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# A Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD): Which diagnostic pathways work best, for whom and in what context? Findings from a rapid realist review.



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# A Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD): Which diagnostic pathways work best, for whom and in what context? Findings from a rapid realist review.

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# Abstract

**Objectives**

Waiting times in the UK for an autism diagnostic assessment have increased rapidly in the last five years. This review explored research (including 'grey' literature) to uncover the current evidence base about autism diagnostic pathways and what works best, for whom and in what circumstances, to deliver high quality and timely diagnosis.

**Design**

We performed a Rapid Realist Review (RRR) consistent with recognised standards for realist syntheses. We collected 129 grey literature and policy/guidelines and 220 articles from seven databases (Jan 2011-Dec 2019). We developed programme theories of how, why and in what contexts an intervention worked, based on cross-comparison and synthesis of evidence. The focus was on identifying factors that contributed to a clearly defined intervention (the diagnostic pathway), associated with specific outcomes (high quality and timely), within specific parameters (Autism diagnostic services in Paediatric and Child & Adolescent Mental Health services in the UK). Our Expert Stakeholder Group, including representatives from local parent forums, national advocacy groups and clinicians, was integral to the process.

**Results**

Based on 45 relevant articles, we identified seven programme theories that were integral to the process of diagnostic service delivery. Four were related to the clinical pathway: initial recognition of possible autism; referral and triaging; diagnostic model; and providing feedback to parents. Three programme theories were pertinent to all stages of the referral and diagnostic process: working in partnership with families; inter-agency working; and training, service evaluation and development.

**Conclusions**

This theory informed review of childhood autism diagnostic pathways identified important aspects that may contribute to efficient, high quality and family-friendly service delivery. The programme theories will be further tested through a national survey of current practice and in-depth longitudinal case studies of exemplar services.

**Trial registration number NCT04422483**. This review relates to Pre-results.

**Strengths and limitations of this study**

- This realist review focussed on reviewing and synthesising recent evidence to determine what approaches to autism diagnostic assessment worked best, for whom and in what context. The approach is better suited than more empirical methods that assume there is one model to suit all situations.
- Our Expert Stakeholder Group and parent representatives engaged with all stages of the review and enabled an iterative approach to identifying relevant literature and refining our findings.
- As appropriate to our research question, we limited the search to UK literature but may have missed relevant literature from similar health systems. Although synthesis was based on UK literature, we have considered how this relates to relevant international literature.

# Introduction

The number of children and young people (CYP) diagnosed with autism spectrum disorder (autism) has increased significantly in recent years (1) (2) with a median age for diagnosis of 55 months (3). This is reflected in increasing pressures on diagnostic assessment and long waiting times in some services, with associated family dissatisfaction (4). The NHS Long Term Plan (5) highlighted the need for research to identify the most effective ways to improve timely access to diagnosis whilst maintaining high-quality assessment.

Autism is characterised by persistent severe deficits in social interaction, social communication, and restricted, repetitive, inflexible patterns of behaviour and interests (6), although the level of symptoms varies considerably between individuals. It is commonly associated with, other neurodevelopmental and mental health conditions, such as anxiety, ADHD and developmental language disorder (7-9), making reliable diagnosis a complex process. National guidelines for Autism in the UK (1) recommend multidisciplinary assessment, with the skills to consider both the presence of other neurodevelopmental and mental health conditions (for example, ADHD, anxiety disorders), and co-existing conditions (for example eating or sleeping related). However, this holistic assessment is time-consuming and costly (10, 11). There are significant variations between diagnostic pathways and only limited evidence of which models work best, for whom and in what circumstances.

Although the formal research base is limited, some local providers have already reconfigured their services to address these issues (12-14). However, robust evidence is needed to identify which models have the most significant potential to meet the growing demand for diagnostic assessment in a timely, clinically valid, and family-friendly way. This Rapid Realist Review (RRR), the first step in a national

Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD), aimed to explore how particular approaches aspired to deliver high quality and timely autism diagnostic services. High quality was defined as compliant with NICE guidelines (1). 'Timely' refers to diagnostic pathways that must be started within three months of referral, in-line with NICE guidelines (1), and last no more than one calendar year.

