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A comprehensive policy review of evidence-based practices in autism policy across the United Kingdom's four nations

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Abstract

This review provides an overview of how the four nations construct policy around supporting autistic people and identifies supports which are considered evidence-based practice (EBP). Video-based interventions are a recommended EBP for supporting autistic people and are recommended specifically within the National Institute for Health and Care Excellence autism guidelines. We highlight that EBP's can be difficult to identify and conclude with the recommendation that evidence and gap maps are a valuable tool that should be used to present evidence in an accessible way to policy makers, autistic people and their families and carers.

KEYWORDS

autism, autism policy, evidence and gap map, evidence synthesis, video-based interventions

PREFACE ON TERMINOLOGY

The use of person-first language, or language that describes the individual first and their disability, only if necessary, has previously been the preferred way to describe Autism amongst professionals. However, people on the autism spectrum, their families and carers, have argued that the use of person-first language separates them from their autism, which is a fundamental part of who they are (National Autistic Society, 2020). Research endorsed by the National Autistic Society

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concluded that while there is no single way of describing autism, the term 'autistic' was endorsed by 61% of autistic adults, followed by 'on the autism spectrum' (45%) (Kenny et al., 2016). The research presented herein will therefore use the terms 'autistic' and 'on the autism spectrum' interchangeably whilst acknowledging that individual preference should take precedence above all else, when referring to persons on the autism spectrum (National Autistic Society, 2020).

OVERVIEW

Between 2010 and 2019, the prevalence of autism in UK schools has risen dramatically with an average increase in prevalence of 140.5% across the four nations, with Northern Ireland and Scotland having higher prevalence rates than England and Wales (McConkey, 2020). As a result of the delays in diagnostic services during the Covid-19 pandemic, exact prevalence rates are difficult to uncover, but based on the number of referrals, currently in the system, there are approximately 100 000 children and 1 000 000 adults on the autism spectrum in the UK and approximately 150 000 people are receiving services for learning disabilities and autism. The goal of the NHS is to evaluate an autism referral within 13 weeks, but as of 2019, only 10% of suspected autism cases resulted in any form of intervention or treatment. The consequences of a delayed diagnosis can be severe and include added stress, the identification of other mental health issues, and increased financial expenses. However, private assessments, which can cost up to £2000, are not affordable for everyone (NHS Digital, 2020). Whilst a more recent cost analysis is needed, on average the UK spends around £32 billion to support autistic individuals, demonstrating the need for autism policy to recommend evidence-based, effective approaches to support autistic people in living independent lives (Buescher et al., 2014).

POLICY SUMMARY

A comprehensive review of each nation's (England, Northern Ireland, Scotland, Wales) primary autism strategy document was conducted to gather information pertaining to three crucial themes: (1) strategic outcomes, (2) decision-making, and (3) evidence-based practices (EBPs). A list of related policy documents was also created and reviewed for each nation to ensure that all relevant information across these key themes was captured. The primary sources used were:

- The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 (UK Department for Health and Social Care, 2021)
- The Northern Ireland Interim Strategy 2021–2022 (Department of Health, 2021)
- The Scottish Strategy for Autism (Scottish Government, 2011)
- The Autism and Learning Disability Towards Transformation Plan 2021 (Education Scotland, 2021)
- The Refreshed Autistic Spectrum Disorder Strategic Action Plan (Welsh Government, 2016).

In addition, each nation's Special Educational Needs Code of Practice was reviewed for additional relevant information regarding recommended EBPs. The Code of Practice outlines that a child or young person has Special Educational Needs (SEND) if they have a learning difficulty or disability that requires special educational support. The Code of Practice is concerned with the

recognition, assessment, and provision made for all children who may need special educational support during their schooling or earlier (<https://www.education-ni.gov.uk/>).

