regarding living arrangements, of the 40 US-based studies identified by Elienberg et al. (2019), two related to this topic

- Quantitative findings were drawn from the National Longitudinal Transition Study-2 data, with both studies showing that autistic young adults from lower income households were more likely to live with their parents or carers following secondary education.
- This was also true for autistic young adults from an ethnic minority background.

Regarding social participation, this systematic review (Elienberg et al., 2019) identified seven relevant studies, highlighting evidence of disparities in social participation for ethnic minority and lower income autistic young adults. Specifically:

- Autistic young adults from a White ethnic background, or from higher income households were more likely to be qualified drivers (one study);
- Autistic young adults from lower income households were less likely to participate in wider social activities (including leisure or recreational activities; meeting with friends) (three studies); and,
- Autistic young adults from an African-American ethnic background were less likely to spend time with their friends, compared to those from a White ethnic background (one study)

Access to health and care services

Barriers and facilitators to access; access to general healthcare; access to diagnostic services, mental health services and post-diagnostic support.

Access to health and care services: barriers and facilitators

Barriers and facilitators to healthcare access

Published academic literature- secondary sources

An Australian systematic review by Calleja et al. (2020) synthesised 3 studies (2003-2019) to identify barriers to healthcare access for autistic adults. Studies included six qualitative and seven quantitative studies, mostly US (n=5) or UK (n=3). There is a global lack of evidence concerning autistic adults' levels of access to healthcare services.

Variability in the designs, sizes, demographics collected and quality of included studies has prevented the identification of enablers. Barriers to accessing healthcare included:

- **Higher rate of co-morbid chronic physical, and mental health conditions.** The authors point to evidence of a higher rate of multiple and more complex health conditions, the potential impact on family and caregivers as a source of barriers to accessing appropriate healthcare.
- **Communication difficulties.** Poor communication or miscommunication of needs undermines access to care and may be caused by a range of factors, including due to language used by inexperienced practitioners.

Lack of transition support during major life changes, was a barrier to healthcare access, for example not having a support period for transitioning between childhood to adulthood healthcare services, limited coordination of this transition is often the norm.

Organisational level barriers included:

- **Lack of support or reluctance to treat from some service providers** (e.g. primary care providers) was reported as a barrier; lack of information on autism and access to services was also a barrier.
- **Care coordination.** A handful of studies highlighted lack of effective coordination of the different agencies involved in autistic peoples' health and care, with agencies seldom talking to one another. Particularly, no study identified key workers or care coordinators here, this was largely left to GPs as initial gatekeepers.
- **Importance of environmental and physical barriers to access** for autistic adults- phone calls, long waiting times in brightly lit waiting areas, the stress of uncertainty may all contribute to sensory overstimulation and anxiety.
- **Several barriers were identified in relation to a lack of provider knowledge of autism**. Namely, incorrect assumptions about autism, lack of knowledge, and unwillingness to communicate in writing were identified as barriers to access.

Access to health and care services: barriers and facilitators

Barriers and facilitators to healthcare access

Published academic literature- secondary sources

A UK-based systematic review by Mason et al. (2019) identified six studies (n=2 qualitative; 2 quantitative; 2 mixed-methods; combined sample n= 683; age range= 18-64) relevant to barriers to access for physical health services.

- **Patient-provider communication.** Five studies highlighted communication as a barrier; difficulties included registration, communication with the GP., and providers not adopting the patient’s preferred mode of communication.
- **Executive functioning and planning difficulties.** Several studies described individual level factors related to the autistic person’s level of information processing and memory or ability to carry out and plan complex and day-to-day tasks (e.g. taking medication; remembering to plan for and attend an appointment).
- **Sensory sensitivities.** Five studies reported different kinds of sensory sensitivities as barriers, including waiting room environment, unpredictability (of sensory environment and waiting times), and travelling to the appointment.

Published academic literature- primary sources

These barriers and facilitators dovetail with categories of different reasonable adjustments (and their importance) reported by autistic adults in two large cross-sectional UK surveys (Brice et al., 2021; mental health n=537; physical health n= 407). Three themes were identified concerning important reasonable adjustments:

1. **Sensory environment;**
2. **clinical and service context; and,**
3. **clinician knowledge and communication.**

Concerningly, survey findings indicate that while reasonable adjustments were perceived as important in supporting healthcare access, these adjustments be seldom offered. As 69 per cent of autistic adults were not offered mental health service adjustments, though this was slightly lower for physical health service adjustments (56%).

Access to health and care services: barriers and facilitators

Barriers and facilitators to healthcare access

Grey literature

As part of a national inquiry into access to healthcare for autistic people in England (Christou, 2016), the Westminster Commission on Autism surveyed n= 863 autistic people, family advocates and professionals contributed, to understand and inform how to reduce barriers to access. Several key barriers to healthcare access were identified:

- **Lack of training for health professionals and lack of accountability.** A high proportion (88%) stated they felt healthcare professionals did not always understand autism. In 2014, only 29% of local areas survey rated themselves green for having autism training available to all staff (Self-Assessment Framework).
- **Sparse data collection and reasonable adjustments.** The inquiry notes a lack of data collection on autism have been seldom collected in England at a general-practice and national level. As three-quarters of autistic and parent advocates stated that their doctor does not make any changes or adjustments to meet their needs, which may suggest health professionals may struggle to proactively identify and make adjustments for autistic people.

.

- **Even when access barriers are surmounted, autistic people may receive poorer health care services than those without autism.** Around 74% of autistic, parents, and professionals surveyed stated they felt autistic people receive ‘worse’ or ‘much worse’ healthcare than non-autistic people.

Access to health and care services: healthcare and transition-services

Healthcare and transition-services

Published academic literature- secondary sources

Smith et al. (2020) identified and systematically reviewed ten US-based research articles relevant disparities in service use and access to treatment and care for autistic children. All articles found evidence that ethnic minorities were less likely to be able to access and use health and care services.

- Children from African American or Hispanic backgrounds had lower use of gastrointestinal and nutritional services, neurological, psychiatric and psychological services; and higher difficulty accessing acute care compared to White autistic children.
- This was also the case for autism care and treatment services (including school-based services, occupational therapy, community-based therapies).
- Seven of the ten studies examined socioeconomic status, with several reporting that families with lower socioeconomic status had lower levels of access and use of health, care and treatment services compared to families in higher socioeconomic groups. Lower socioeconomic groups also reported increased difficulty accessing speciality referrals, with lower hospitalisation rates among lower income groups.

> *"The evidence supporting racial, ethnic, and economic disparities in ASD diagnosis and service access is strong and has been replicated across multiple studies." **(Smith et al., 2020).***

Disparities in access to transition related services has also been reported for lower-income and ethnic minority autistic young people. A US-based systematic review Eilenberg et al. (2019) identified 40 US-based studies (39 quantitative, 1 qualitative). Six studies related to disparities in access to healthcare transition services. Key findings include:

- Two studies drawn from nationally representative US-based samples demonstrated that ethnic minority and lower income youth were less likely to receive transition related healthcare planning services.
- One study also demonstrated a higher level of unmet healthcare service needs for youth from ethnic minority backgrounds, compared to those from a White ethnic background.
- Notably, no studies explored disparities in transition outcomes or access for mental health services.

While some evidence in this area is mixed, most of the evidence base supports the existence of disparities in access and participation of transition-related services, on the basis of ethnicity and socioeconomic status.

> *"Although these race/ethnicity- and income-based disparities are likely to continue into adulthood [9, 10], few studies have examined ASD service disparities over the life course. " **(Eilenberg et al., 2019)**.*

Access to health and care services: mental health services

Adult mental health services

Published academic literature- primary sources

A UK-based cross-sectional mixed-method study (Crane et al., 2019) examined the experiences of autistic young adults' (16-25 years old) lived experience of mental health and accessing mental health services, using a community-based participatory research approach with an online survey (n=109) and in-depth interviews (n=21). Key demographics include: 87.1% white ethnic background; 51.4% female; 15.6% non-binary; mean age= 20). Key survey findings include:

- While a high proportion (90.1%) indicated having sought help from mental health services previously, comparatively fewer indicated that this support was 'extremely' (13.7%) or 'very useful' (23.2%).
- Around a quarter of respondents felt comfortable disclosing or discussing their mental health issues with professionals (23.5% felt 'very' or 'extremely' comfortable disclosing).

Findings from in-depth qualitative interviews highlight several common themes relating to access and mental health services:

- **Stigma.** Experiencing stigma related to mental health concerns was a major barrier to seeking help; particularly for psychosis or personality disorder related diagnoses. Stigma around mental health from family members was also reported; respondents felt it was important for clinicians and professionals to address issues such as stigma.
- **Barriers to accessing mental health services.** Several barriers were reported as prominent, including: lack of available services for both autism and mental health needs; mental health problems being deemed "[not] severe enough for support"; lengthy waiting times for access; mental health services not being tailored to autism; and poor transition to adult services ("*you hit 18 and all your services just go "poof" and just disappear.*").
- **Quality of care.** The authors report that "*Overall, interviewees were generally unhappy about the standard of the services they accessed: 'I wasn't very happy with any way that my mental health was handled my whole entire life really'.*"- reflecting that some interviewees reported a pressure to show gratitude for support they felt did not go far enough: *"I just felt like a burden 'cause I didn't get as much as I wanted to but I was made to feel that that was more than I deserved.".*

Access to health and care services: mental health services

Adult mental health services

Grey literature

Autistica (Harper et al., 2019) outline key findings from research into the mental health of autistic adults.

Several quotes from this briefing highlight interaction between the increased burden of mental health difficulties in autistic adults, and systemic barriers to accessing both timely and sufficient mental health support:

"Autistic people are often unable to access community mental health support. [1,5,6,7] [They] report being "punted" between different settings; often from mental health services that are not confident in "dealing with autism" [...]"

"Up to 10% of adults in inpatient mental health settings are autistic, 3 even though only 1% of the population is on the spectrum. [4 ▪]"

"Mental health problems are often misdiagnosed amongst autistic adults. Autistic people are more likely to be given a sequence of diagnoses for their mental health problems and to disagree with the diagnosis they receive [1,2,5,13]"

"[...] treatment may need to be adapted for autistic people. Healthcare professionals can lack experience in the nuances of autistic people's mental health and confidence in identifying when someone's autistic traits are or are not a significant factor. [5,12,13]"

Children and young people's mental health services

Grey literature

Autistica have also produced a similar resource (Harper et al., 2019) outlining key findings from recent research concerning autistic children and young people's mental health. Many themes highlighted echo Autistica's briefing on adult mental health, outlining the high burden of mental health conditions in autistic children, and systemic challenges in accessing timely and appropriate support:

"7 in 10 autistic children have a mental health condition. 4 in 10 autistic children have more than one. [2] [...] Anxiety disorders are the most common type of mental health problem for autistic children to develop, affecting more than 4 in 10. [2]"

"Some children's mental health problems are dismissed as untreatable after being confused with autistic traits. [1,9] Others have been refused help from CAMHS who did not feel equipped to support them or told that CAMHS are not commissioned or funded to see autistic children."