This study aimed to explore evidence about autism diagnostic pathways that have been adopted across the UK to determine works best, for whom and in what circumstances. The RRR aimed to use the literature to address the following questions:

1. How do various pathways of autism diagnostic and support services address the differing needs of different service user groups and what contexts and mechanisms affect their ability to do so?
2. How do different pathways of autism diagnostic and support services improve service user diagnostic experience?
3. What aspects of implementation, staffing and organisational context influence how models of autism diagnostic and support services operate?

## Method

Autism diagnostic models vary in terms of complex differences in local service configurations and settings, lending itself to realist review that can tease out contextual factors, resources and responses of those delivering and accessing the services. A systematic review would not be best matched to the heterogeneity of autism diagnostic services nor to capturing what is most helpful for policy decisions. Realist reviews present evidence as programme theories (PTs) which are key features of the service and describe what appears to lead to certain outcomes (15), often phrased as 'if…. Then…' statements. PTs are supported by details of the context (C), mechanisms (M) and outcomes (O). These relationships are presented as CMO configurations (16). In using a rapid realist review (RRR) approach we worked backwards from the intended outcomes (efficient , high quality and family friendly service delivery) as identified in our research questions.

RRR is explicitly designed to engage with stakeholder to accelerate the search process and validate findings (17). Our Expert Stakeholder Group included clinicians (consultant paediatricians, child psychology, speech and language therapy), policymakers and third sector advocacy groups (Council for Disabled Children and Autistica) who were involved in all stages of the process.

## Changes to protocol

No changes to the review process proposed in the published protocol (https://bmjopen.bmj.com/content/10/7/e037846).

## Search methods

This RRR was carried out from 1 September 2019 to 30 June 2020 following RAMESES standards (15) for realist reviews. Through discussions within the RE-ASCeD project team and with our expert stakeholders, we confirmed and refined the research questions and scope; prioritised areas for investigation; identified search terms; and collected grey literature, policy and guideline papers iteratively throughout the review.

Search terms were identified and developed with support from the RE-ASCeD project team and expert stakeholders. The primary search was conducted across Medline (Ovid), Embase (Ovid), PsycINFO (Ovid), Social Policy & Practice (Ovid), CINAHL Plus (EBSCO), Cochrane Library and Web of Science (Clarivate) limited by date (2011–2019), language (English) and country (UK only). Our focus was a clearly defined intervention (the diagnostic pathway, from receipt of referral to diagnosis), associated with specific outcomes (high quality and timely) within a particular set of parameters (autism/CAMHS services in the UK). All study types were included. The search strategy was created by an information specialist (AP) using a combination of free text and MeSH index terms after iterative pilots in Medline and adapted for each database. Search strings were based on a combination of terms covering "Children", AND "Autism" AND how they "Relate to diagnostic pathway OR assessment". For full search terms see Supplementary Document 1. Table 1 provides our inclusion/exclusion criteria.

Secondary searching was conducted iteratively throughout the review with input from our expert stakeholders. Two reviewers used papers identified in the primary and background search to look through reference lists for relevant articles; check forward citations; and search key authors and research teams to identify further literature, using Google scholar. Primary and background searches were restricted to UK only, given UK NHS context. On the advice of our expert stakeholders, we then reviewed high level national policy documents and guidelines and a few research articles from similar countries (USA, Canada, Australia, New Zealand) to help elucidate findings.

