Exploring Autism Policies and Strategies for Individuals with Autism in England, Wales, Scotland, and Northern Ireland.

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This study aims to review the evolving trends in inclusion policies for individuals with Autism Spectrum Disorder (ASD). Autism policies and strategies are essential for ensuring the inclusion of students with autism in the education system. However, a lack of awareness among teachers about these policies often results in students with autism being treated as typical learners, placing them at a disadvantage. This research seeks to identify relevant policies, analyse how they have changed over time. The scope of the research includes autism policies across England, Scotland, Wales, and Northern Ireland. By examining these policies and strategies in different nations of the United Kingdom, the study aims to uncover diverse approaches and enhance comparative insights into their effectiveness. This study uses narrative literature approach, identifying strengths, challenges, and areas for improvement. Key research questions include: What autism policies currently exist in each UK nation? And how do these policies address critical area such as inclusion? Through a review of policy documents, academic literature, and relevant reports, this research will provide a comprehensive overview of autism policies, highlighting the effectiveness and limitations of current frameworks while offering insights for future policy development.

Keywords: Autism, Policy, Strategy, United Kingdom, Autism Services, Public Awareness, Autism Diagnosis, Support, Stakeholder Involvement, Neurodiversity, Advocacy, Inclusion, Employment, Education, Transition Services, Evidence-based Interventions.

England

The Autism Act of 2009 in England was a groundbreaking piece of legislation, as it was the first disability-specific act in the country (Department for Education, 2021; UK Parliament, 2024). However, this Act applies only to England and Wales. According to Barber (2024), since the 1980s, disability-related laws such as the *Mental Health Act* (1983), *Disability Discrimination Act* (1997), and *Valuing People* (2001) have emerged, but only *Valuing People* specifically addresses a particular disability. The Autism Act provides a framework for addressing the needs of adults with autism spectrum conditions and related matters.

Since the enactment of the Autism Act in 2009, three national strategies have followed, developed by the NHS and shared with local authorities. The first strategy, *Fulfilling and Rewarding Lives*, published in 2010, focuses on adults with autism. This was followed by *Think Autism*, published in 2014, which built upon the initial strategy, again focusing on adults with autism. The most recent, *The National Strategy for Autistic People, Children and*

Young People, published in 2021, expanded the scope of the previous strategies to include children and young people.

Despite the significance of the Autism Act of 2009, it has faced various criticisms for its limitations. One major critique is its narrow scope. The Act focuses solely on adults and excludes autistic children, failing to address their unique needs (Department for Education, 2021; UK Parliament, 2024; Dillenburger, Makerr, and Jordan, 2014). This omission is particularly problematic given that autism spectrum disorder (ASD) manifests in early childhood, and adequate support and education during these formative years are critical for the child's development and future integration into society (Roleska et al., 2018). Recognizing this limitation, the 2021 National Autism Strategy for England expanded its scope to include children and young people (Department for Education, 2021; UK Parliament, 2024).

Another significant critique is the Act's lack of robust enforcement mechanisms. While the Act outlines objectives, it does not include strong provisions to ensure effective implementation (Dillenburger, Makerr, and Jordan, 2014). Although multidisciplinary practice has been endorsed by the United Nations Convention on the Rights of Persons with Disabilities as an enforcement mechanism, Dillenburger et al. (2014) argue that there is limited empirical evidence of its effectiveness. The heterogeneous nature of autism means that a one-size-fits-all approach is insufficient, leading to inconsistencies in service provision and support for autistic individuals.

The Act has also been criticized for its emphasis on diagnosis over post-diagnostic support (Dillenburger, Makerr, and Jordan, 2014). While it has led to significant advancements in diagnostic services (Department for Education, 2021), critics argue that securing a diagnosis is often prioritized at the expense of providing adequate post-diagnostic support and resources. This overemphasis on diagnosis leaves many autistic individuals and their families struggling to access necessary services. A lack of understanding of inclusion within mainstream education systems further exacerbates this issue, highlighting the need for studies such as this one. The 2010 strategy for adults with autism in England also reflected this concern by primarily focusing on improving diagnostic services rather than addressing long-term support needs (Roleska et al., 2018).

In terms of employment, the Autism Act of 2009 aimed to support autistic individuals in finding and retaining jobs. However, it has proven ineffective in addressing the employment gap faced by autistic people (Grant and Williams, 2023). Autistic individuals continue to have significantly lower employment rates compared to non-autistic individuals, reflecting the need for more targeted and effective measures. Many employers require prior work experience, yet autistic individuals often lack access to high-quality work experience opportunities. This barrier prevents them from making informed career choices and gaining the skills necessary to navigate the workplace successfully.