"Some overstretched services are forced to use risk assessment tools to determine who to support with restricted capacity. This practice is explicitly criticised in NICE guidelines, [15] has been a repeated theme in inquests [16] and is particularly dangerous for autistic children, especially girls, whose suicide risk is even less likely to be predicted by these tools.[17]"

Access to health and care services: mental health services

Children and young people’s mental health services

Grey literature

As part of a regional analytical support programme, The Strategy Unit (Hood et al., 2021) undertook a mixed-methods analysis of primary and secondary relating to access to mental health services among children and young people within the midlands region.

This highlighted several findings of concern with respect to autistic children and young people and access to mental health support.

- For users of autism services (as well as those using LD and/or autism services), inequities in access to mental health services were more pronounced.

> *“You might have someone that’s got strong autistic tendencies [...] but they can't get into CAMHS to get the holy grail of a diagnosis, until they get the diagnosis they can't access other [specialist autistic] services [..], because they haven't got the magic diagnosis.”*

Several recommendations made in relation to children and young people’s mental health services may also have relevance to improving mental health services for autistic children and young people:

1. **Improve data collection and data use, particularly around inequities in access.** For example, by disaggregating service data by relevant demographic characteristics.
2. **Measure, monitor and maintain**. This relates to continuous and robust evaluation of initiatives and interventions, to understand 'what works’.
3. **Co-design and co-produce service research** that meaningfully involves children and young people.

> *“[Services need a] better understanding of autism. Not dismissing my mental health needs because of my autism diagnosis and realising that CBT will not work for me. Being able to spend time to build a trusting relationship with someone do I feel I can talk to them before they start asking questions”*

Access to health and care services: diagnostic services

Child and adolescent diagnostic services

Published academic literature- secondary sources

A recent systematic review of UK qualitative studies by Legg and Tickle (2019) (n=11 studies; n= 342 participants across studies) explored parents' experiences of pursuing an autism diagnosis for their child; using meta-ethnography several key themes were synthesised, including:

- **Pre-diagnosis.** Professionals such as GPs often did not recognise concerns identified by parents, or did not identify these concerns before parents- some parents reported dismissal of their concerns by professionals.
- **Assessment process.** Some reported satisfaction in receiving timely assessment, whereas others reflected on the negative emotional impact of long delays in accessing diagnosis.
  - Some parents reported being apprehensive in their interactions with professionals, referencing the power dynamic. The structure and content of assessment, for some parents, did not meet their expectations in being comprehensive, as some felt time more time interacting with the child was needed to make a diagnostic decision.
- **Post-diagnosis responses.** Responses varied, from relief, to experiencing distressing emotions such as loss, grief or anger. Gender differences were also reported by two studies, where fathers struggled to reconcile an autism diagnosis, relative to mothers. The authors state that this highlights unmet needs in terms of emotional support.

Published academic literature- primary sources

Stahmer et al. (2019) conducted a qualitative multi-site study to understand cross-cultural variation and input concerning how to improve access to autism services. Focus groups were conducted with a multi-cultural sample of caregivers of autistic children (n=58 participants speaking English, Spanish or Korean) and autism service providers and administrators (n=55).

The authors recognise disparities in access to healthcare services on the basis of ethnicity and income as enduring barriers to providing the right support for autistic children and their families. Crucially, previous studies have relied on quantitative data, and no previous study explored and synthesised the perspectives of autistic community stakeholders across diverse cultural and economic groups.

Access to health and care services: diagnostic services

Child and adolescent diagnostic services

Published academic literature- primary sources

Stahmer et al., (2019) conducted a qualitative multi-site study to understand cross-cultural variation and input concerning how to improve access to autism services.

- Focus groups were conducted with a multi-cultural sample of caregivers of autistic children (n=58 participants speaking English, Spanish or Korean) and autism service providers and administrators (n=55).

The authors recognise disparities in access to healthcare services on the basis of ethnicity and income as enduring barriers to providing the right support for autistic children and their families.

- Crucially, previous studies have relied on quantitative data, and no previous study explored and synthesised the perspectives of autistic community stakeholders across diverse cultural and economic groups.

While not exhaustive, some key themes identified by Stahmer et al. (2019) are:

- **Challenges to timely diagnosis and service access.** Including: concerns being dismissed, a confusing system that is complex to navigate, and limited provider availability
- **Promoting access for underserved groups requires building authentic partnerships** between autistic children, their families, and healthcare providers.
- **Cultural differences in the way systemic barriers to engagement are experienced.** Language barriers were more prominent for Korean and Spanish speaking families, whereas discrimination (on the basis of perceived youth) or paternalistic views towards parenting were more commonly experienced by Black parents.
    - Spanish-speaking families reported a lack of provider understanding of community or "collectivist" approaches to understanding child development.

Access to health and care services: diagnostic services

Child and adolescent diagnostic services

Grey literature

Findings from the British Medical Association, and Healthwatch echo many of these challenges for children and young people accessing a diagnosis.

Between 2014 and 2017, 33 local Healthwatch organisations survey over 1,000 people to understand potential improvements to autism services, informed by common challenges faced by autistic children and their parents (Healthwatch, 2017). These findings are triangulated with a recent briefing from the British Medical Association (2019) regarding waiting times for autism diagnostic assessments. Key themes include:

- **Understanding and knowledge in primary care and education.** Parents reported a lack of identification and understanding of autism in schools (Healthwatch 2017). While many reported adequate knowledge from their GP, some had negative experiences related to GP hesitancy in making a referral. Some parents reported a lack of empathy in their experiences with education and health systems.
- **Waiting times.** Work by Healthwatch Bradford and District (Healthwatch 2017) found local waiting times to be around 12 to 18 months to receive a diagnostic assessment. Others report similar challenges around lengthy waits from referral to assessment, and for receiving a diagnostic report.
    - This dovetails with a BMA (2019) report, showing that fewer than 10% of children's diagnostic assessments were commenced within three months of referral. This briefing draws on data from public health organisations, noting that in 2016 only 22% of local authorities fulfilled this target.
- **Inconsistencies in service pathways and the way in which different services communicate.** The BMA (2019) highlights inefficient communication between health, educational and local government agencies; inappropriate referrals or re-referrals or delays due to inefficient care pathways. This mirrors findings across several local Healthwatch (2017) engagement exercises conducted across England, highlighting a lack of consistency in pathways for diagnosis and support, and a lack of clear and accessible information about local referral pathways.

Access to health and care services: diagnostic services

Adult diagnostic services

Published academic literature- secondary sources

An Australian scoping review by Huang et al. (2020) summarises available research on adult autism diagnosis (n= 82 studies [62 quantitative, 16 qualitative and 4 mixed-methods] with 39% conducted in the UK), highlighting gaps in the evidence base regarding the pathways and processes for diagnosis.

- **13 out of 20 studies concerning diagnostic pathways were UK-based.** Highlighting that many adults sought diagnosis due to social interaction challenges and mental health issues, prompted by parents, partners or themselves.
- **Referral via general practitioner or generic mental health professional was the norm**; several studies highlighted that, prior to diagnosis, many had received prolonged mental health treatment. Studies also highlighted that many autistic adults cited negative experiences with services as a barrier to access.
- **A span of years between initial presentation, consultation and receipt of diagnosis**, is suggested by two sources, where autistic adults and their parents reported a process of multiple referrals and lack of recognition of the signs of autism.

A narrative review by Green et al. (2019) focussing on diagnosis for autistic women highlights that many are misdiagnosed or remain undiagnosed until later in life, reporting barriers to accessing diagnostic evaluation such as health professionals not being familiar with 'camouflaging' and how presentations of autism may vary, some report feeling dismissed.

Green et al. (2019) also highlight that with many who present late in life, gaining verifiable information about the patient's early social development to make a valid and reliable diagnosis can be challenging. Particularly when the patient's parents or caregivers may be deceased and unable to verify information- the authors report that this can be a major barrier to accessing treatment and support.

Access to health and care services: diagnostic services

Adult diagnostic services

Published academic literature- primary sources

A large scale survey of 11 EU member states (Autism Spectrum Disorders in the European Union; [ADESU] Scattoni et al., 2021) gathered data on autistic adults, carers of autistic adults, and professionals in exploring real-world experiences of diagnostic services and post-diagnostic support, comparing them to NICE guidelines on adult diagnosis.

Key findings and sample demographics from Scattioni et al. (2021) include:

- n=356 autistic adults, 88 carers, and 151 professionals took part in the survey, the majority of respondents were from Denmark (34%, Finland (16%) or France (16%). The sample was mainly female (73%; 90%; 74%), with most autistic adults (62%) being 26-45 years old;
- Waiting times for diagnostic evaluations were reported at around one to three months by around 30% of respondents across all groups; an equal proportion also reported waiting times in excess of six months; and,
- Less than 50% of respondents across all groups reported that information on diagnostic services or how to get a diagnosis was easy to access and understand; the authors also report generally low knowledge of diagnostic services that 'work well for autistic adults.

Grey literature

Autistica summarises recent UK research to highlight several issues with access to diagnosis in England (Harper et al., 2019):

- **Services differ in the information they collect prior to assessment**, which diagnostic screening tools to use, and in involving different groups of health professionals.
- **There is also variation in whether services use standardised autism diagnostic measures and screening tools**; some report being assessed by tools designed to assess children. Existing tools are also poor at distinguishing autism symptoms and traits from comorbid mental health conditions in autistic adults.
- **Part of the diagnostic process for autism involves parental or historical input** regarding the individual's social development in childhood. Meaning that a diagnosis may not be accessible to those who are estranged from their parents.

Access to health and care services: diagnostic services

Adult diagnostic services

Grey literature (cont.)

Several priority areas for action are informed by gaps in the existing literature, these are crucial to standardising the diagnostic process (Harper et al., 2019):

A. **The degree of variation in diagnosis rates across the country is not known,** further work should aim to understand this at a national and regional level (particularly around the factors that underpin different rates of diagnosis such as sociodemographic factors, or variation in tool use).

B. **Understanding best-practice in autism diagnostic service models-** such as whether some diagnostic models enhance accuracy and cost-effectiveness. And, understanding what level of diagnostic capacity is sufficient to action referrals for diagnosis, so that that adults across the country may access a timely autism diagnosis where required.

C. **Exploring the use and adaptation of different diagnostic tools to more effectively identify autism where co-occurring mental health condition exist-** particularly, how may this screening be performed effectively and efficiently within diagnostic pathways for autism.

Several sources (Harper et al., 2019; Hull et al., 2020; Green et al., 2019) provide an overview of research into the unique difficulties and challenges faced by women and girls when seeking an autism diagnosis:

1. **Prevalence evidence suggests underdiagnosis and under-recognition of autism in women and girls-** and, many women and girls receive a diagnosis much later in life than men, creating delays in accessing the right support. For example, a quote from an unpublished online consultation by Autistica outlines these challenges- *"[My] Daughter was refused a diagnosis as a child because 'girls don't get autism'. Now she's trying for adult diagnosis but was told it will not help her and she does not need it."* (cited in Harper et al., 2019).