STRATEGIC OUTCOMES

The review process identified four common goals, henceforth referred to as strategic outcomes, that were synonymous across each of the four nations' autism strategy documents:

1. Increasing community awareness and training; this refers to increasing public awareness of autism and is an essential step in ensuring that we increase societal acceptance of autism.
2. Promoting independence; this goal refers to ensuring that autistic individuals receive equitable access to education, health and social care services and support in employment, such that they can live a fulfilling and independent life.
3. Timely access to effective support; an important goal for every nation is to ensure that diagnostic and assessment pathways are improved, and following a diagnosis, the appropriate community, education, and healthcare supports are available for autistic individuals.
4. Stakeholder engagement across the lifespan; this refers to putting autistic people and their families at the forefront of all decision making about the care and support that they will receive and ensuring that policy documents such as those reviewed herein, are designed in consultation with autistic people, their families, guardians, and professionals involved in their care.

PARTICIPATORY PROCESS

A common theme across each nation's autism policy was the importance of consultation with, and participation from autistic people, their families, and carers in making decisions about their own care, in shaping support services and informing policy. Each nation's current autism strategy has been developed in accordance with feedback from public consultation. Involving relevant stakeholders in this way will inevitably lead to an increase in the effectiveness and legitimacy of policy, because the needs and perspectives of each individual that the policy relates to are considered. Wales was the first of the four nations to adopt a national approach to autism (developing the Autistic Spectrum Disorder Strategic Action plan in 2008) but their most recent strategy has been co-produced with autistic people, their carers, and relevant professionals to identify those areas of the initial action plan which worked well and areas which need to be addressed for improvement (Welsh Government, 2016).

Similarly in Northern Ireland (NI) the earlier 2011 *Autism Act*, Action Plan and Strategy (Department of Health, 2011) was heavily criticised by the Broken Promises (Autism NI & The National Autistic Society, 2016) report. This report found that 35% of autistic adults and 46% of carers felt that life was getting more, instead of less, difficult for autistic people and their families since the 2011 action plan was released, and that promises made regarding the involvement of autistic people, their families and carers in developing policy and support were unfulfilled. As a result of this, stakeholder engagement, whereby stakeholders are actively involved, is now a focal point of NI's interim autism spectrum disorder (ASD) strategy. The mechanism for engaging stakeholders is through an All-Party Parliamentary Group on autism, who will act as

an independent evaluator of the actions proposed in the interim strategy in consultation with autistic people, their families, and carers. NI's interim strategy also includes a questionnaire for autistic people, their families and carers, and anyone working directly with autistic people such that lived experiences will directly inform the expected 2023 policy.

England and Scotland have also employed consultation groups to inform policy and shape services for autistic people. In England, a review of the Think Autism strategy included a public consultation on the care and support experiences of autistic people and their families and carers (Department of Education, 2021). This ultimately shaped the 2021–2026 national strategy resulting in statutory guidance in England which determines that autistic individuals should be involved at all levels in decisions about their care, and through the direct payments and personal budget schemes, they can decide upon the support services that are right for them (UK Department for Health and Social Care, 2021).

The Scottish Autism strategy is clear that autistic people and their carers should be involved in all levels of decision making and that a clear mechanism for this should be developed by the ASD Reference Group, the Self-Directed Support (SDS) Strategy Implementation group and the SDS Bill Reference Group. The SDS scheme provides individuals with a personal budget to spend on the support that will be most relevant to them. Despite these claims, it was difficult to uncover how autism *policy* in Scotland is constructed. Regarding the reported mechanism that should have been developed for this, a review of the 10-year strategy found that autistic people in Scotland report lower levels of trust and higher exasperation towards the Scottish government due to difficulties accessing services. This may have resulted in a challenge building partnerships and collaboration therefore the individuals involved in working groups to influence policy were mainly representatives from larger third sector organisations (Scottish Government, 2021). While the 2021 transformation plan states that it reflects the voices of autistic people and their carers, it is apparent that increased transparency on decision-making at a local and national level in Scotland is necessary.