**Table 1 Inclusion/exclusion criteria**

| Inclusion criteria: |
| --- |
| • Children (preschool, primary or secondary school and adolescents) with Autism Spectrum Disorder OR Autism spectrum condition AND<br>• UK healthcare system (England, Scotland, Wales and/or N. Ireland) AND<br>• Published 2011 onwards when the NICE guidelines for recognition, referral and diagnosis of autism in under 19s (2011) was published AND |

- Relates to diagnostic pathway and model of service provision OR
- Relates to assessment process e.g. single discipline (paediatric consultant) or multidisciplinary

Primary exclusion criteria:

- Non-UK based literature
- Relates *only* to adult diagnostic pathway
- Relates only to *tertiary* services
- *Only* relates to treatment
- Relates to support services only *after* diagnosis.

Secondary exclusion criteria:

- Descriptive or irrelevant commentary on materials we already included; no added insights relevant to context or mechanisms
- Specific tools in terms of assessment tools or psychometric properties e.g. reliability/validity of the tool
- Prevalence only studies
- Studies only related to symptoms or aetiology
- Articles about special needs in general, no mention of ASD (or ADHD)
- Duplicate material of Co-Is' previous research, excluded by Co-Is
- Conference paper with only abstract available
- The data collected or published on-line before 2011

## Article selection and appraisal

As shown in Figure 1, we collected 338 articles (once duplicates removed) from the primary search (n=294), grey literature records suggested by the RE-ASCeD project team members and our expert stakeholders (n=129) and iterative secondary searches by searching all publications for key authors using Google Scholar and consulting our Expert Stakeholder Group (n=9). Two researchers (VA and WZ) carried out screening in two stages: an initial stage by title and abstract and second stage by full-text. Title-sifting of papers that deemed 'relevant' or 'maybe relevant' from both stages was also cross-checked by three team members (PW, WF and IM). Data extraction and appraisal were carried out by two researchers (VA and WZ) using a hybrid approach (18): basic details from each included article (n=79) were recorded; appraisal of evidence was based on concepts of relevance, rigour and richness (18, 19), with highly relevant articles (n=45, including nine from iterative secondary search) coded in NVivo. For 20%per cent of papers, a series of calibration exercises were undertaken by the RRR Lead (PW). When two reviewers were uncertain about the extraction or appraisal of a paper, this was discussed with the RRR Lead (PW). The quality and relevance of the selected papers were also assessed during the synthesis process by members from the RE-ASCeD project team.

Mapping the sources to test and develop PTs, we divided papers involved in NVivo analysis into three categories: 1) key papers that described a model of service delivery (e.g. integrated neuro-developmental service) in detail and were conceptually rich, 2) 'medium' papers that mentioned a model with some useful information but were not conceptually rich, 3) papers with a few 'nuggets'

(20) relevant to PTs. This helped us focus on key and medium papers (Supplementary Document 2) that could contribute most to developing a conceptual framework (21) and refining PTs.

### Synthesis and refinement

Based on analysis of individual papers, we then conducted cross-evidence comparisons to build PTs and confirm/refute and refine CMO configurations (Table 2). We also consulted with our expert stakeholders iteratively during the review process and at a data interpretation workshop in April 2020. Our expert stakeholders collectively reviewed the PTs, provided feedback and were invited to identify any omissions based on their clinical experience. We also asked them to suggest any further literature to help elucidate PTs. Based on feedback collected from the data interpretation workshop, two reviewers (VA and WZ) checked and added new papers suggested by our expert stakeholders; refined the programme theories and conceptual framework.

*Insert*: **Figure 1. Search and review flow diagram.**

### Patient and public involvement

Our co-investigators included a PPI representative from a local parent organisation (West Sussex Parent Carer Forum) who was able to consult a wider group of families with lived experience and a parent who had previously managed Sussex Autism Support. Our PPI representatives were equal partners within the Expert Stakeholder Group. This helped focus the review on the questions they were most interested in answering and enabled the identification of salient grey or unpublished documents for review (22). PPI was embedded into the review protocol and was particularly helpful when synthesising and interpreting the data (Stage 5). A separate PPI Reference Group (all parents of CYP with autism), whose inception was delayed due to covid-19, is integral to the wider project.