Finally, financial constraints have hindered the full implementation of the Act's provisions (Dillenburger, Makerr, and Jordan, 2014). Insufficient funding for autism-related services, support, and research undermines the Act's goals and leaves many autistic individuals and their families without adequate resources. Addressing these funding challenges is essential to ensure the Act fulfils its intended purpose.

Wales

Wales is recognized as a leader in Autism policy development, with the Autism Act of 2009 being the first disability-specific legislation in the region (Crane et al., 2016). Wales published its first Autism Action Plan in 2008, which significantly increased awareness of Autism. The Welsh Government also established local-level structures and personnel to implement this strategic action plan, which was designed in response to the voices of Autistic individuals, their families, and carers regarding what matters most to them (Welsh Gov., 2016). The plan addresses the needs of children, youths, adults, and their families, aiming to enable them to lead fulfilling lives. This all-age Autism strategy has led to increased public awareness and understanding of Autism, improved access to diagnostic and support services, and the development of numerous resources for Autistic individuals and their families.

Stakeholder involvement has been central to Autism policy development in Wales. Policies are crafted through consultations with Autistic people, their families, and professionals in relevant fields (Hurt et al., 2017; Storey, McConnell, & Keenan, 2023; Welsh Gov., 2016). The Welsh Government Autism Advisory Group includes Autistic individuals, family members, and representatives from service delivery organizations. Another key initiative is the Integrated Autism Service (IAS), which began in 2016 and became fully operational in 2019. The IAS provides diagnostic assessments, community support, and advice for adults with Autism and their families (Welsh Gov., 2016). It also seeks to standardize diagnostic pathways and implement waiting time targets.

Additionally, the Code of Practice on the Delivery of Autism Services, introduced in 2021, outlines a comprehensive set of requirements for public bodies to meet the needs of Autistic individuals (Welsh Gov., 2022). These requirements include provisions for assessment and diagnosis, access to health and social care services, pre-diagnostic support, and staff training on Autism. The Welsh Government has also committed to becoming an Autism-friendly employer and encourages other organizations to adopt Autism-friendly workplace practices (Welsh Gov., 2016).

Despite these significant strides, gaps and inconsistencies remain. Long waiting times for diagnosis are a major concern (National Assembly for Wales, 2019; Welsh Gov., 2016). Although a 26-week waiting time target for children has been implemented, it is still shorter than waiting times in England and Scotland, which can range from nine months to over a year. However, concerns have been raised that the shorter waiting time proposed under the Autism (Wales) Bill could divert resources from other services (National Assembly for

Wales, 2019). Critics have also argued that an overemphasis on diagnosis risks prioritizing Autism over other conditions and services (National Assembly for Wales, 2019).

Another challenge is the lack of clarity and accessibility regarding evidence-based practices (EBPs) in Welsh Autism policy (Storey, McConnell, & Keenan, 2023). The primary policy documents often refer readers to external sources, such as the National Institute for Health and Care Excellence (NICE) guidelines, which can be difficult for individuals without a research background to navigate. This lack of clarity can hinder Autistic individuals, families, and practitioners from accessing appropriate support. Additionally, while the Code of Practice is comprehensive, its effective implementation and enforcement remain areas for improvement (Storey, McConnell, & Keenan, 2023). The success of the Code depends on the capacity of local authorities and health boards to fulfil its requirements, emphasizing the importance of effective monitoring and evaluation (Welsh Gov., 2021).

Philanthropy has also played a significant role in shaping Autism policy in Wales. Philanthropic contributions have supported research initiatives that inform policy decisions and have facilitated the creation of community-based organizations that provide vital support networks for families. For example, Autism Cymru, a small charity, has been instrumental in influencing government policy and research (Morgan, 2024). This highlights the potential impact of strategic philanthropic funding in advancing Autism-related work in Wales.

There is a need for continued research and evaluation to assess the effectiveness of existing policies and identify areas for improvement. This includes exploring innovative approaches such as video-based interventions and developing accessible resources on EBPs for all stakeholders (Storey, McConnell, & Keenan, 2023).

Overall, Wales has demonstrated a strong commitment to improving the lives of Autistic individuals through its policies and strategies. However, ongoing efforts are required to address remaining service gaps, ensure consistent provision across the country, and translate policy goals into tangible outcomes for Autistic individuals and their families.

Scotland

The Scottish Autism Strategy, launched in 2011, was designed to improve care and support for individuals with ASD (Scottish Parliament, 2017; Bocioaga, 2022). This 10-year strategy outlined key values, time-defined goals, and indicators for best practices in delivering Autism services (Scottish Parliament, 2017; Scottish Gov., 2017). It included 26 specific recommendations across six themes, aiming to address diverse aspects of Autism support (Scottish Gov., 2021). However, a 2021 evaluation of the strategy revealed that, while it funded and supported a range of local and national initiatives, it failed to create substantial, long-lasting change for Autistic individuals (Scottish Gov., 2021). The evaluation emphasized the need for services and support to have greater reach, be embedded consistently, and achieve sustainability to create a meaningful impact.