EVIDENCE-BASED PRACTICES

The 'Individuals with Disabilities Education Act' (IDEA, 1990) and the 'No Child Left Behind' (NCLB) Act (2001) mandate that children and young people with disabilities, including those on the autism spectrum, must be supported through the use of EBP's (Guldborg, 2017). In 2014, the Department for Education allocated £135 million to increasing the availability of quantitative data and the application of research within schools (Department for Education, 2017). Given this legal right, it stands to reason that autism policy documents should recommend specific EBP's or indicate where this information is, such that this is easily accessible, especially for autistic people in Scotland and England who are given personalised budgets to pay for specific interventions that will support their own individualised needs.

This review found that English and Scottish policy references the importance of using EBP's and outlines clear mechanisms through which the research to policy gap can be bridged. The English National Strategy highlights the importance of supporting autistic people with "well-evidenced interventions" that are targeted at specific areas of difficulty and recommends the use of specialist equipment or software. Encouragingly, the strategy highlights that designing policy based on high-quality evidence is a more efficient way to meet the nations' strategic goals. The Autism Education Trust was developed to ensure that early year's professionals are trained in evidence-based interventions to support autistic people. Whilst

specific EBP's are not included in the main strategy document, the English SEND Code of Practice directs readers to the National Institute for Clinical Excellence (NICE) guidance and the Campbell and Cochrane collaborations for the best available evidence on the efficacy of specific interventions.

Similarly, Scottish policy recommends that a request is made to NHS Quality Improvement Scotland to develop clear guidance in EBP's for both diagnosis and management of autism. In general, research is a key theme in the Scottish strategy document (specifically in the section on providing support), recognising the importance of disseminating findings from quality research and putting those findings into practice through the development of the Scottish Autism Services network. Whilst the Scottish strategy refers to learning from pilot projects, no specific information is provided on the nature of these projects, or the interventions being piloted. A key target of Scottish policy is the idea of creating a menu of evidence-based interventions for autistic people, which aligns with the recommendations made by the Scottish Intercollegiate Guidelines Network (SIGN). SIGN is an internationally recognised guidance document for providing evidence-based interventions for autistic people and will be discussed in more detail, alongside the NICE guidance below.

Whilst NI policy refers to individualised interventions for autistic people, and there being no 'one size fits all' approach, there is no reference in NI policy to specific supports (evidence-based or otherwise), readers are instead directed to the National Autistic Societies webpage which offers support for all four nations. Related policy documents were examined for any reference to EBP's and the Six Steps of Autism Care document from HSCNI signposts stakeholders to SIGN, the New Zealand ASD Guide and NICE guidelines for further information on adopting EBP's (Health and Social Care Board, 2011). The Welsh strategic action plan also does not include any reference to specific EBP's in their refreshed policy document, but they do direct readers to the Autism Wales website where those practitioners supporting autistic people can access a practitioner toolkit, which claims to advise on EBP's and will be discussed below.

Overall, whilst the four main policy documents recognise the importance of autistic people, their families, and carers, being involved in choosing the supports which best fit their own needs, available EBP's from which autistic people can choose are not transparent in the main autism policy documents, and readers are signposted elsewhere.

SIGN, NICE AND AUTISM WALES

Since the main four nation policy documents signpost to SIGN, NICE and Autism Wales, we undertook a review of these documents to ascertain if any specific supports were recommended for autistic people. The Autism Wales resource (<https://autismwales.org>) contained a practitioner toolkit which is adapted directly from the NICE guidance for support and management of ASD in under 19's. The toolkit's recommendations for supporting the core symptoms of ASD include five points (1) modelling (2) peer feedback or individual feedback (3) discussion and decision-making (4) explicit rules (5) suggested strategies for dealing with socially difficult situations. The final note made by the toolkit is that facilitated communication (FC) should not be used (<https://autismwales.org/en/community-services/i-work-with-young-people-adults-in-health-social-care/practitioner-toolkit-support-and-interventions-for-adults-with-asd/>). FC became popular in the early 1990's as a means of providing a method of expressive communication to non-verbal individuals with autism or other communication difficulties. It involves a facilitator guiding the individual's hand over a keyboard and by the mid to late 1990's it was overwhelmingly refuted

by scientific research (Lilienfeld et al., 2014). No further information or advice on how to put any of these recommendations into practice through examples, or links to external resources are offered. For an autistic person, their carers and other stakeholders such as teachers, the lack of clarity around these five recommendations and how they would look in practice may leave them very vulnerable to the sale of untested, non-evidence-based interventions that claim effectiveness but have no scientific support, such as is the case with FC.