## Results

We developed seven PTs, based on cross-comparison and synthesis of 45 highly relevant articles: the first four focused on referral and diagnostic process and the last three on cross-cutting themes (Table 2). Figure 2 summarises the interrelationship between these PTs, set in the wider context of structural and organisational barriers affecting autism diagnostic pathways. Our focus was exploring solutions, so we did not focus on wider constraints, already widely documented, and incorporating chronic underfunding; increasing caseloads; reduced training budgets; and recruitment/retention issues, particularly paediatricians, child psychiatrists, clinical psychologists and SALTS (23, 24). Similarly, we

did not focus on causes of service user dissatisfaction, rather ways of addressing it. Full PTs with CMO configurations are provided as Supplementary Document 3.

*Insert*: **Figure 2. Programme theories for the autism diagnostic pathway**

**Table 2: Programme theories**

***{INSERT TABLE 2}***

## PT1: Listening and recognition

Although professionals had to balance early referral against the consequences of mislabelling (25), parents concerns needed to be listened to and taken seriously (4, 26, 27) because they were often the first to notice atypical patterns of development or behaviour in their child (4, 25-28). Managing parental expectations (29) and developing a co-operative relationship appeared to help manage this balance but 'was perceived to be particularly problematic because access to services is based on diagnosis, rather than an assessment of the child and family's needs (29, p215). From parents' perspective, one autism charity website suggested they "develop a talent for making a polite nuisance of themselves (more properly known as 'advocacy')" to transverse barriers to referral (25, p29).

Additionally, greater autism awareness and training for frontline professionals, particularly general practitioners (GPs) and teachers, alongside training in how, when and who to refer to (1, 4, 25, 26, 30-32) was suggested as a strategy to improve early identification.

## PT2: Referral and triaging

Comprehensive information gathering pre-assessment reduced the number of contacts, assessment duration and total time taken to reach diagnosis (33). A systematic approach to information gathering (1, 31, 34) improved efficiency, but referrers also wanted feedback when referrals were declined (1, 31, 35).

Innovative approaches to triaging included: sufficient information gathering pre-assessment to enable same-day assessment in the context of tertiary services (36-38); initial interview with an experienced clinician (39); community paediatrician carrying out a General Developmental Assessment (GDA) (35, 38, 40); assessment by CAMHS or a community paediatrician and Speech and Language Therapy (SALT), then allocating to an abbreviated (local) or complex (specialist) pathway (35); triage meetings across CAMHS and CDS (35). However, whether these strategies constituted triaging or the first stage in the diagnostic pathway was arguable.

## PT3: Diagnostic assessment

Services had different condition-specific remits, catchment areas and commissioning agreements. Where the same Trust managed both community paediatrics and mental health services, this allowed a seamless transition, avoiding duplicated waits and enabling families to see all relevant professionals at once (14, 38).

Few papers clearly delineated the service pathway (14, 29, 34, 35, 38, 41, 42) and within these were wide variations, including the balance of standardised assessments, observations and clinical judgement. As recommended by NICE (9), most services were multidisciplinary, and many offered a single point of access, bridging the autism-ADHD diagnostic divide (14, 38). For example, Peterborough's integrated pathway provided assessments for ADHD and autism (14, 38) and combined a single point of access with a comprehensive skill mix, including access to therapies. This reduced the number of assessments per individual, saved time and money, and provided a better diagnostic experience (38). Another approach was to extend the role of available professions, for example, SALTs, by training them to carry out aspects of the assessment previously carried out by child psychiatrists (34). However, disadvantages of multidisciplinary assessment and/or multi-agency working included being labour intensive and costly (10); being negatively affected by the dissonance between medical and educational paradigms (41); and a 'perceived power differential' evidenced by the 'decision-making power of doctors and psychologists over other clinicians' (43, p322).

