

Institution: University of Northumbria at Newcastle		
Unit of Assessment: 4 (Psychology, Psychiatry and Neuroscience)		
Title of case study: Improving diagnosis of Autism Spectrum Disorder (ASD) and associated support services in Scotland		
Period when the underpinning research was undertaken: July 2014 – 2018		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Karen McKenzie	Professor	01/07/2014 – Present
Period when the claimed impact occurred: December 2014 – 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words) <p>Currently approximately 700,000 people have a diagnosis of Autism Spectrum Disorder (ASD) in the UK. However, the complex and interrelated nature of ASD symptoms, compounded by issues associated with assessment practices and protocols, inhibits timely completion of formal diagnostic processes. Research undertaken at Northumbria University has facilitated the first systematic, national exploration of factors influencing ASD assessment waiting times, at individual, service, and policy level, to improve the ASD diagnostic pathway. This research informed strategies that ultimately led to an average reduction in waiting times for ASD assessment in Scotland by 4.3 weeks. The research has directly influenced Scottish government, NHS, and local authority policy and practice through the development of new systems and processes for clinicians working in ASD services. Further, Northumbria's research is recommended within the Scottish Intercollegiate Guideline Network (SIGN) ASD guidelines, which influence clinical practice across Scotland.</p>		
2. Underpinning research (indicative maximum 500 words) <p>Autism Spectrum Disorder (ASD) is a lifelong developmental disorder. Symptoms are multidimensional and include social and communication impairments, restricted repetitive activities, and associated features including attention deficits and a range of medical and psychological comorbidities [R1]. Despite ASD being a developmental condition, longstanding failure to carry out timely assessments has meant that many diagnoses do not occur until adulthood [R2]. Delayed ASD diagnosis can have serious implications for children and adults, including stress, dissatisfaction with the diagnostic process, and the inability to access appropriate support and resources [R2]. Research undertaken by Professor Karen McKenzie, since joining Northumbria in 2014, has helped to identify a range of factors that inhibit the timely assessment of those with ASD. The findings have guided ongoing work in this area, and the design of interventions that reduce waiting times and thus help individuals (including families and carers) more readily access the support and resources that are available [R1-R6].</p> <p>McKenzie's work has sought to address the lack of available evidence, both nationally and internationally, relating to the underlying causes of delays in ASD diagnostic processes, and which models for assessment provide the most optimal results [R1, R2]. In collaboration with colleagues from the University of Edinburgh and NHS Fife, McKenzie produced an empirical assessment of diagnostic tools such as the Autism-Spectrum Quotient (AQ), a subjective self-assessment questionnaire designed to measure the expression of Autism-Spectrum traits in an individual [R1]. The study indicated how it can be difficult to capture the multidimensionality of</p>		

ASD in a single measure, which can lead to difficulties when attempting to estimate an association between a specific symptom measured by the AQ and a resultant diagnosis [R1].

McKenzie made similar, vital contributions to this field through her work with the Autism Achieve Alliance (AAA), a multidisciplinary partnership of clinicians and clinical researchers investigating child and adult ASD services. This collaboration represents the first, systematic national exploration (in Scotland) of factors influencing ASD assessment to improve the ASD diagnostic pathways. McKenzie was lead for the adult aspect of the programme, with specific responsibility for coordinating the research in respect of adult services. McKenzie was also responsible for working collaboratively with (5 of 11) participating adult-specific services, to identify and address specific areas for improvement. McKenzie's research was relevant to both adult *and* child services and played an important role in shaping methodologies and analysis across the entirety of the AAA project [R2-R6].

McKenzie led an analysis of 150 case notes (80 child and 70 adult cases) from 16 diagnosing services across Scotland, which demonstrated that, within children's services, increasing the amount of relevant information available pre-assessment is likely to lower the total duration of the assessment process by reducing the number of contacts required [R2]. The study also showed that having a high risk of ASD as an adult appears to result in being seen more quickly following referral, but also increases the number of contacts needed and total assessment duration [R2]. The results suggested that comprehensive information about the individual that is directly relevant to the diagnosis of ASD should be routinely sought prior to, or at the point of, referral. These findings were supplemented by research that highlighted a significant difference in the mean age of referral and diagnosis for girls compared to boys, supporting evidence of delayed recognition of ASD in younger girls prior to assessment [R3].

A further study drew on focus group interviews with 95 clinicians from 8 child and 8 adult services on the duration and quality of the diagnostic pathway and highlighted the need to develop efficient assessment and communication processes [R4]. These findings supported conclusions offered in McKenzie's earlier study, which had stressed the importance of information collected by non-specialist services (such as general psychiatric services) in relation to the diagnosis of ASD to speed up diagnostic processes [R2, R4]. Again, these recommendations were bolstered by additional research in which McKenzie recommended that more training in the use of current diagnostic interviews, combined with a systematic use of evidence-based standardised assessment screening tools and protocols, would improve the efficiency and effectiveness of ASD care pathways [R5, R6].