2. **Misdiagnosis with mental health conditions is a common experience for autistic women and girls**, who often present to eating disorder or mental health services; many reflect that gender stereotypes, and the different presentation of autism in women and girls (and lack of knowledge and recognition of these differing presentations in non-specialist and primary care services) may also contribute to under-diagnosis, particularly in service areas without specialist knowledge of autism (e.g. primary care).

Access to health and care services: post-diagnostic support services

Post-diagnostic support services

Child services

The UK qualitative systematic review by Legg and Tickle (2019) also explored experiences of post-diagnostic support, several key constructs were identified:

- those who received support reflected on the benefits of receiving adequate post-diagnostic support, whereas some parents reported feeling abandoned post-diagnosis.
- These parents reported 'active support seeking' in response to this lack of accessible support. Crucially, parents indicated the need for a key-worker throughout the process, to enhance communication and joint working between services.

Specialist autism teams

An NIHR funded study (Beresford et al., 2020) evaluated how different Specialist Autism Teams are operating across different organisational and care settings in England. This study consisted of two cohorts: one receiving only diagnosis (n=56), and one receiving either diagnosis and support (n=164), or support only (n=88). Across these participants, 18 specialist autism teams were identified. Several findings are notable:

- Practitioners who were part of these teams reported that referral rates had increased each year, without an increase in funding.
- At the final stage of this study, for those receiving only diagnosis there no changes in mental health outcomes; whereas for those receiving support, or diagnosis and support, the authors report *"evidence of prevention of deterioration in outcomes and positive benefit"*.
- The authors also report that qualitative interviews with those in the diagnosis and support group highlighted the potential impact of extended psychoeducation following a diagnosis; noting potential impacts on short-and-long-term adjustment.
- Finally, the authors conclude that *"extended psychoeducation post diagnosis is a critical element of Specialist Autism Team provision."*

Access to health and care services: post-diagnostic support services

Post-diagnostic support services

Adult services

Published academic literature- secondary research

A scoping review (Shattuck et al., 2020) concerning services for autistic adults in western English speaking countries (2013-2018) outlines the methods and topics covered in 52 studies (42 US, four Canadian two Australian and three UK).

Most studies covered services related to employment (27), social participation (15), postsecondary education support (11) or healthcare services (8). The authors highlight several gaps in the literature:

- Samples included largely White Men, and no study reported demographic information related to gender-diversity or sexual orientation.
- This limits understanding what services might be appropriate and effective for more potentially vulnerable populations of autistic adults.

The authors highlight healthcare service related research for autistic adults as an emerging area, making wider recommendations for further research regarding service development based on gaps in the literature. Including:

  - **a) conducting research into more diverse samples of autistic adults;**
  - **b) co-produced research with autistic community stakeholders and professionals;** and,
  - **c) adopting a systems perspective or using improvement science to enhance care for vulnerable populations of autistic adults.**

- Overall, studies reportedly measured outcomes and demographic factors very variably, and some studies were missing this information.
- The authors conclude that this limits the generalisability of findings, particularly in understanding how service-related research for autism may be applied effectively and appropriately in different contexts and populations.

Access to health and care services: post-diagnostic support services

Post-diagnostic support services

Adult services

Published academic literature- secondary research (cont.)

Huang et al. (2020) also identified nine studies relevant to post-diagnostic support services. Highlight a consistent lack of clear of and accessible pathways to support for autistic adults after receiving a diagnosis, this was found across several studies and stakeholders (Autistic people, families and providers).

Published academic literature- primary sources

A large scale survey of 11 EU member states (Scattoni et al., 2021) gathered data on 356 autistic adults, and 88 carers of autistic adults. Key findings include:

- Across the groups, 67% autistic adults and 70% of carers surveyed reported experiencing none of the features or levels post-diagnostic support recommended by clinical guidelines.
- Under two per cent of adults and carers surveyed reported having experienced each of the features of post-diagnostic support recommended by clinical guidelines.
- The authors also highlight that limited literature exists on what constitutes good diagnostic and post-diagnostic support services for autistic adults.

Current policy and recommended changes to policy

Previous and current policy, legislation and guidance; Planned changes to policy: LeDeR (learning from lives and deaths) and Annual health checks; and policy recommendations.

Previous policy, legislation and guidance

Several key developments and changes in UK legislation and policy set out the statutory responsibilities of health, care and local government organisations to children, young people and adults with autism, and their families. The following slides will give a brief overview of a) autism policy within the last decade, b) forthcoming changes to current policy, and c) recommendations and changes to policy advocated by a range of sources.

Synthesising information across key autism policy documents (The Autism Act, 2009; Think Autism, 2014; Think Autism-update, 2016; NHS Long Term Plan, 2019), several key themes speak to the priorities and associated actions stated in autism policy over the last decade:

Key areas of Autism policy in England (2009- 2019)

1. Multi-sector autism awareness and training to enhance societal understanding of autism (at strategic/ operational levels, and for clinical and administrative NHS staff; and wider sectors, including social care, transport, policing, employment).
2. Improving consistency of local and national data collection to build a more robust understanding about who is autistic. Statutory guidance for local authorities and NHS organisations (Department of Health, 2015) outlines the need to commission and implement services for autistic people using representative population-level data.
3. Creating governance structures to support and oversee implementation of autism policies at a local and regional level; aspiring to more consistent and meaningful involvement of autistic people and their families in decision making at all levels.
4. Ensuring consistent pathways to access diagnosis and post-diagnostic services (and wider healthcare services for autistic people) across the whole of England.
5. Taking action to prevent excess mortality and morbidity in this population, and to use this action to learn how services can be improved for autistic people.
6. Improving outcomes around the wider determinants of health which mean that autistic people are able to lead fulfilling lives and participate fully in society (Education, housing, employment, criminal justice system).

However, it is notable that prior to the most recent national autism policy, ambitions set out in previous policy documents applied only to autistic adults, and not to autistic children and young people.

Previous policy, legislation and guidance

The past decade has seen several key developments and changes in English policy related to autism.

As the first and only piece of disability-specific legislation in England, the Autism Act (2009) led to the Department of Health (2010) publishing England's first strategy for autistic people, and later, accompanying statutory guidance for public sector bodies to support implementation.

"Think Autism Strategy" (2014) built on provisions laid out in the Autism Act. These policies also support local authorities to complete yearly Autism Self-Assessment Frameworks, to understand and assess progress in local service development against the ambitions set out.

The Autism Act (2009)

This act mandated national government to produce the first autism strategy for adults in England- "Think Autism: Fulfilling and rewarding lives: the strategy for adults with autism in England" (Department of Health, 2010). This strategy outlined several key ambitions for the next 10 years, including:

- Increasing awareness and understanding;
- Ensuring consistent diagnostic pathways are developed locally;
- Providing support for local agencies to plan and develop appropriate services for autistic adults;
- Access to services and living in the community; and
- Employment.

Statutory guidance (2010) published by the Department of Health sets out guidance on several key areas for supporting implementation, including:

a) staff training;

b) identification, diagnosis and assessing needs;

c) service-transition planning; and

d) local planning and leadership arrangements related to service provision.

Think Autism Strategy (2014)

The Autism Act (2009) legally requires the government to periodically (5 years) review progress and priorities associated with the autism strategy. The Think Autism Strategy (2014) is therefore an update to the earlier strategy, informed by stakeholder engagement, and local service self-assessment exercises to inform.

This outlines fifteen "priority challenges for action" (derived from engagement and local self-assessment exercises) across three core areas. These core areas include:

- Community involvement and equal participation;
- Receiving the right support at the right time; and
- Providing equitable opportunities for autistic people to develop their skills and independence.

Earlier statutory guidance for public sector agencies was updated to reflect an increased focus on (Department of Health, 2015):

a) reasonable adjustments and equity;

b) preventative support and safeguarding vulnerable people;

c) supporting those with complex needs; and

d) employment and the criminal justice system.

Previous policy, legislation and guidance

In 2016 the national government published a progress update to the earlier "Think Autism Strategy".

This document reviews progress against the aims of the earlier strategy, while also setting out new actions around employment, education and the criminal justice system. The focus of this document was to develop further policies to support local implementation of key actions.

It is notable that limited number of sources were identified in assessing the impact of successive policy changes. The three resources identified (Lemmi et al., 2017; Marshall-Tate, 2019; National Autistic Society & APPGA, 2019;) were consistent in suggesting that the potential benefits of such changes were slow to be realised, and that the pace of change must increase.

Think Autism Strategy- Update (2016)

The Department of Health published this as a progress report on the earlier Think Autism Strategy. Outlining aims of the previous strategy, highlighting progress towards each of the 33 actions described. Setting out several areas for further action across the 18 months following publication of the update:

- **Progress and planning.** Joint chairing arrangements for Autism Programme boards, and arrangements for Public Health England to conduct the self-assessment exercise.
- **Training and awareness.** Adaptation of existing resources to enhance autism awareness among HCP training programmes; planning for next phase of autism awareness project.
- **Diagnosis.** Using Self-Assessment Framework (SAF) data and working with local authorities to identify local diagnosis barriers.
- **Transforming care.** Reviewing proposals from national consultation to ensure significant progress by 2020.
- **Care and support.** Conducting research to understand low level support interventions for autistic people.
- **Employment for autistic adults.** Autism training in job centres; developing e-learning resources for managers.
- **Contact with the criminal justice system.** Developing training in collaboration with policing organisations; developing a new digital marker for vulnerability in the Police National Computer.

What does the published and grey literature say about previous policies?

Outlining findings from local Autism Self-Assessment Framework exercises conducted by Public Health England (2017), Marshall-Tate (2019) (pp. 40-51 in Robertson et al., 2019) note that while some positive changes are evident (e.g. over 90% of local authorities having a designated autism lead), challenges around low levels of local data collection and engagement of autistic people had persisted. Marshall-Tate highlight that these changes *"may not always be perceptible in the immediate term for [autistic people] […] the pace of change needs to increase"*. More recently low compliance with commitments to provide autism training to all health and care staff is reported, with under half of local authorities providing specialist autism training for staff conducting care assessments (PHE, 2019, cited in National Autistic Society & APPGA, 2019).

Two grey literature sources reflect several findings suggesting a slower pace of change:

- A survey conducted by National Autistic Society and APPGA (2019) (n= 12,500 autistic people and their families) showed that under half were aware of the Autism Act; under ten per cent reported improvements in local services since inception; around 71 per cent reported not getting as much support as they need, and only 14 per cent said local mental health services were sufficient in meeting their needs.
- Reflecting on the impact of successive policies, a report from The National Autism Project (Lemmi et al., 2017) highlights that: best-evidence is not always used to inform service development, and the needs of many autistic people remain unmet.

Current policy, legislation and guidance

More recently, the NHS Long Term Plan (2019) and associated implementation framework (2019) outline areas of action for improving healthcare for autistic people.

Key policy aims stated within these documents are presented in further detail on this slide.

Many commitments within this document pertain to 'learning disability and/or autism' or 'both learning disability and/or autism' owing to the considerable overlap between the two.

Without making a clear distinction between the groups of people within those categories (people with learning disabilities, autistic people, and autistic people with learning disabilities), it is difficult to determine which actions pertain to which groups, and how similar actions taken might be tailored to the diverse needs and perspectives of each group. Acknowledging that needs and experiences also differ considerably within these groups.