The NICE full guideline for autism is a 784-page document that includes systematic review and meta-analysis of the available evidence on a range of interventions for psychosocial and pharmacological interventions for autism and uses evidence from the meta-analysis to make recommendations for research and clinical practice (<https://www.nice.org.uk/guidance/cg128>). Shorter summaries relating to key areas of autism (assessment, diagnosis, support and management, autism in under 19's, autism in adults) are created with the intention of being more accessible to stakeholders. The NICE summary document "autism spectrum disorder in Under 19's: Support and Management" reiterates the information that was found on the Autism Wales website but additionally, it specifically recommends the use of modelling and video interaction feedback. The summary makes further recommendations regarding interventions that have no evidence-base and should not be used to support autistic people. These include both psychosocial and biomedical interventions: antipsychotics, antidepressants, anticonvulsants, exclusion diets, neurofeedback, auditory integration, omega-3 fatty acids for sleep problems, secretin, chelation, and hyperbaric oxygen therapy.

Whilst the NICE summary documents are clear on which interventions are not evidence-based and therefore should not be used to support autistic people, the recommendations for EBP's are still vague and lack the specificity needed for an autistic person, or their family or carers to decide on what specific support to engage with. For further clarity, the full NICE document was reviewed to identify EBP's for supporting the general challenges faced by people on the autism spectrum. Section "Video-based interventions" of the full guideline highlights that such interventions are limited and furthermore, the evidence-base for their effectiveness is poor (Charman, 2011). A systematic review and meta-analysis found that there was a favourable effect of educational interventions such as ESDM (Early Start Denver Model), COMPASS (Collaborative Model for Competence and Success) and LEAP (Learning Experiences and Alternate Program) when compared with treatment as usual, but that the available evidence was low-quality. The available evidence for interventions that are typically used to support social communication and interaction such as TEACCH (Treatment and Education of Autistic and Related Communication), LEGO therapy, Child's Talk Intervention and PACT (Parent-Mediated Communication-focused Treatment) were examined closely in the NICE guideline and it was discovered that due to wide variability in comparators and outcome measures, only low-powered meta-analysis was possible, but they produced small to moderate effects for promoting social communication and interaction. Overall, interventions such as the PACT which utilises video feedback to increase parental sensitivity and responsiveness to child communication, was recommended by the Guideline Development Group (GDG) at a lower intensity (to enable cost-effectiveness) as an effective, evidence-based intervention for promoting social communication in autistic children. The GDG specifically recommend that social-communication interventions are pitched at the child or young person's developmental level and include modelling and video-feedback by a trained professional.

In cross checking the recommendations of the NICE guidelines with SIGN (<https://www.sign.ac.uk/assets/sign145.pdf>), similar recommendations pertaining to the use of EBP's were discovered. Parent-mediated interventions (like PACT) were recommended for use with autistic

children and young people due to the positive outcomes associated with child–parent interaction. SIGN also highlight the importance of using visual supports, suggesting that these can take many forms (photographs, picture symbols, objects of reference) and that these can be displayed in a multitude of ways, including using educational technology. SIGN presents an overview of the available evidence on specific interventions such as TEACCH, LEGO therapy and PACT, using a ‘levels of evidence’ key, to illustrate the quality of available evidence on the intervention. Controversially, SIGN indicates that Auditory Integration Training may be a useful social communication intervention for autistic children and young people, using the key “1++” to indicate “high-quality meta-analyses, systematic reviews of RCTs or RCTs with a very low risk of bias” whereas NICE specifically list Auditory Integration Training as an intervention that should not be used with autistic people (section 1.6.2). Inconsistencies in recommended EBP’s will result in further difficulties bridging the research to practice gap that will ensure that autistic people receive evidence-based interventions to support them across the lifespan.