Based on the preliminary findings, McKenzie and the AAA team proposed a strategy to reduce waiting times for ASD diagnosis. This approach suggested the use of practice development interventions for clinical staff to share best practice and increase their skills and confidence in effective diagnostic pathways (through mentorship, peer group forums, workshops to drive/sustain change, and validating the roles of practitioners [R6]). McKenzie played a central role in evaluating the implementation of a pilot scheme in 11 adult ASD diagnostic services in Scotland (across 6 NHS board regions), using multi-level statistical analysis to determine if, and to what extent, it effectively reduced waiting times for ASD diagnostic assessment [R6]. The results indicated how this approach can successfully reduce the wait time for ASD diagnostic assessment in adult services (from 21.3 weeks down to 17 weeks on average), raising the potential for significant improvements to be made at a national level [R6].

3. References to the research (indicative maximum of six references)

R1. Murray, A. L.^{1,2,3}, **Karen McKenzie**, Kuenssberg, R.⁴, and Booth, T.³ (2015) 'Do the Autism Spectrum Quotient (AQ) and Autism Spectrum Quotient Short Form (AQ-S) Primarily Reflect General ASD Traits or Specific ASD traits? A Bi-Factor Analysis' *Assessment* **24** (4): 444-457
<https://doi.org/10.1177/1073191115611230>

R2. Karen McKenzie, Forsyth, K.^{2,5}, O'Hare, A.³, McClure, I.^{3,5}, Rutherford, M.^{2,5}, Murray, A.L., and Irvine, L.⁵ (2015) 'Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults' *Research in Developmental Disabilities* **45-46**: 300-306 <https://doi.org/10.1016/j.ridd.2015.07.033>

R3. Rutherford, M., **Karen McKenzie**, Johnson, T.², Catchpole, C.², O'Hare, A., McClure, I., Forsyth, K., McCartney, D.^{2,5}, and Murray, A.L. (2016) 'Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with Autism Spectrum Disorder' *Autism* **20** (5): 628-634 <https://doi.org/10.1177/1362361315617879>

R4. Rutherford, M., **Karen McKenzie**, Forsyth, K., McCartney, D., O'Hare, A., and McClure, I. (2016) 'Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of Autism Spectrum Disorder in adults and children' *Research in Autism Spectrum Disorders* **31**: 53-65 <https://doi.org/10.1016/j.rasd.2016.06.004>

R5. Rutherford, M., **Karen McKenzie**, McClure, I., Forsyth, K., O'Hare, A., McCartney, D., and Finlayson, I.^{2,5} (2016) 'A national study to investigate the clinical use of standardised instruments in autism spectrum disorder assessment of children and adults in Scotland' *Research in Autism Spectrum Disorders* **29-30**: 93-100 <https://doi.org/10.1016/j.rasd.2016.05.003>

R6. Rutherford, M., Forsyth, K., **Karen McKenzie**, McClure, I., Murray, A.L., McCartney, D., Irvine, L., and O'Hare, A. (2018) 'Implementation of a practice development model to reduce the wait for Autism Spectrum diagnosis in adults' *Journal of Autism and Developmental Disorders* **48**: 2677–2691 <https://doi.org/10.1007/s10803-018-3501-5>

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4. Details of the impact (indicative maximum 750 words)

McKenzie's research on the factors affecting the diagnosis of ASD has led to impact in relation to 1) policy, strategy, and planning, 2) practice, and 3) outcomes regarding waiting times.

4.1 Informed national policy, strategy, and planning

As a result of McKenzie's research expertise, she was part of the 2016 Scottish Intercollegiate Guidelines Network (SIGN) guidance development group, to update the existing national clinical guidelines and checklist for the 'Assessment, diagnosis and interventions for ASD' [E1]. SIGN guidelines facilitate the implementation of effective measures to improve the standards of healthcare in ASD services across Scotland. The resulting SIGN 145 guidance document, published in 2016, now incorporates guidance that applies to adults and older people as there was a '*need for a guideline which reflects the whole age range*' [E1, p1]. It now recommends, in line with the research, the need to include '*all relevant information regarding any concerns, the individual's current situation and details of any professionals involved*' and the development of protocols to '*gather as much relevant information preassessment as possible, in order to reduce assessment duration*' [E1, p44].

McKenzie's research also informed the development of NHS Education for Scotland Autism Training Framework: Optimising Outcomes Training Plan [E2], which sets the standards for all autism-related clinical training in Scotland's health services – as part of professional training or as CPD – and provides a framework to enable service leads and individual practitioners to establish the training needs of their staff. The plan recognises that acquiring more information for a person prior to their diagnostic assessment can be key to reducing the wait for diagnosis, as highlighted in the research [R2], and highlights the need for training clinical staff to facilitate better identification, screening, assessment, and diagnosis of ASD, particularly within adult services [E2, p33].