NHS Long Term Plan (2019)

The NHS Long Term Plan outlines six priority areas of action (and associated actions) with the aim of improving the health, longevity and quality of life of autistic people and people with learning disabilities. Owing to this review remit, this overview focuses on autistic people:

1. Enhance community-based support for autistic people; moving care into the community.
2. Ensure all NHS services provide a good standard of care and treatment for autistic people and their families.
3. Increase investment in intensive, crisis, and community forensic services for autistic people.
4. Reducing waiting times for specialist services.
5. Reducing health inequalities.
6. Improving understanding of autism across the whole NHS, and working to improve the health and wellbeing of autistic people.

Since publication of the Long Term Plan, the NHSE/I national autism team has been established to oversee delivery of the commitments set out, aiming to achieve a clearer focus on autistic children, young people and their families.

Specific areas of focus include:

- Reducing waiting times and increase quality of autism diagnostic pathways (assessment waiting times; pre-and–post support).
- Develop and pilot annual health checks.
- Ensuring health services put reasonable adjustments in place for autistic people.
- Expanding programmes which aim to reduce and stop overuse of psychotropic medications in autistic people.
- Working with primary care partners to expand sight, hearing and dental checks to autistic children and young people in residential settings.
- Helping autistic people with complex needs to access personal health budgets, and ensuring access to a designated key worker.
- Working with local service providers to a) reduce avoidable inpatient admissions, and b) plan high-quality person-centred inpatient services that may be accessed as close to home as possible.
- Increasing awareness of the importance of employing autistic people.

Current policy, legislation and guidance

Following public consultation and review of the Think Autism strategy in 2019, the Government has published its national autism strategy for England. This now extends provision outlined under The Autism Act and Think Autism to autistic children and young people, where previously these policies applied to autistic adults.

An overview of this document and the priority areas stated within it is provided on these slides.

Notably, two areas relate to policy changes that are currently underway to reduce health inequalities and avoidable deaths in autistic people without a learning disability.

These will be covered in further detail on subsequent slides:

- Learning Disability Mortality Review (LeDeR/ learning from lives and deaths).
- Annual health checks.

National strategy for autistic children, young people and adults: 2021 to 2026

The recently published national strategy replaces "Think Autism", extending the scope of the strategy to autistic children and young people. This sets out the ambitions of national government, and actions for local government, the NHS and other public institutions, for how to improve the lives of autistic people in the next five years.

Around £75 million in funding and an implementation plan have been announced for year one of the strategy.

The strategy covers the following six priority areas, though similar to the areas outlined under "Think Autism, including:

1. Improving societal understand and acceptance of autism;
2. Improving access to education and supporting positive experiences of transition;
3. Improving employment outcomes for autistic people;
4. Addressing healthcare inequities;
5. Ensuring the right support is available for autistic people to live well in the community; and,
6. Enhancing and improving available support for autistic adults and young people in the criminal and youth justice systems.

Year one of implementation focuses on establishing three enablers required to deliver other elements of the strategy, including:

A) Improve research and innovation;

B) Improve data collection and reporting; and,

C) Strengthen governance, leadership and accountability.

Planned changes to policy: LeDeR (learning from lives and deaths)

This slide gives a brief overview of the existing LeDeR process, highlighting forthcoming changes to the process as they pertain to changes in responsibility and expectations for local systems.

It should be noted that specific guidance on carrying out reviews for autistic people is anticipated later this financial year.

However, several key changes in existing documentation (NHS England, 2021) and wider sources (Local Government Association, 2021) allude to what might be expected of local systems in conducting these reviews.

Learning Disability Mortality Review (LeDeR/ learning from lives and deaths)

Starting in 2015, the Learning Disability Mortality Review (LeDeR; or learning from lives and deaths, as it is now known) is a formal process for reviewing the lives of individuals with learning disabilities (> 4 years old) who have died.

Reviews such as these are conducted to understand the health and care services that the person who died has received throughout their life. And, to inform how healthcare services can be improved to address health inequities, and ultimately prevent further early deaths. Clinical Commissioning Groups (CCGs) currently hold responsibility for conducting these reviews.

One of the most notable changes is the inclusion of autistic people in these reviews.

The focus of planned changes to LeDeR governance and processes is to ensure that the findings of such reviews are acted upon by local health and care systems.

For example, NHS England note that from September 2021, LeDeR will be incorporated into quality reporting arrangements for local ICSs. This mechanism for accountability is intended to improve local learning from these reviews, leading to clear steps for how this learning is translated into tangible service improvements for autistic people.

Since June 2021**, several key changes to this process have been announced** (NHS England, LeDeR Policy, 2021):

- Responsibility for conducting reviews will be transferred from CCGs to integrated care systems (ICSs), in addition to responsibility for training local reviewers.
- Creation of local governance structures must include those with lived experience of autism, and responsible professionals from within the ICS who are able to make changes to improve services.
- LeDeRs will now be extended to all autistic adults who do not have a learning disability; from 2021-2023, all deaths of adults who have an autism diagnosis (without a learning disability) will have a focused review to develop data and initial learning.
- The process for LeDeR for autistic adults will be put in place during 2021. The final deadline for ICSs to implement all changes to LeDeR policy is the 1 April 2022.
- Development of a web-based platform for conducting reviews and access to clinical records.
- Creation of NHS E/I Autism Programme, with a focus on collecting reliable data of health inequities for autistic people.
- Focused reviews will be automatically carried out for autistic people from Black, Asian and other minority ethnic backgrounds, given known health inequities and frequent reporting of deaths.

Planned changes to policy: Annual health checks

This slides gives an overview of planned changes to policy relating to the provision of annual health checks of autistic adults.

While guidance on population screening for autistic people and people with learning disabilities has recently been published (Public Health England, 2021), research to explore the barriers to annual health checks, what conditions might be screened for, and the effectiveness of such health checks is still underway. Including, whether there might be any unintended harms associated with annual health checks.

This means it is difficult to anticipate what might be expected of local systems and primary care organisations in delivering annual health checks, and in what timeframes; the degree to which existing provision for annual health checks for people with learning disabilities might be adapted also requires clarification.

Annual health checks for autistic people

Annual health checks were previously offered to people with learning disabilities, or people with learning disabilities and autism, but not to autistic people without a learning disability. This is despite a higher burden of health problems in this group compared to the general population (Harper et al., 2019).

Based on this, one of the key commitments of the NHS Long Term Plan (2019) is to pilot annual health checks for autistic people, and extend this more widely if successful. However, there is limited information available about: what this might entail. The degree to which existing screening tools or areas of the learning disability annual health checks might be adapted is also unclear.

Relevant national guidance for population screening of autistic people and people with learning disabilities has recently been published by Public Health England (2021); and, research funded by Autistica (in collaboration with academic partners and NHS England) to design and test such health checks is due to enter its third phase in Autumn 2021. Culminating in a randomised controlled trial to understand the feasibility, acceptability and effectiveness of health checks for autistic people.

Further research should aim to use secondary datasets to understand the most common causes of hospitalisation and other adverse health or service utilisation outcome; this might inform priority areas for health screening (Harper et al., 2019).

Annual health checks for autistic people (cont.)

Autsitica outline several recommendations (Harper et al., 2019) for action regarding annual health checks, including:

a) **Integrate autism health checks into CQC inspections** for general practices (assessing how prepared local practices are to deliver this);

b) Regulatory organisations should **collaborate with primary care IT system providers to ensure GPs can access relevant information they need to invite individuals for annual health checks**; this might also ensure that relevant information is accessible to the individual and that it becomes part of the health record;

c) Regulatory organisations, health education providers and Royal Colleges should **collaborate to understand how clinicians in primary care might be supported and incentivised to offer annual health checks** for autistic people;

d) Health education providers and Royal Colleges should come together to **develop ways of recognising processionals who have developed specialist knowledge and expertise in the health of neurodivergent people** (this might include accreditation of a General Practitioner with Extended Role); and,

e) To improve inconsistent coding of autism diagnoses across GP records, regulatory organisations should collaborate with Royal Colleges and autistic community stakeholders to **simplify clinical coding for autism diagnoses and audit local records**.

Policy recommendations

This slide gives an overview of recommended changes to policy highlighted by The National Autism Project (Lemmi et al., 2017), and a more recent inquiry by the National Autistic Society and All Party Parliamentary Group on Autism (NAS & APPGA, 2019). These sources make a series of recommendations across broad areas of policy and practice related to autism. These are synthesised by topic area below:

Understanding, training and awareness

The inquiry by NAS and APPGA (2019) highlighted the need commit to mandatory training on autism to be developed and delivered to all police officers, Jobcentre Plus staff, and as part of education professional development.

This also includes the recommendation to create and fund a longer-term campaign for understanding autism at a national level. Relevant training and campaigns for awareness should also challenge stigma and discrimination around autism (Lemmi et al., 2017).

Additionally, the government should clarify the legal duties of health and social care bodies and to establish a mechanism for monitoring implementation of any plans to deliver mandatory autism training (NAS & APPGA, 2019).

Governance, leadership and accountability

Both sources make recommendations related to improving data and information collection about autism, and the need to enhance cross-sector collaboration generally (Lemmi et al., 2017; NAS & APPGA, 2019). More recently, NAS and APPGA (2019) recommend conducting a cross-party review of government data collection about autism to understand where better information might enhance support.

The National Autism Project (Lemmi et al., 2017) makes several recommendations related to building better systems to capture information about autism, and coordinating action across healthcare, criminal justice, education and employment sectors.

The Autism Act inquiry report (NAS & APPGA, 2019) makes more detailed recommendations, including that the government should make a commitment to produce statutory guidance for any actions in the new autism strategy related to children and young people. And, to establish an inter-ministerial group to provide accountability on delivery of any programmes which aim to support transition of care from hospital to the community.

Enhancing service provision and understanding autistic peoples' journey through services

This area had the most recommendations from both sources. Recommendations from the NAS and APPGA (2019) include a) establishing and reporting on a new waiting time standard from referral to diagnosis, b) committing to establishing consistent specialist autism team provision across all local authorities, and c) setting clear requirements (to regulatory organisations and local commissioners) for appropriate community mental health service provision for autistic people.

The government should commission two reviews: 1) to understand autistic peoples' journey and experiences in prison and secure mental health settings; and 2) to conduct an independent and co-produced review of the mental health act definition of autism (NAS & APPGA, 2019).

A key recommendation of the National Autism Project (Lemmi et al., 2017) is to ensure timely identification and diagnosis of autism; noting the potential benefits of earlier identification, the authors state that the evidence base concerning effective interventions is limited and varies in coverage and quality. Highlighting a considerable need for further research in this area.

Policy recommendations

Several autistic community stakeholder and advocacy groups make a number of recommendations in relation to national government policy around autism generally, and for specific priority areas that affect autistic people, such as mental health and social care policy. The following slides provides an overview of recommendations made across policy briefings published by Autistica and other sources identified, broken down by topic area.