In summary, identifying EBP’s for autistic people in UK policy documents is challenging, and it is apparent that a basic understanding of research methodology is necessary for comprehending the NICE and SIGN guidelines. This review of the UK policy context has highlighted the need for an accessible mechanism by which autistic people, their families and carers and practitioners working with autistic people can identify EBP.

VIDEO-BASED INTERVENTIONS

While identification of EBP’s was somewhat difficult in the policy review, the use of video-feedback and video interaction was specifically recommended by the GDG. From this point onwards we will use video-based interventions (VBIs) as a centre of discussion around which to describe an accessible way of presenting current and emerging research into an effective EBP for autistic people.

Video-based interventions are an EBP that incorporate visual and audio cues with modelling, self-modelling, virtual reality, prompting and feedback to teach or maintain skills (Munandar et al., 2020). VBI is a method of teaching a skill whereby the presentation of that skill can be systematically replicated every time the teaching takes place. A recording is made of the skill being completed in its entirety, and video software allows the instructor to play that skill in its entirety or in component parts to the learner, who will then repeat what they see on the screen. VBI’s can be a particularly useful instructional method for teachers of autistic individuals because they allow the teaching of a skill to become standardised by removing inconsistencies which may result from individual differences in teaching styles. They are cost-effective, require little training to implement, and can be used in busy classrooms where educational targets differ across students and teachers therefore need to deliver a range of content simultaneously. Table 1 describes the wide range of VBI’s that can be utilised in accordance with the specific skill being taught, or the resources available to practitioners.

The theoretical underpinnings of VBI’s lie in behavioural science and Bandura’s learning theory. The evidence-base behind VBI’s, particularly with autistic individuals is extensive and clearly the use of video-feedback and video-interaction has been impactful enough to be included in both the NICE and SIGN guidelines which are signposted in the four nations’ autism Policy Documents. The evidence-base for VBI supports its use across a broad range of behaviours, individuals, settings and diagnoses, but the sheer quantity of this evidence could be overwhelming

TABLE 1 A table displaying the variation in video-modelling categories with examples.

	Description	Example	Model
Video modelling	Learner watches a video of other people/another person engaging in a desired task or skill from beginning to end. When the video ends, the child imitates the behaviour	Learner watches a video of a person completing all of the steps necessary during tooth brushing	Adult Sibling Peer Avatar Cartoon animations
Video self-modelling	Learner watches a video of themselves engaging in a desired task or skill (created using video editing software) from beginning to end. When the video ends, the child imitates the skill in real time	1. Learner watches a video of themselves reading a paragraph from a textbook, without any pauses 2. Learner watches a video of themselves making a cheese toastie from beginning to end, without any pauses or disruptions	Learner (Self)
Point-of view modelling	Video is filmed from the perspective of what the learner will see when they are performing the target behaviour Recording typically takes place from the eye level of the model, thus the learner will only see the hands/arms of the model	1. Learner watches a video of a person tying their shoelaces. The learner can only see the hands/arms of the model 2. Learner watches a video of their route to work. Learner views the exact route to take to work from their front door to their office door. Learner only sees the street ahead with one shot displaying the models' hand on the door of their office	Adult Sibling Peer Avatar Cartoon animation Self
Video prompting	The video serves as a cue for the individual steps of a task. Records someone going through the routine of brushing their teeth and breaks the video down into steps that the learner watches while completing the task. Video prompting breaks the task down into steps whereas video modelling presents the whole task to the learner	1. Video prompting procedure is used to teach a learner with autism spectrum disorder to do their own laundry. Learner watches step 1 of the video, which shows a model separating clothes into colours/whites. Learner completes this step in real time. Learner then watches step 2, place whites in drum of machine. Learner completes this step Learner may see the model in their entirety or only the part of their body completing the task	Adult Sibling Peer Avatar Cartoon animation Self

TABLE 1 (Continued)