4.2 Improved understanding of, and practices involved in, ASD referral and assessment

McKenzie's research (and subsequent clinical recommendations listed above) informed the action plans of health and social care partnerships (HSCPs) in Scotland, including: The Autism Strategy in Fife (2014-2024) [E3], the East Lothian Strategy (2015) [E4], and the Perth and Kinross Autism Strategy (2016-2021) [E5]; areas serving a combined population of approximately 632,000. Collaboration between these HSCPs and the AAA: *'worked to upskill the workforce and improve processes to reduce waits and evidence best practice'* for adult services in Fife [E3, p9], led to quicker referral to diagnosis times in East Lothian child services [E4, p6], and in Perth and Kinross *'all diagnostic teams have been made aware of...up to date research on reducing waiting times'* [E5, p8].

The AAA Autism Knowledge Hub was created to enable Scottish autism diagnostic services and clinicians (e.g. from Lothian, Fife, Ayrshire and Arran, Borders, Highland, and Glasgow) to share best practice and collate documentation, protocols, action plans and recommendations from the research, and subsequent practice, in one place. The Scottish Government identified the Knowledge Hub as a key resource to *'facilitate improvement for autism assessment and diagnosis for all age groups and genders'* [E6, p10].

4.3 Reduced wait for ASD assessment

The research clarified the causes and extent of delays in ASD diagnosis in Scotland and developed a strategy to improve the ASD diagnostic pathway. Once implemented, these strategies introduced more efficient working and communication into services, improving the effectiveness of care pathways in both child and adult services [E7]. Mentoring and support were also made available to clinicians involved in diagnosing ASD [E8]. Results from the implementation of this strategy in 11 adult diagnostic services across Scotland concluded that waiting times reduced by an average of 29.9 days (4.3 weeks) [E8; E9, p16].

Andy Fleming, Autism Spectrum Disorder Nurse Practitioner, NHS Lanarkshire (population of 650,000), acknowledged the benefits of the research and intervention in this area of Scotland, noting an average reduction in wait times of 36 days. He stated that this strategy led Lanarkshire's ASD diagnostic pathway to become *'more focused, effective, and efficient for both staff and patients'* by: 1) introducing a clear assessment pathway focused on information gathering and reporting back to patients (to adhere to good practice guidance specified by SIGN and NICE), 2) timely provision of information to potential referrers to ensure the appropriateness of referrals, 3) introducing systems to pre-empt, and ultimately prevent, non-attendance at appointments (e.g. sending reminders), and 4) working to improve information sharing between team members [E10]. Fleming identified key benefits of improved post-diagnostic support and the opportunity to share good practice with, and learn from, the experiences of other services throughout Scotland:

'The timely diagnosis of autism and reduced waiting times for assessment and diagnosis...allow those who are diagnosed to receive additional support and resources that they may require and they can be signposted to organisations and support networks that may be of benefit to them, which will help to improve the outcomes for them. The sooner that diagnosis takes place the sooner that such support can be arranged. This might include specialist input from staff to provide interventions to help with social interaction, managing anxiety, and behaviours that challenge, such as aggression. As long waiting times can lead to dissatisfaction with and loss of confidence in services, reduced waits can counter this' [E10, p2].

5. Sources to corroborate the impact (indicative maximum of 10 references)

Ref.	Source of corroboration	Link to claimed impact
E1	SIGN 145: Assessment, diagnosis and interventions for autism spectrum disorders - A national clinical guideline (June 2016)	Research cited in SIGN 145 and influenced the wider development of the guidelines

E2	The NHS Education for Scotland Autism Training Framework: Optimising Outcomes Training Plan for ASD (May 2015 Update)	Research cited and highlighted required training needs for Scotland
E3	Autism Strategy in Fife, 2014-2024 - Published 15 Jan 2017 by Fife Council	Confirms collaboration to upskill workforce and reduce waits
E4	East Lothian Autism Strategy 2015	Confirms quicker referral to diagnosis times
E5	Perth and Kinross Autism Strategy, 2016-2021	Confirms diagnostic teams made aware of waiting times research
E6	The Scottish Strategy for Autism Outcomes and Priorities 2018-2021	Refers to benefits of the research and Knowledge Hub for sharing good practice
E7	Rutherford, M. <i>et al.</i> (2016) 'Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of Autism Spectrum Disorder in adults and children' <i>Research in Autism Spectrum Disorders</i> 31: 53-65	Confirms strategy implementation and improvements to care pathways. Also R4
E8	Rutherford, M. <i>et al.</i> (2018) 'Implementation of a practice development model to reduce the wait for Autism Spectrum diagnosis in adults' <i>Journal of Autism and Developmental Disorders</i> 48: 2677–2691	Evaluation of new strategy – demonstrates success in reducing waiting times for ASD diagnosis. Also R6
E9	Scottish Parliament - SPICe Briefing Autism Spectrum Disorder, 2017	Scottish Government briefing on the research and associated significant reduction in waiting times
E10	Testimonial - Andy Fleming, Autism Spectrum Disorder Nurse Practitioner, NHS Lanarkshire	Example of benefits of the research to a large clinical service and to those being assessed for ASD