Access to diagnosis

A briefing by Autstica (Harper et al., 2019) makes several general recommendations for increasing access to diagnosis for adults:

a) The new Autism Strategy should **explicitly commit to increasing the availability of specialist autism diagnostic services.**

b) National government and regulatory bodies should **work with local systems to ensure they recognise the gains in commissioning effective diagnostic services**;

c) Using national datasets, **commission an analysis of service use patterns for later diagnosed autistic adults**; and,

d) The Long Term Plan workstream for autism should also **prioritise action around addressing geographical variation in access to diagnosis** (including identifying what an optimal diagnostic pathway looks like).

Gender disparities in diagnosis

Recommendations made to improve parity of access to diagnosis between men and women include (Harper et al., 2019):

a) The new autism strategy should **acknowledge and address the challenges faced by women and girls in autism diagnostic pathways**;

b) The Long Term Plan workstream for autism **must consider and explore ways to reduce and remove barriers to diagnosis;** and,

c) Regulatory bodies should **conduct an audit of autistic women and girls in eating disorder and inpatient mental health settings** to understand the role that earlier diagnosis may play in improving outcomes.

Diagnostic process

Recommendations made in relation to the improving the diagnostic process include (Harper et al., 2019):

a) NHS Digital should **publish annual rates of diagnosis in adults** (with rate of referral and referral-to-assessment time recorded**) disaggregated by age, gender, ethnicity, geography and commissioning area;**

b) Accompanying action at a national level, NHS England should **collaborate with relevant professional bodies to map existing adult autism diagnostic networks;** and,

c) Local systems must demonstrate to NHS England that their local commissioning arrangements **provide sufficient resource and planning to provide diagnostic and support services for autistic people with learning disabilities, and autistic adults without a learning disability**.

Policy recommendations

Social care

A recent briefing by Autistica (Smith et al., 2020) makes several recommendations for improving social care for autistic people. Many of these relate to improving research and understanding around 'what works' for providing social care for autistic people, given lack of research and funding in this area. Key recommendations include:

a) **Build the capacity and infrastructure to conduct better quality research into social care** by: encouraging public research funders to invest in *'nurturing a new cohort of social care researchers'*, and trial innovative approaches to encourage care staff to collaborate on research;

b) **Invest in fully-funded or 'pump-prime' studies into the effectiveness of different social care models and interventions;** and,

c) **Develop a new funding settlement for social care which ensures any improvements may be sustained;** and which creates parity of esteem between providing care for adults who are of working age and providing care for older adults.

Additionally, the Autism Act (National Autistic Society & APPGA, 2019) inquiry report recommends that the government establish an autism social care commissioning fund to be managed by councils to enhance and extend local social care service provision for autistic people.

Mental health

Autistica have given a series of recommendations across topic areas relevant to the mental health of autistic people.

Children and young people (Harper et al., 2019):

Recommendations made in relation to adult mental health include:

a) Sections in the new Autism Strategy which apply to this group should explicitly focus on enhancing access to effective and consistent mental health service provision;

b) Investment in specialist community mental health teams for autistic children and young people, so that demand on lower tier CAMHS services (and risk-management and gate-keeping practices) may reduce, ensuring that those who needs this support in a crisis can access it without having to meet an arbitrary threshold for risk;

c) Working with local systems, NHS England should ensure there are clear pathways in place for seeking and accessing mental health support for young autistic people in every area; and,

d) Support through the diagnostic process should focus on earlier identification of mental health difficulties and providing practical support and adjustments to families to prevent mental health difficulties from worsening.

Mental health (cont.)

Adults (Harper et al., 2019):

Recommendations made in relation to adult mental health include:

a) In developing the new framework for community mental health services, NHS England should ensure that the mechanisms to collect data and evaluate this framework are in place; additional, this framework should reflect involvement of autistic people and their families;

b) Local systems should demonstrate that commissioning plans include mental health service provision for autistic people that is sufficiently funded;

c) Health education providers, regulatory organisations and professional bodies should collaborate to increase local capacity of health professionals with a sufficient specialist knowledge of autism; and,

d) Ensure that supporting autistic adults with mental health problems remains a high priority in the new Autism Strategy.

References

References

Adak B & Halder S. (2017) Systematic review on prevalence for autism spectrum disorder with respect to gender and socio-economic status. Journal of mental disorders and treatment. Available at https://www.hilarispublisher.com/open-access/systematic-review-on-prevalence-for-autism-spectrum-disorder-with-respect-to-gender-and-socioeconomic-status-2471-271X-1000133.pdf

All Party Parliamentary Group on Autism (2017) Autism and education in England 2017. Available at https://www.autism-alliance.org.uk/wp-content/uploads/2018/04/APPGA-autism-and-education-report.pdf

Allen M & Coney K (2021) WHAT HAPPENS NEXT? 2021 A report on the outcomes of 2018 disabled graduates. Available at https://www.agcas.org.uk/write/MediaUploads/Resources/Disability%20TG/AGCAS_What_Happens_Next_2021_-_February_2021.pdf

Alley CS (2018) A systematic PRISMA review of individuals with autism spectrum disorder in secure psychiatric care: prevalence, treatment, risk assessment and other clinical considerations. J Crim Psychol. Available at https://www.emerald.com/insight/content/doi/10.1108/JCP-06-2017-0028/full/html#sec004

Anderson KA et al. (2018) Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. Pediatrics, 141(S4), S318-S327. Available at https://pediatrics.aappublications.org/content/141/Supplement_4/S318

Ayres M et al. (2017) A systematic review of quality of life of adults on the autism spectrum. Autism. Available at https://eprints.ncl.ac.uk/file_store/production/239271/033EF3F5-FEA1-451F-BC2D-0B5035957100.pdf

Beresford B et al. (2020) Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. NIHR journal library, HSDR. Available at https://pubmed.ncbi.nlm.nih.gov/33320485/

Berg KL et al. (2016) Disparities in adversity among children with autism spectrum disorder: a population-based study. Developmental medicine and child neurology, 58(11), 1124-1131. Available at https://onlinelibrary.wiley.com/doi/10.1111/dmcn.13161

Botha M et al. (2021) Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. J Autism Dev Disord, 1-9. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7817071/

Brice S et al. (2021) The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: findings from UK surveys. Health services research. Available at https://bmjopen.bmj.com/content/11/3/e043336

British Medical Association (2019) Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder. Available at https://www.bma.org.uk/media/2056/autism-briefing.pdf

References

Brugha TS et al. (2011) Epidemiology of autism spectrum disorders in adults in the community in England. Arch Gen Psych. Available at https://pubmed.ncbi.nlm.nih.gov/21536975/

Calleja S et al. (2020) Healthcare access for autistic adults: A systematic review. Medicine, 99(29), e20899. Available at https://journals.lww.com/md-journal/fulltext/2020/07170/healthcare_access_for_autistic_adults__a.25.aspx

Cashin AB et al. (2018) A scoping review of what is known of the physical health of adults with autism spectrum disorder. J Int Disabil, 22(1), 96-108.

Cawthorpe D. (2017) Comprehensive Description of Comorbidity for Autism Spectrum Disorder in a General Population. The Permanente journal, 21, 16-88. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5283790/

Chen JL et al. (2014) Trends in Employment for Individuals with Autism Spectrum Disorder: a Review of the Research Literature. Rev J Aut Dev Disord, 2, 115-127. Available at https://link.springer.com/article/10.1007/s40489-014-0041-6

Christensen DL et al. (2018) Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. MMWR Surveill Summ, 65(13), 1-23. Available at https://www.cdc.gov/mmwr/volumes/65/ss/ss6513a1.htm?s_cid=ss6513a1_w

Christou E. (2016) A spectrum of obstacles: an inquiry into access to healthcare for autistic people. The Westminster Commission on Autism. Available at https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf

Coleman-Fountain E et al. (2020) Improving mental health in autistic young adults: a qualitative study exploring help-seeking barriers in UK primary care. Br J Gen Pract, 70(694), e356-363. Available at https://pubmed.ncbi.nlm.nih.gov/32312761/

Cooke J (2018) We need an education- exclusions report. Ambitious about Autism. Available at https://www.ambitiousaboutautism.org.uk/sites/default/files/resources-and-downloads/files/we-need-an-education-exclusions-report.pdf

Crane L et al. (2016) Experiences of Autism Spectrum Disorder and Policing in England and Wales: Surveying Police and the Autism Community. J Aut Dev Disord, 46, 2028-2041. Available at https://link.springer.com/content/pdf/10.1007/s10803-016-2729-1.pdf

Crane L et al. (2019) Something needs to change': Mental health experiences of young autistic adults in England. Autism, 23(2), 477-493. Available at https://journals.sagepub.com/doi/full/10.1177/1362361318757048

Curtin C et al. (2014) Obesity in children with autism spectrum disorder. Harvard review of psychiatry, 22(2), 93-103. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4105159/

da Silva SN et al. (2017) Oral health status of children and young adults with autism spectrum disorders: systematic review and meta-analysis. Int J Paed Dent, 27(5), 388-398. Available at https://www.researchgate.net/profile/Rafael-Souza-37/publication/309590663_Oral_health_status_of_children_and_young_adults_with_autism_spectrum_disorders_Systematic_review_and_meta-analysis/links/5e7ed0cba6fdcc139c0c58c0/Oral-health-status-of-children-and-young-adults-with-autism-spectrum-disorders-Systematic-review-and-meta-analysis.pdf

References

DaWalt LS et al. (2019) Mortality in individuals with autism spectrum disorder: Predictors over a 20-year period. Autism, 23(7), 1732, 1739. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6713622/

De Giorgi R et al. (2019) Prevalence of non-affective psychoses in individuals with autism spectrum disorders: a systematic review. Journal of clinical medicine. Available at https://www.mdpi.com/2077-0383/8/9/1304/pdf

Department of Health (2010) Implementing "Fulfilling and rewarding lives" Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216129/dh_122908.pdf

Department of Health (2014) Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf

Department of Health (2015) Adult autism strategy: supporting its use. Available at https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance

Department of Health (2016) Progress Report on Think Autism: the updated strategy for adults with autism in England. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/492011/autism-progress-report.pdf

Department of Health and Social Care and Department of Education (2021) The national strategy for autistic children, young people and adults: 2021 to 2026. House of Commons. Available at https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026

Dillenburger K et al. (2015) The Millennium child with autism: early childhood trajectories for health, education and economic wellbeing. Developmental neurorehabilitation, 18(1), 37-46. Available at https://www.researchgate.net/publication/266388725_The_Millennium_child_with_autism_Early_childhood_trajectories_for_health_education_and_economic_wellbeing

Eilenberg JS et al. (2019) Disparities Based on Race, Ethnicity, and Socioeconomic Status Over the Transition to Adulthood Among Adolescents and Young Adults on the Autism Spectrum: a Systematic Review. Current psychiatry reports, 21(5), 23. Available at https://pubmed.ncbi.nlm.nih.gov/30903399/

Fortuna RJ et al. (2016) Health Conditions and Functional Status in Adults with Autism: A Cross-Sectional Evaluation. J Gen Int Med, 31(1), 77-84. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4700008/

Frith U & Happé F. (2020) Annual Research Review: Looking back to look forward – Changes in the concept of autism, and implications for future research. Journal of child psychology and psychiatry. Available at https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.13176