Rutherford et al. (35) presented a multi-agency diagnostic pathway with an abbreviated pathway when the signs and symptoms of autism were easily identified and a 'complex' pathway for CYP with, for example, co-existing conditions needing onward referral to a specialist team. This resulted in fewer CYP unnecessarily going through the full process (35).

An interesting theme within the literature considered the balance of clinical expertise against standardised assessments. Less experienced clinicians appeared to prefer using standardised tools, while more experienced clinicians expressed confidence in their clinical judgement (39). Some clinicians found diagnostic tools helpful, while others described them as 'very cumbersome and very time consuming' (41, p.118). Rogers et al. (44, p824) referred to 'upgrading', whereby the majority of professionals (78 out of 116) erred on the side of a positive diagnosis when faced with uncertainty. The main reasons were to facilitate access to funding/support (n=17; 22%); enable individuals to get a statement of Special Educational Needs (n = 8; 10%); or differing opinions among colleagues in a team (n=32; 41%).

Finally, there was limited but positive literature around the use of technology. Aims included 'remote' observational assessments carried out by families during a short telehealth assessment to screen for

autism in children under 3 years (45); using mobile technology to collect observational data in advance of formal assessment (46); educational games to assess risk of autism (46); an automated story ('A Pirates Adventure') scoring emotional cognition (47); and the use of computer-based Continuous Performance Tests (48). Our expert stakeholders also suggested that where the presence of ADHD is suspected, the use of Qbtest (48) may enable an objective measurement of attention, concentration, impulsivity and distractibility but the evidence is limited. Since carrying out the RRR, Lord (49) has provided guidance on adapting autism diagnostic assessment during social distancing, including the Autism Diagnostic Observation Schedule (ADOS) (although unvalidated), for remote use, demonstrating that the current covid-19 crisis has become a driver for telehealth approaches.

## PT4: Diagnostic feedback

Most parents regarded autism diagnosis as a gateway to services (44) but there was no consensus on best practice regarding feedback (42). Parents valued a sensitive approach and positive comments about their child and their parenting (27) but found it hard to absorb feedback (27, 50). Practical strategies included a structured approach; using consistent and straightforward terminology; opportunity to ask questions (including later); and recognising their child's skills/strengths (1, 27, 41, 50, 51). Guidelines recommended a needs-based and tailored management plan, co-developed with parents (1, p.15, 52).

Only one paper provided detailed information on the report format (34) and used a digital report-writing tool and visual profiling tool. Reports were available within a few days, enabling parents to review the content, improving partnership working. The visual profiling tool provided a concise visual aide for understanding, explaining, and communicating the abilities of each CYP.

## PT5: Working in partnership with families

The diagnostic process was enhanced by integrating 'expertise from several perspectives… that of the individual, their family, and the professionals' (53, p.3762) and acknowledging parents as co-experts. When parents understood the diagnostic process in advance, this improved satisfaction and helped moderate expectations (27, p.373). Open and honest dialogue involving parents in decision-making (44), helped promote engagement and manage differences of opinion (54). Having a named 'case coordinator' (1) or 'keyworker' (55) helped reduce stress and increase engagement (54). Parents offered support following diagnosis were, unsurprisingly, more satisfied than those who were not (53). A simple suggestion to improve satisfaction was to tailor links to relevant services and explore the full range of services that might prove useful (4). Another approach was to help parents develop strategies

to manage difficulties, for example, meeting families wherever most convenient to reduce non-attendance (54).

## PT6: Inter-agency working

Integrating the pathways into a single assessment process potentially saved time and cost less (10, 14, 24) but we found little evidence of how to address macro-level constraints such as chronic underinvestment (25). Much appeared to rest on personal relationships at the micro-level (56) and/or parents co-ordinating services (29). While joint working was endorsed (57, p.240) suggestions to promote it were limited to establishing clear pathways (58); creating opportunities to work in different teams, such as split posts or secondments (54); and an Additional Learning Needs Coordinator (a teacher at the school) (29).