The Scottish Autism Strategy faced significant challenges, including a lack of focus, clarity, and effective implementation. The evaluation found the strategy overly broad and ambitious, making it difficult to deliver and sustain effectively (Scottish Gov., 2021). Ambiguity around actions and implementation hindered measurable progress. While the strategy was initially well-received, it has been criticized for its limited impact. Ten years after its launch, many Autistic individuals and their families still lack the critical support needed to live meaningful lives. According to the *Accountability Gap* report by the National Autistic Society Scotland (2021), 72% of respondents felt they did not receive adequate support under the strategy.

Another significant issue was insufficient data collection. The evaluation recommended that the Scottish Government explore mechanisms for routine evidence and data collection to inform local and national service delivery (Scottish Gov., 2021). Inconsistencies in the adoption and application of the strategy's priorities across Scotland made it challenging to capture an accurate picture of service delivery outcomes.

The debate over whether Autism should be classified as a disability, or a neurodiverse condition also complicates Autism policy in Scotland. Different organizations adopt varying definitions of Autism. For example, the National Autistic Society defines Autism as "a lifelong developmental disability," whereas Scottish Autism describes it as "a lifelong developmental condition" (Scottish Gov., 2021). This lack of consensus has implications for the design and implementation of services.

The strategy evaluation highlighted several areas requiring urgent attention, including diagnosis, transitions, support for Autistic adults, and employment (Scottish Gov., 2021). Much of the responsibility for implementing the strategy fell on local authorities, yet no binding requirements ensured they fulfilled these responsibilities effectively. There was also criticism about insufficient engagement with Autistic individuals and their families in the policymaking process. The *Accountability Gap* report emphasized the lack of long-term resourcing to support Autistic individuals and highlighted concerns about merging the Autism and learning disability agendas, as this could dilute the focus on the specific needs of Autistic individuals (Scottish Gov., 2021).

Critics argue that merging these agendas risks undermining efforts to address the unique challenges faced by Autistic individuals, particularly as their needs are distinct from those with learning disabilities (Scottish Gov., 2021). This concern underscores the need for a tailored approach that respects the specific experiences and requirements of Autistic individuals.

In response to these shortcomings, the Scottish Government has committed to developing a new strategy addressing the issues raised in the 2021 evaluation (Cage et al., 2024). The new strategy, expected to be published in 2023, aims to prioritize key areas such as improved service provision, clearer implementation frameworks, and more robust engagement with Autistic individuals and their families (Scottish Gov., 2021). The effectiveness of this upcoming strategy remains to be seen, but there is cautious optimism that lessons from the past will inform a more successful approach to supporting Autistic individuals in Scotland.

Northern Ireland

Autism policies and strategies in Northern Ireland have played a key role in raising awareness and improving services, but they also face significant criticisms and areas for improvement. Public awareness of Autism in Northern Ireland is notably high, with 82% of adults surveyed in 2012 reporting an awareness of Autism This widespread awareness is attributed to the implementation of Autism-specific legislation and public awareness campaigns (Dillenburger, Jordan, and Kerr, 2013).

The Autism Act (NI) 2011 has been a landmark piece of legislation. It amended the *Disability Discrimination Act 1995* to include difficulties with social interaction within the definition of disability (Dillenburger, Jordan, and Kerr, 2013). The Act also mandated the creation of a cross-departmental Autism Strategy, launched in 2014, which provided a comprehensive framework for improving services across the lifespan (Dillenburger et al., 2014). The strategy outlined key focus areas, including awareness, accessibility, education, transitions, and employment (Davidson, 2020). To support its goals, action plans have been regularly developed and updated.

Northern Ireland has made considerable progress in providing Autism services and increasing funding. The establishment of the Regional Autism Spectrum Disorder Network (RASDN) was a key development, leading to the reorganization and integration of Autism services within Health and Social Care (HSC) Trusts. Each Trust now has a dedicated ASD coordinator and budget, improving the coordination and delivery of services (Dillenburger et al., 2014). In addition, €2 million was allocated in 2020 to further enhance services, with a focus on awareness campaigns and professional training. Despite these advancements, inconsistencies in service provision across Northern Ireland persist, creating a "postcode lottery" where access to services depends on geographic location (Dillenburger et al., 2014). This inequitable access leaves many individuals with Autism and their families underserved.