Garrido D et al. (2020) Siblings of children with autism spectrum disorders: social support and family quality of life. Int J QoL, 29(5), 1193-1202. Available at https://link.springer.com/article/10.1007/s11136-020-02429-1

References

Glidden D et al. (2016) Gender Dysphoria and Autism Spectrum Disorder: A Systematic Review of the Literature. Sexual medicine reviews, 4(1),3-14. Available at https://www.smr.jsexmed.org/article/S2050-0521(15)00004-9/fulltext#%20

Green RM et al. (2019) Women and Autism Spectrum Disorder: Diagnosis and Implications for Treatment of Adolescents and Adults. Current psychiatry reports, 21(4), 22. Available at https://pubmed.ncbi.nlm.nih.gov/30852705/

Harmuth E et al. (2018) Barriers and Facilitators to Employment for Adults With Autism: A Scoping Review. Annals of international occupational therapy, 1(1). Available at https://journals.healio.com/doi/pdf/10.3928/24761222-20180212-01

Harper G et al. (2019) Autistica Action Briefing: Access to Adult Diagnosis. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Access-to-Adult-Diagnosis.pdf

Harper G et al. (2019) Autistica Action Briefing: Adult Diagnosis Process. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Adult-Diagnosis-Process.pdf

Harper G et al. (2019) Autistica Action Briefing: Adult Mental Health. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Adult-Mental-Health.pdf

Harper G et al. (2019) Autistica Action Briefing: Children and Young People’s Mental Health. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Children-and-Young-Peoples-Mental-Health.pdf

Harper G et al. (2019) Autistica Action Briefing: Diagnosing Autistic Women and Girls. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Diagnosing-Autistic-Women-And-Girls.pdf

Harper G et al. (2019) Autistica Action Briefing: Employment. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Employment.pdf

Harper G et al. (2019) Autistica Action Briefing: Health Checks. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Health-Checks.pdf

Harper G et al. (2019) Autistica Action Briefing: Suicide Prevention. Available at https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Suicide-Prevention.pdf

Hayward SM et al. (2018) Challenges for females with high functioning autism in the workplace: a systematic review. Disability and rehabilitation, 40(3), 249-258.

Healthwatch (2017) Children and young people with autism Findings from the Healthwatch network. Healthwatch briefing. Available at https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/children_and_young_people_with_autism_-_findings_from_the_healthwatch_network_0.pdf

Helverschou SB et al. (2017) Personal experiences of the Criminal Justice System by individuals with autism spectrum disorders. Autism. Available at https://journals.sagepub.com/doi/10.1177/1362361316685554

Herrera-Moncada M et al. (2019) Autism and Paediatric Dentistry: A Scoping Review. Oral health and preventive dentistry, 17(3), 203-210. Available at https://www.researchgate.net/profile/Juan-Hernandez-Cabanillas-2/publication/333878974_Autism_and_Paediatric_Dentistry_A_Scoping_Review/links/5f08e3a2a6fdcc4ca45d3790/Autism-and-Paediatric-Dentistry-A-Scoping-Review.pdf

References

Hillier A et al. (2019) LGBTQ + and autism spectrum disorder: Experiences and challenges. Int J Transgender Health, 21(1), 98-110. Available at https://www.tandfonline.com/doi/abs/10.1080/15532739.2019.1594484

Hirvikoski TM et al. (2016) Premature mortality in autism spectrum disorder. The British journal of psychiatry, 208(3), 232-238. Available at https://www.cambridge.org/core/services/aop-cambridge-core/content/view/4C9260DB64DFC29AF945D32D1C15E8F2/S0007125000279385a.pdf/div-class-title-premature-mortality-in-autism-spectrum-disorder-div.pdf

HM Government (2009) The Autism Act. Available at https://www.legislation.gov.uk/ukpga/2009/15/contents

Hood A et al. (2021) Inequities in Access to Children and Young Peoples Mental Health Services in the Midlands. Report for the Midlands Decision Support Network. The Strategy Unit. Available at https://www.strategyunitwm.nhs.uk/sites/default/files/2021-07/210727%20Inequities%20in%20access%20to%20CYP%20MH%20Services%20in%20the%20Midlands%20-%20Strategy%20Unit%20Report%20-%20FINAL.pdf

Huang Y et al. (2020) Diagnosis of autism in adulthood: A scoping review. Autism, 24(6), 1311-1327. Available at https://pubmed.ncbi.nlm.nih.gov/32106698/

Hull L et al. (2020) The Female Autism Phenotype and Camouflaging: a Narrative Review. Rev J Aut Dev Dis, 7, 306-317. Available at https://link.springer.com/article/10.1007/s40489-020-00197-9

Kapp SK. (2018) Social Support, Well-being, and Quality of Life Among Individuals on the Autism Spectrum. Paediatrics, 141, S362. Available at https://www.researchgate.net/publication/324158103_Social_Support_Well-being_and_Quality_of_Life_Among_Individuals_on_the_Autism_Spectrum/link/5c82a924299bf1268d485520/download

Kassee C et al. (2020) Physical health of autistic girls and women: a scoping review. Molecular autism, 84. Available at https://link.springer.com/article/10.1186/s13229-020-00380-z

King C & Murphy GH (2014) A systematic review of people with autism spectrum disorder and the Criminal Justice System. J Autism Dev Discord, 44(11), 2717-2733. Available at https://pubmed.ncbi.nlm.nih.gov/24577785/

Kinnaird E et al. (2019) Investigating alexithymia in autism: A systematic review and meta-analysis. Eur Psychiatry, 55, 80-89. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6331035/

Koukouriki E & Soulis SG. (2020) Self-reported Health-Related Quality of Life (HRQOL) and Anxiety Among Greek School-Age Siblings of Individuals with Autism Spectrum Disorders (ASD) in Relation to Parental Mental Health and Social Support. J autism dev disorder, 50(8), 2913-2930. Available at https://pubmed.ncbi.nlm.nih.gov/32040799/

Kronenberg LM et al. (2014) Everyday life consequences of substance use in adult patients with a substance use disorder (SUD) and co-occurring attention deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD): a patient's perspective. BMC psychiatry, 14, 264. Available at https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-014-0264-1

Lai MC et al. (2019) Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. The Lancet Psychiatry. Available at https://discovery.ucl.ac.uk/id/eprint/10081954/7/Mandy%20THELANCETPSYCH-D-19-00008R4_.pdf

Lallukka T et al. (2020) Unemployment Trajectories and the Early Risk of Disability Pension among Young People with and without Autism Spectrum Disorder: A Nationwide Study in Sweden. In J Environ Res, 17(7). Available at https://www.researchgate.net/publication/340457518_Unemployment_Trajectories_and_the_Early_Risk_of_Disability_Pension_among_Young_People_with_and_without_Autism_Spectrum_Disorder_A_Nationwide_Study_in_Sweden/fulltext/5e8b1fb24585150839c45300/Unemployment-Trajectories-and-the-Early-Risk-of-Disability-Pension-among-Young-People-with-and-without-Autism-Spectrum-Disorder-A-Nationwide-Study-in-Sweden.pdf

References

Legg H & Tickle A (2019) UK parents’ experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. Autism, 23(8), 1897-1910.

Lemmi V et al. (2017) THE AUTISM DIVIDEND Reaping the rewards of better investment. Available at https://nationalautistictaskforce.org.uk/wp-content/uploads/2020/02/autism-dividend-report.pdf

Magen-Molho H et al. (2020) Spatiotemporal distribution of autism spectrum disorder prevalence among birth cohorts during 2000-2011 in Israel. Annals of epidemiology, 48, 1-8. Available at https://pubmed.ncbi.nlm.nih.gov/32778226/

Marshall-Tate K (2019) Chapter 3: Autism Legislation and Policy. In Chaplin E et al. (2019) A Clinician's Guide to Mental Health Conditions in Adults with Autism Spectrum Disorders: Assessment and Interventions. Publisher: Jessica Kingsley. Available at https://books.google.co.uk/books?hl=en&lr=&id=KvqXDwAAQBAJ&oi=fnd&pg=PA40&ots=UZ5Lr3l4lF&sig=UoMUGhDBxuAptb0z7smWEd5LL5g&redir_esc=y#v=onepage&q&f=false

Mason D et al. (2019) A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. J Autism Dev Discord, 49(8), 3387-3400. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6647496/

National Autistic Society (2016) The autism employment gap: Too Much Information in the workplace. Available at https://www.basw.co.uk/system/files/resources/basw_53224-4_0.pdf

National Autistic Society and All Party Parliamentary Group on Autism (2019) The Autism Act, 10 years on: a report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England. Available at https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf

NHS England (2019) NHS Long Term Plan. Available at https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

Nicholas DB et al. (2018) An Ecosystem Approach to Employment and Autism Spectrum Disorder. Journal of autism and developmental disorders, 48(1), 264-275. Available at https://pubmed.ncbi.nlm.nih.gov/29071564/

Parkin E et al. (2020) Autism – overview of policy and services. House of Commons Library Briefing Paper. Available at https://researchbriefings.files.parliaPercora LA et al. (2016) Sexuality in High-Functioning Autism: A Systematic Review and Meta-analysis. J Autism Dev Disord, 46(11). Available at https://pubmed.ncbi.nlm.nih.gov/27565655/

Pezzimenti F et al. (2019) Depression in Youth with Autism Spectrum Disorder. Child and adolescent psychiatric clinics of North America, 28(3), 397-409. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6512853/

Powell PS et al. (2021) Health Status and Health Care Use Among Adolescents Identified With and Without Autism in Early Childhood - Four U.S. Sites, 2018-2020. Morbidity and mortality weekly report, 70(1), 605-611. Available at https://pubmed.ncbi.nlm.nih.gov/33914722/

Reinders NJ et al. (2019) Scoping Review: Physical Activity and Social Functioning in Young People With Autism Spectrum Disorder. Frontiers in psychology, 10(120). Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6381857/

Roestorf A et al. (2019) "Older Adults with ASD: The Consequences of Aging." Insights from a series of special interest group meetings held at the International Society for Autism Research 2016-2017. Res Autism Sepctr Disord, 63, 3-12. Available at https://pubmed.ncbi.nlm.nih.gov/31275429/

References

Roman-Urrestarazu A et al. (2021) Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. JAMA pediatrics, 175(6). Available at https://jamanetwork.com/journals/jamapediatrics/fullarticle/2777821

Russell G et al. (2013) Prevalence of Parent-Reported ASD and ADHD in the UK: Findings from the Millennium Cohort Study. J Autism Dev Disord, 44, 31-40. Available at https://link.springer.com/article/10.1007%2Fs10803-013-1849-0

Russell G et al. (2021) Time trends in autism diagnosis over 20 years: a UK population-based cohort study. Journal of child psychology and psychiatry. Available at https://acamh.onlinelibrary.wiley.com/doi/10.1111/jcpp.13505?af=R

Rutten AX et al. (2017) Autism in adult and juvenile delinquents: a literature review. Child and adolescent psychiatry and mental health, 11(45). Available at https://capmh.biomedcentral.com/articles/10.1186/s13034-017-0181-4