## PT7: Training, service evaluation and development

Several papers identified the importance of training in improving the quality and efficiency of autism diagnostic services (30, 35). It was recommended that training should go beyond those working in autism services, include the educational sector (59) and be geared to the needs of managers as well as frontline staff (30) through multi-agency training (1).

Rutherford et al. (35) advocated a training framework with different skill levels, depending on the 'nature, extent and likely impact of daily contact with individuals with ASD' (35, p.1583) and now reflected in Health Education England recommendations (60). Other training suggestions included an opportunity to observe specialist autism services; buddying with experienced clinicians; regular review of training needs and succession planning; and a national forum to share experiences and knowledge (31, 58).

Finally, service evaluation was advocated to check adherence to standards/guidelines (23) and provide evidence for commissioners (31); one strategy was a guidelines checklist at the front of each patient file (31). Service development suggestions included having one person to champion change; generating research within clinical teams; encouraging practitioners to co-create contextually sensitive solutions (31); and drawing on the expertise of people with autism, carers and specialist organisations (30). Our stakeholders highlighted the importance of good quality national data to facilitate a whole system approach, with the current approach appearing somewhat fragmented (61).

# Discussion

This RRR explored diagnostic pathways that have been adopted across the UK, to determine what works best, for whom and in what circumstances. Four PTs related to the clinical pathway, addressing ways to improve initial recognition of possible autism, referral and triaging, the diagnostic model and post-diagnostic feedback. Whilst there were specific service delivery models of interest, such as adopting a broader neurodevelopmental approach to assessment, or the use of skill mix, there also appears to be scope to adapt stages within the process. For example, gathering information about a CYP's strengths/needs at the point of referral may enhance the process, regardless of the specific model. The three cross-cutting PTs centred on working in partnership with families; inter-agency working; and training, service evaluation and development. Collectively, these PTs evidence different approaches that could contribute to a better experience for families, improved efficiency (and potentially cost savings) and shorter waiting lists.

Many of the issues identified in the RRR could be addressed by full adherence to NICE guidelines (1) and quality standards (62). However, a gap exists between guidelines and local interpretation, exacerbated by demand outstripping capacity and resourcing constraints. In particular, the guidelines indicate the need for a team with the competencies to deliver a broader neurodevelopmental and mental health assessment, producing a comprehensive description of a CYP's strengths and needs, but some services appeared focused solely on autism diagnosis, partly reflecting resourcing constraints (30) . A broader neurodevelopmental approach may also ameliorate the concerns of those families whose child does not fully meet criteria for an autism diagnosis but has significant needs which may otherwise remain, or feel, unrecognised. This would be additionally aided by clinical teams resourcing the development of strengths and needs planning or working in consort with other agencies.

As previously noted, there may also be a trade-off between carrying out comprehensive assessments for all CYP with possible autism and 'providing a more streamlined approach that is tailored to the child's presentation' (63, p.526) which could reduce diagnostic validity. This mirrors feedback from our expert stakeholders – that there may need to be a discussion around the potential to increase investment in service delivery to enable high quality and timely approach versus the potential challenges associated with accepting lower quality and less timely diagnostic assessment.

## Implication for practice and future research

From the PTs we identified six key areas that would benefit from further exploration. These were evaluation of: training and support materials available for non-specialist staff and parents/CYP accessing the diagnostic pathway which would increase early recognition that a child may need

assessment and improve information gathering at the point of referral; training packages to upskill those working in autism services and the subsequent impact on workforce shortages; asset-based approaches to diagnosis, management and support; barriers and facilitators to comprehensive needs-led diagnostic assessment; approaches to integrating services dealing with autism; and increased use of technology in assessment which has already started in the context of COVID-19 (64).