	Description	Example	Model
Video feedback (VFB)	An instructor reviews previously filmed footage of the learner engaging in a target behaviour, with the learner present. Instructor provides feedback (or reinforcement for appropriate behaviours) and teaches the learner to discriminate between correct and incorrect responses	9-Year-old Adam is filmed during a group science project in a typical classroom. Prior to the next science lesson, a classroom assistant sits with Adam and reviews the video. She reinforces his conversation initiations with his peers and addresses his interruptions. They strategize that during the upcoming science lesson, he will replace his interruptions with 'excuse me'	Model is generally the learner (self), but this can also be an adult, peer, sibling etc. Person providing feedback is generally an adult/parent/guardian
Computer-based video instruction	Computer-based video instruction (CBVI) provides simulated instruction within realistic, interactive learning environments through incorporation of video models and captions. This form of simulation offers multiple teaching examples that replicate the varied environments in which the skills will be used. CBVI is often presented in a very game like format	14-Year-old Clare's teachers decide to use CBVI to prepare Clare for independent shopping in the community. Every day, during Clare's citizenship class, her teachers show her a video on the iPad which simulates a supermarket. Clare must put virtual items into a virtual basket and when the model in the video gets to the till and the cashier asks for £7.50, Clare must count this out from her virtual wallet	Adult Peer Avatar Cartoon animation

for any teacher or clinician wishing to learn more about the intervention for incorporation in their own practice or teaching.

An effective way of ensuring easy access to evidence-bases to support autistic individuals is through the use of evidence syntheses, such as Systematic Reviews, rapid reviews, EGMs and Meta-analysis.

EVIDENCE SYNTHESIS

Systematic reviews are the "gold standard" for summarising research to aid decision-making in policy and practice (Alonso-Coello et al., 2016). The authors have conducted a comprehensive and rigorous Systematic Review of the existing evidence on VBI's that are used with autistic

children aged 3–18. This work is published through the Campbell Collaboration (<https://onlinelibrary.wiley.com/doi/full/10.1002/cl2.1171>) which provides a measure of excellence for systematic reviews in the social sciences.

Stakeholder engagement is one of the four strategic outcomes across the four nation's autism strategy documents. These documents recognise the importance of involving autistic people, their families, and carers, in decisions about their care and services provided. In tandem with this, involving stakeholders in research is an expectation in disability research (Kerr et al., 2022), and this is not limited to primary research. Indeed, involving stakeholders in secondary research, such as evidence synthesis, has a plethora of benefits due to the relevant knowledge and lived experiences of stakeholders (Haddaway & Crowe, 2018). Therefore, whilst undertaking the systematic review of evidence on VBI's that are used with autistic children aged 3–18, the authors invited stakeholders, including autistic persons, their families, health, and education professionals, to contribute to the review by completing an online questionnaire survey. Stakeholder responses were subsequently used to identify relevant items for data extraction, inform additional analyses and advise on the most appropriate communication and dissemination methods for the findings of the review. Involving stakeholders in this way has positively impacted the review by ensuring it is more relevant and useful to those who will ultimately use it or benefit from it.

CONCLUSION

This policy review has highlighted two key points; Firstly, specific EBP's that can be used to support autistic individuals are difficult to identify in each nation's policy document. This is not a criticism of any specific policy, this is a direct result of the individual nature of autism, to which a “one-size-fits-all” approach cannot be applied. Secondly, where specific EBP's are recommended (<https://www.nice.org.uk/guidance/cg128>), this is technical, and therefore may be considered inaccessible for those without an understanding of research methodologies.

The Systematic Review on VBI's provides a clear and up-to-date overview of the current state of knowledge through the use of an [Evidence and Gap Map](#). The authors provide a visual representation that outlines the available evidence, as well as the gaps in the evidence. The map is easily accessible to autistic people, practitioners, researchers, and funders to identify what is known, what is unknown, and where further research is needed. EGMs are commonly used in the field of evidence-based practice to inform decision making and prioritise research initiatives. Conclusively, evidence syntheses that adhere to the highest methodological standards, also allow better allocation of public resources. To ensure that these resources are used in the most effective manner, it is important to target areas where the returns on investment are greatest. By focusing resources in areas where there is evidence of efficacy, we can maximise the impact of these resources and achieve the best possible outcomes for autistic children.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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