Rydzewska E et al. (2018) Prevalence of sensory impairments, physical and intellectual disabilities, and mental health in children and young people with self/proxy-reported autism: Observational study of a whole country population. Autism, 23(5), 1201-1209. Available at https://journals.sagepub.com/doi/abs/10.1177/1362361318791279?journalCode=auta

Rydzewska E et al. (2019) Age at identification, prevalence and general health of children with autism: observational study of a whole country population. BMJ Open, 9(7), 22. Available at http://eprints.gla.ac.uk/188623/7/188623.pdf

Scattoni ML et al. (2021) Real-World Experiences in Autistic Adult Diagnostic Services and Post-diagnostic Support and Alignment with Services Guidelines: Results from the ASDEU Study. J Autism Dev Discord. Available at https://link.springer.com/article/10.1007/s10803-021-04873-5

Scott M et al. (2018) Factors impacting employment for people with autism spectrum disorder: A scoping review. Autism, 23(4). Available at https://www.researchgate.net/publication/326815473_Factors_impacting_employment_for_people_with_autism_spectrum_disorder_A_scoping_review

Sedgewick F et al. (2019) Autistic adult outcomes on weight and body mass index: a large-scale online study Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity. Available at https://link.springer.com/article/10.1007%2Fs40519-019-00695-8

Shattuck PT et al. (2020) Services for Adults With Autism Spectrum Disorder: a Systems Perspective. Current psychiatry reports, 22. Available at https://link.springer.com/article/10.1007/s11920-020-1136-7

Simantov T et al. (2021) Medical symptoms and conditions in autistic women. Autism. Available at https://journals.sagepub.com/doi/full/10.1177/13623613211022091

References

Skokauskas N & Frodl T. (2015) Overlap between autism spectrum disorder and bipolar affective disorder. Psychopathology, 48(4), 209-216. Available at https://epub.uni-regensburg.de/37656/1/21.pdf

Smith E et al. (2019) We cannot accept another Whorlton Hall. We need better evidence of what works. Autistic Action Briefing. Available at https://www.autistica.org.uk/downloads/files/Social-care-briefing.pdf

Smith IC et al. (2020) Socio-emotional determinants of depressive symptoms in adolescents and adults with autism spectrum disorder: A systematic review. Autism, 24(4), 995-1010.

Smith KA et al. (2020) Disparities in Service Use Among Children With Autism: A Systematic Review. Pediatrics, 145(S1), S35-S46. Available at https://pediatrics.aappublications.org/content/145/Supplement_1/S35

Stahmer AC et al. (2019) Caregiver Voices: Cross-Cultural Input on Improving Access to Autism Services. Journal of racial and ethnic health disparities, 6(4), 752-773. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6936957/

Steenfeldt-Kirstensen C et al. (2020) The Prevalence of Self-injurious Behaviour in Autism: A Meta-analytic Study. J Aut Dev Disord. Available at https://link.springer.com/article/10.1007/s10803-020-04443-1

Vasilopoulou E & Nisbet J et al. (2016) The quality of life of parents of children with autism spectrum disorder: A systematic review. Research in autism spectrum disorders. Available at http://faratarjome.ir/u/media/shopping_files/store-EN-1483168696-3165.pdf

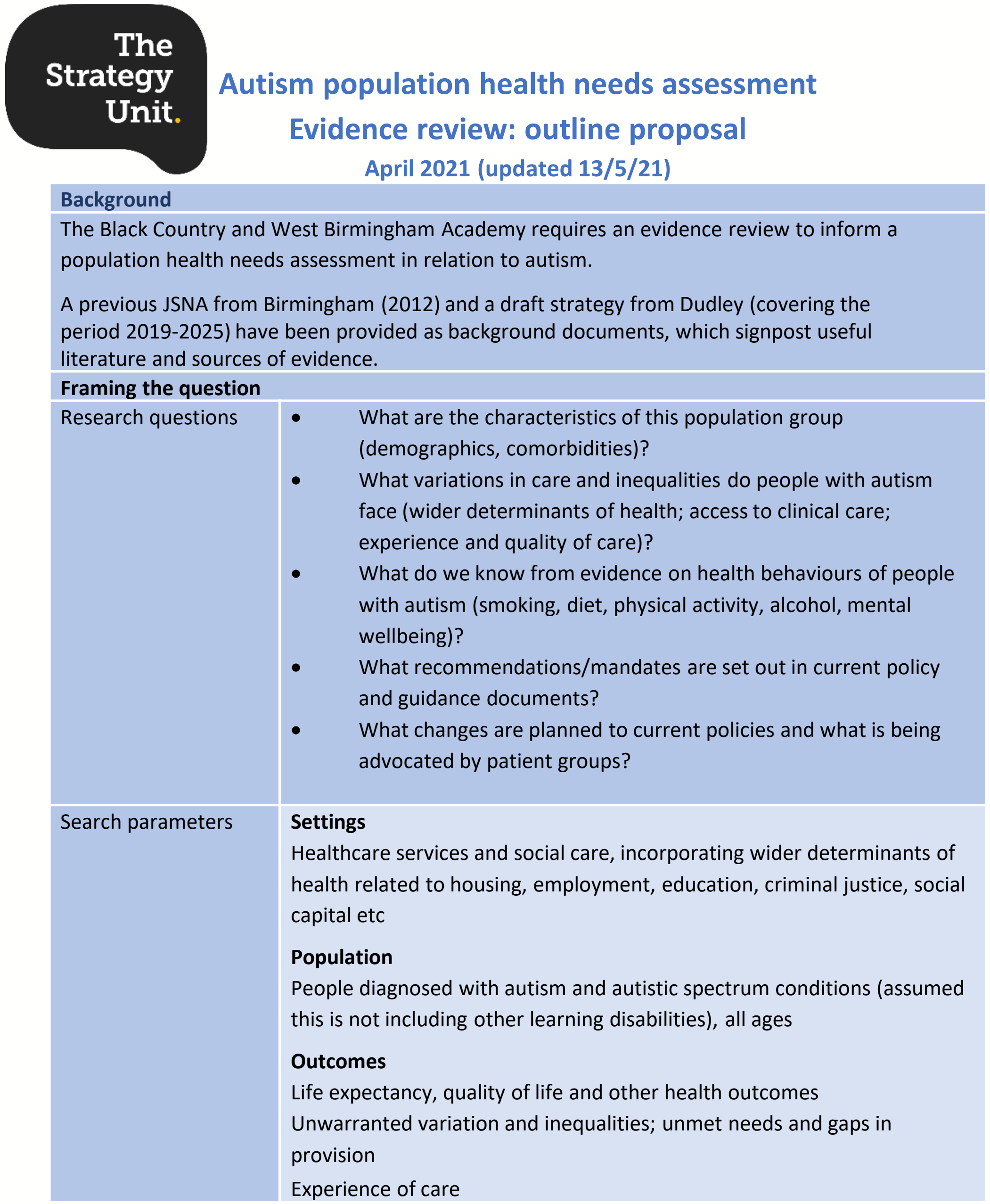
Warrier V et al. (2020) Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. Nature communications. Available at https://www.nature.com/articles/s41467-020-17794-1

Watson L et al. (2021) A systematic review of the experience of being a sibling of a child with an autism spectrum disorder. Clin Child Psychol Psychiatry. Available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8264626/

Weir E et al. (2021) Understanding the substance use of autistic adolescents and adults: a mixed-methods approach. The Lancet psychiatry, 8(8), 673-685. Available at https://www.sciencedirect.com/science/article/pii/S2215036621001607

Appendix A: Methodology

Methodology: outline proposal



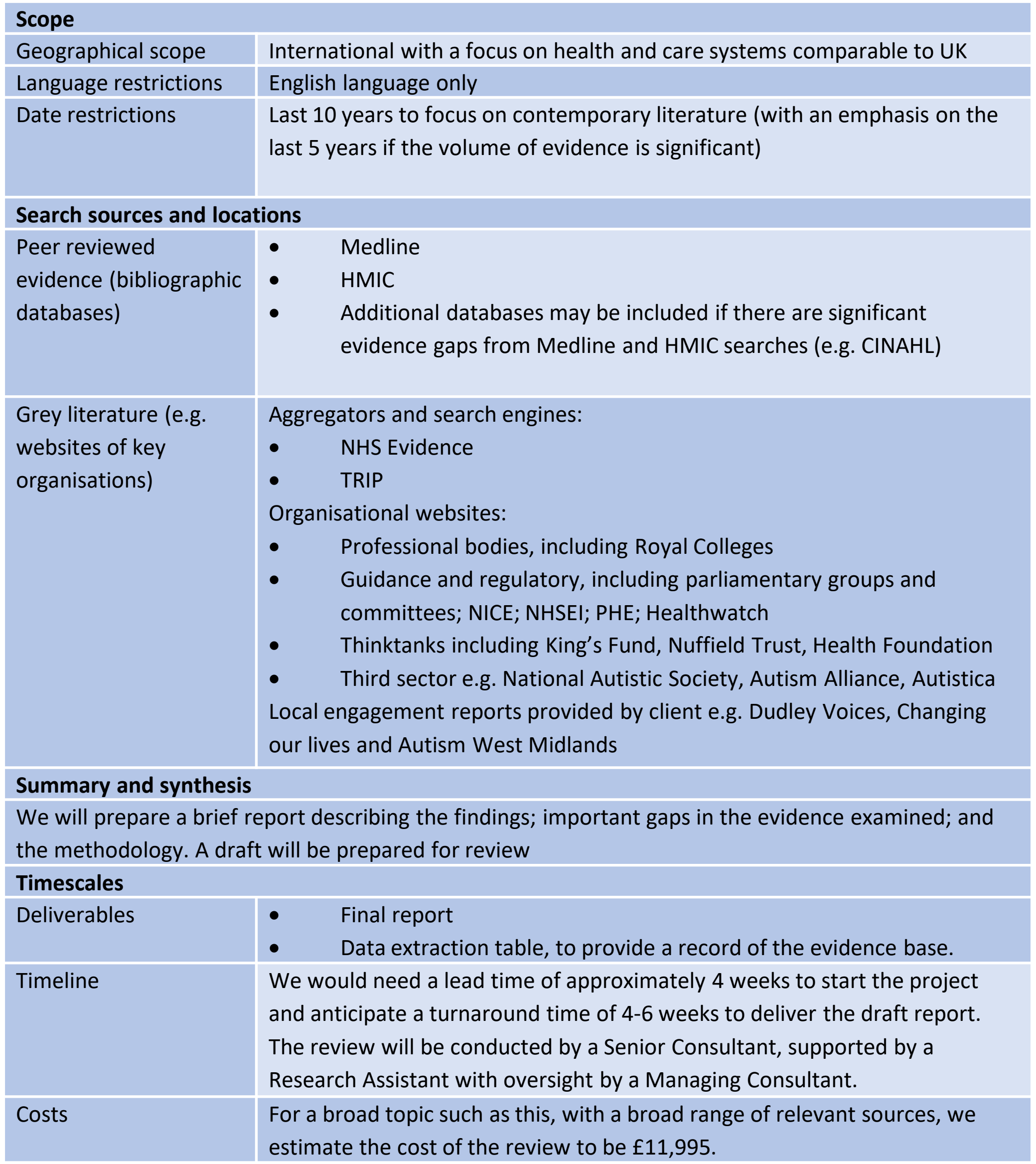
The Strategy Unit.