Another major criticism is the insufficient emphasis on evidence-based interventions, particularly Early Intensive Behavioural Intervention (EIBI). Although robust evidence supports EIBI's effectiveness, it is not consistently offered by statutory bodies. Instead, there has been reliance on less effective interventions such as the TEACCH approach or sensory integration therapy, which has drawn criticism from experts and advocates (Dillenburger et al., 2014).

While there has been progress in services for children with Autism, support for adults remains underdeveloped (Joint Committee on Health and Children (JCHC) debate, 2008). The transition from child to adult services is often fraught with challenges, including inadequate support for education, employment, housing, and independent living (Dillenburger et al., 2014). Advocacy groups have consistently called for increased investment in adult services to ensure lifelong support and better outcomes (JCHC debate, 2008).

The lack of meaningful involvement of Autistic individuals in policymaking and service design is another critical issue. Advocacy efforts stress the importance of including Autistic people in decision-making processes that directly impact their lives (Hagan and Byrne, 2022). This includes incorporating their perspectives into the design of support services, research, and policy development (Hagan and Byrne, 2022).

A further challenge is the lack of comprehensive data collection on Autism prevalence and service utilization. This gap limits the ability to effectively plan and evaluate services. Data collection, particularly regarding adults with Autism, is inadequate. A robust data system is necessary to monitor Autism prevalence, track service use, and measure outcomes, thereby informing policy decisions and resource allocation (Dillenburger et al., 2014).

Recommendations for Improvement

To address the criticisms and challenges, Northern Ireland should focus on several key areas for improvement. First, it is essential to address the inconsistencies in service provision across the region, ensuring that all individuals with Autism have equitable access to services, regardless of their geographic location. This would help mitigate the "postcode lottery" issue and create a more level playing field for families seeking support.

Second, there is a need to prioritize evidence-based interventions, particularly Early Intensive Behavioural Intervention (EIBI). Incorporating EIBI into statutory service provision and ensuring that professionals are trained in these methods would help enhance the quality and effectiveness of Autism services across Northern Ireland.

Another important area for improvement is the provision of services for adults with Autism. While much progress has been made in supporting children, services for adults remain underdeveloped. Increasing investment in adult services, particularly in areas such as employment, housing, social inclusion, and independent living support, is crucial for ensuring that individuals with Autism receive the lifelong support they need.

In addition, it is important to ensure the meaningful participation of Autistic people in all aspects of policy development, service design, and research. Their perspectives should be included in the creation of support services and in the decision-making processes that affect their lives. This will help ensure that policies and services are better aligned with the actual needs of the Autistic population.

Finally, Northern Ireland should develop a comprehensive data collection system to monitor Autism prevalence, service utilization, and outcomes. A more robust data system would enable better planning and evaluation of services, allowing policymakers to make informed decisions and allocate resources more effectively.

Summary and conclusion

The Autism Act of 2009 marked a significant step forward for England and Wales, as it was the first disability-specific legislation in those countries. However, the act has faced criticism for its limited scope. This act only applies to adults, failing to address the needs of autistic children. This omission is significant as autism spectrum disorder is typically diagnosed in early childhood, making adequate support during these years crucial1. Wales is recognized as a leader in autism policy development, and their Autism Act of 2009 coupled with the 2008 Autism Action Plan have demonstrably increased awareness and improved service access. Nevertheless, long waiting times for diagnosis persist. In Scotland, the Scottish Autism Strategy, introduced in 2011, was intended to enhance care and support for individuals with ASD. However, a 2021 evaluation revealed that it fell short of creating lasting, meaningful changes for autistic individuals due to a lack of focus, clarity, and effective implementation. In Northern Ireland, autism policies and strategies have been instrumental in raising awareness and enhancing services, but they too encounter challenges. The Autism Act (NI) 2011 stands as a landmark piece of legislation, amending the Disability Discrimination Act 1995 to include social interaction difficulties in the definition of disability. While Northern Ireland has witnessed substantial progress in service provision and funding for autism, inconsistencies persist, resulting in a "postcode lottery" where service access is contingent upon geographic location.

Although the UK has made progress in developing autism policies, the sources highlight crucial areas for improvement. The Autism Act of 2009, while groundbreaking for England and Wales, has been critiqued for its limited scope and lack of enforcement, with Wales emerging as a leader in policy development due to its comprehensive strategies and stakeholder engagement. Scotland's 2011 strategy, however, failed to achieve lasting change, prompting the need for a more focused approach. Inconsistency in service provision across Northern Ireland creates a "postcode lottery," underscoring the need for equitable access to support. The sources emphasize the importance of prioritizing evidence-based interventions like EIBI, increasing investment in adult services, and involving autistic individuals in policymaking to create a genuinely inclusive environment.

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