Autism population health needs assessment

Evidence review: outline proposal

April 2021 (updated 13/5/21)

Background	
The Black Country and West Birmingham Academy requires an evidence review to inform a population health needs assessment in relation to autism. A previous JSNA from Birmingham (2012) and a draft strategy from Dudley (covering the period 2019-2025) have been provided as background documents, which signpost useful literature and sources of evidence.	
Framing the question	
Research questions	• What are the characteristics of this population group (demographics, comorbidities)? • What variations in care and inequalities do people with autism face (wider determinants of health; access to clinical care; experience and quality of care)? • What do we know from evidence on health behaviours of people with autism (smoking, diet, physical activity, alcohol, mental wellbeing)? • What recommendations/mandates are set out in current policy and guidance documents? • What changes are planned to current policies and what is being advocated by patient groups?
Search parameters	**Settings** Healthcare services and social care, incorporating wider determinants of health related to housing, employment, education, criminal justice, social capital etc **Population** People diagnosed with autism and autistic spectrum conditions (assumed this is not including other learning disabilities), all ages **Outcomes** Life expectancy, quality of life and other health outcomes Unwarranted variation and inequalities; unmet needs and gaps in provision Experience of care



Scope	
Geographical scope	International with a focus on health and care systems comparable to UK
Language restrictions	English language only
Date restrictions	Last 10 years to focus on contemporary literature (with an emphasis on the last 5 years if the volume of evidence is significant)
Search sources and locations	
Peer reviewed evidence (bibliographic databases)	• Medline • HMIC • Additional databases may be included if there are significant evidence gaps from Medline and HMIC searches (e.g. CINAHL)
Grey literature (e.g. websites of key organisations)	Aggregators and search engines: • NHS Evidence • TRIP Organisational websites: • Professional bodies, including Royal Colleges • Guidance and regulatory, including parliamentary groups and committees; NICE; NHSEI; PHE; Healthwatch • Thinktanks including King's Fund, Nuffield Trust, Health Foundation • Third sector e.g. National Autistic Society, Autism Alliance, Autistica Local engagement reports provided by client e.g. Dudley Voices, Changing our lives and Autism West Midlands
Summary and synthesis	
We will prepare a brief report describing the findings; important gaps in the evidence examined; and the methodology. A draft will be prepared for review	
Timescales	
Deliverables	• Final report • Data extraction table, to provide a record of the evidence base.
Timeline	We would need a lead time of approximately 4 weeks to start the project and anticipate a turnaround time of 4-6 weeks to deliver the draft report. The review will be conducted by a Senior Consultant, supported by a Research Assistant with oversight by a Managing Consultant.
Costs	For a broad topic such as this, with a broad range of relevant sources, we estimate the cost of the review to be £11,995.

Methodology: narrative

Searching

A search strategy was developed iteratively in the search builder within the Healthcare Database Advanced Search (HDAS), incorporating key words and subject headings relevant to the areas of interest highlighted within the outline proposal for this work.

Bibliographic databases within HDAS (Health Management Information Consortium [HMIC]; Medline) and search aggregators (NHS Evidence) were used to identify initial published academic and grey literature sources relevant to the research questions specified.

Citation pearl growing and snowballing techniques were also used to identify additional sources of relevance.

In parallel, local system intelligence was requested and reviewed to understand any available information around prevalence rates and local provision.

Screening and extraction

To ensure relevance of the identified evidence base in context to the high volume of published academic literature identified initially (~850 results), evidence synthesis focused on secondary literature sources published within the last five years. However, where a limited amount or no such sources of this type were identified, relevant primary sources were included.

Sources returned from database, grey literature, and additional searching were screened iteratively by title, abstract and full-text *(for an overview of inclusion and exclusion criteria, and the volume of results screened and included, please see the next slides)*.

Following screening for final inclusion, bibliographic information and relevant findings from full-text sources were extracted to a Microsoft excel table ('extraction table').

Methodology (synthesis)

Sources were collated and themed according to the research questions, using an evidence extraction template.

To provide insights relevant to local population context, the evidence analyst aimed to iteratively triangulate information across published and grey literature sources with local system intelligence.

Where a high volume of literature has been found on a particular topic, evidence synthesis and key findings within these slides are structured according to: published academic literature (primary and secondary sources) and grey literature sources.

Methodology: inclusion and exclusion criteria

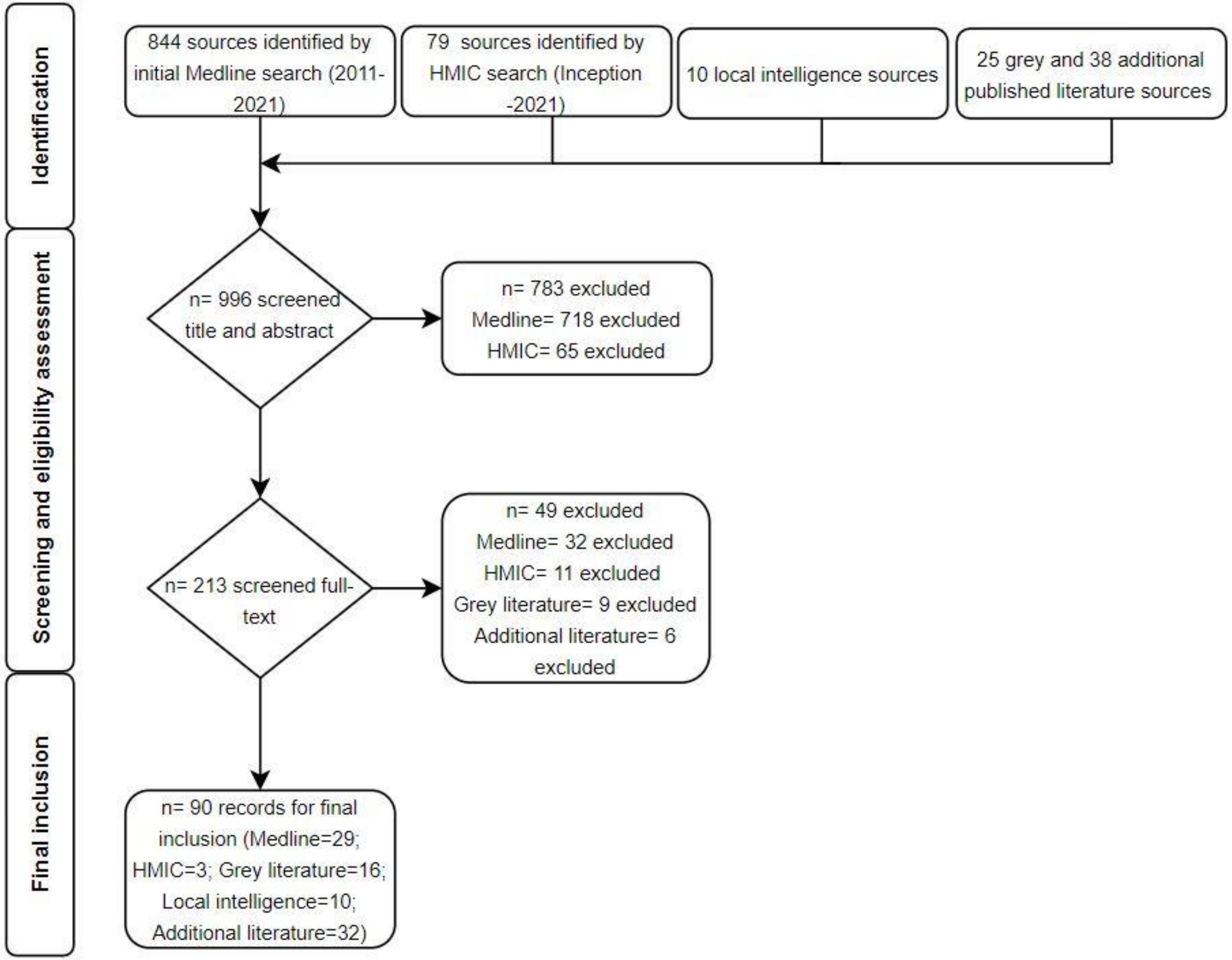
Inclusion criteria.

- English language
- 2011-2021
- Primary and secondary published academic literature or grey literature source
- Title or abstract relates to autism and one of the four research areas outlined: population characteristics (prevalence, demographics and comorbidities); health behaviours; variations in outcomes and access; or current policy and policy change

Exclusion criteria.

- Paper not in English language
- Pre 2011
- Title/ abstract/ full-text did not pertain to autism and one of the four research areas outlined
- Full-text could not be obtained via NHS library services
- Title or abstract suggested that the article pertained to learning disabilities and not autism
- Commentaries or blogs

Methodology: searching and screening process



Search strategy (HMIC and Medline):

(((exp "MORTALITY, PREMATURE"/ OR exp "LIFE EXPECTANCY"/ OR exp "HEALTH STATUS"/ OR exp "QUALITY OF LIFE"/ OR exp "SOCIAL DETERMINANTS OF HEALTH"/ OR exp "HEALTH STATUS DISPARITIES"/) AND ((exp "AUTISM SPECTRUM DISORDER"/ OR autis*) NOT ("intellectual disa*" OR exp "LEARNING DISABILITIES"/))) AND ((((exp RESIDENCE CHARACTERISTICS/ OR exp RESIDENTIAL FACILITIES/ OR exp HOMELESS PERSONS/ OR REFUGEES/ OR TRANSIENTS) AND (MIGRANTS OR EMIGRANTS)) AND (IMMIGRANTS OR CHILD, INSTITUTIONALIZED/ OR ADOLESCENT, INSTITUTIONALIZED/)) OR (exp SEXUAL AND GENDER MINORITIES/ OR gender) OR CULTURAL CHARACTERISTICS/ OR exp ETHNIC GROUPS/ OR RACE FACTORS/ OR ethnic* OR race OR racial OR exp SOCIOECONOMIC FACTORS/ OR SOCIAL CAPITAL/ OR AGE FACTORS/ OR ADOLESCENT/ OR exp CHILD/ OR exp INFANT/ OR exp SOCIAL DISCRIMINATION/ OR HEALTHCARE DISPARITIES/ OR "inequal*" OR "equit*" OR exp HEALTH SERVICES ACCESSIBILITY/ OR exp HEALTH SERVICES NEEDS AND DEMAND/ OR "access*" OR exp HOUSING/ OR exp "SOCIAL SUPPORT"/ OR exp EDUCATION/ OR exp *EMPLOYMENT/ OR (social ADJ care).ti,ab OR ("criminal ADJ justice" OR "recidivism" OR "justice ADJ system" OR "prison" OR "incarcer*").ti,ab)) [Languages English] [Humans]

The Strategy Unit.

Stay connected with us!

https://www.strategyunitwm.nhs.uk/ 💻

@Strategy_Unit 🐦

strategy.unit@nhs.net ✉

NHS
Midlands and Lancashire
Commissioning Support Unit