## Strengths and limitations

The realist approach was well suited to examining and understanding the complexity of autism diagnostic assessment, and the challenges of delivering such services in different contexts. We developed systematic and focused search strategies, within the parameters of RRR (17), although not as extensive as a full realist review. Expert Stakeholder Engagement enhanced the search strategy, enabled an iterative approach to identifying relevant literature and was invaluable when synthesising the findings. Primary and background searches were restricted to UK only, given UK NHS context, but secondary searches included papers from similar countries (USA, Canada, Australia, New Zealand) albeit with different healthcare systems to help elucidate findings, as recommended by our expert stakeholders. Whilst insurance-based health economies are different (63), the literature was largely consistent with our findings. For example, recommendations to engage families in service design, and to produce a needs-based holistic assessment and report are mirrored internationally (65, 66). However, we acknowledge that we may have missed literature from similar health systems that could have informed our PTs.

## Conclusion

In conclusion, this RRR identified important aspects that may contribute to more efficient, high quality and family-friendly service delivery. We will test the PTs and how service design could be further enhanced in the subsequent stages of the wider Re-ASCed study.

# AUTHORS' CONTRIBUTIONS:

VA/WZ: involved in all stages of the review and writing all drafts of this paper

PW: substantial contribution to writing protocol for the overall RE-ASCeD project, all stages of the review and commenting on all drafts of this paper

WF/IM: substantial contribution to writing protocol for the overall RE-ASCeD project, all stages of the review and commenting on drafts of this paper

JP: substantial contribution to writing protocol for the overall RE-ASCeD project, some stages of the review and commenting on a draft of this paper

VR: substantial contribution to writing protocol for the overall RE-ASCeD project, some stages of the review and commenting on a draft of this paper

AP: designing the search strategy and commenting on the methodology section of this paper

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**Data sharing statement**: Not applicable.

**Figures:**

- **Figure 1. Search and review flow diagram.**
- **Figure 2. Programme theories for the autism diagnostic pathway.**

**Table 2: programme theories**

| PTs 1-4: Stage specific programme theories affecting the diagnostic assessment pathway | |
|---|---|
| **PT1 Listening and recognition**<br>If frontline health and education professionals (e.g. GPs, teachers) are confident in recognising the signs and symptoms of autism, are cognisant of referral pathways and listen to parents, taking their concerns seriously then CYP will be referred to an appropriate service, in a timely manner, reducing parental frustration. | NICE, 2011 (1); Reed and Osborne, 2012 (67); Abbott, et al., 2013 (27); The Scottish Government, 2014 (30); Crane, et al., 2016 (4); Rogers, et al., 2016 (44); O'Reilly, et al., 2017 (26); RCPCH, 2017 (23); Potter, 2017 (28); Unigwe et al., 2017 (32); Crane, et al., 2018 (53); Dowden, 2018 (25); Rutherford, et al., 2018 (35); Ford, et al., 2019 (68); Hurt, et al., 2019 (29). |
| **PT2 Referral and triaging**<br>If autism diagnostic services provide clear guidelines for referrers on what information is needed and how to refer, and referrers follow these guidelines, then time will be saved at the triaging stage and proportionately fewer CYP who do not have autism will go through the full process. | NICE, 2011 (1); Carpenter, 2012 (39); The Scottish Government, 2014 (30); McKenzie, et al., 2015 (33); Healthcare Improvement Scotland, 2016 (51); Rutherford, et al., 2016 (31); Rutherford, et al., 2018 (35); Autistica, 2019 (38); Hurt, et al., 2019 (29); Tollerfield and Pearce, 2020 (34). |
| **PT3 Diagnostic assessment**<br>If a structured, consistent and multidisciplinary approach to service delivery is adopted, making best use of available staff and clinical expertise, then the number of assessments per individual may be reduced. | Carpenter, 2012 (39); NICE, 2014a (55); Karim, et al., 2014 (41); Gray, et al., 2015 (42); Crane, et al., 2016 (4); Halpin, 2016 (43); Healthcare Improvement Scotland, 2016 (51); McKenzie, et al., 2016 (69); Rogers, et al., 2016 (44); Rutherford, et al., 2016 (31); Tryfona, et al., 2016 (46); Galliver, et al., 2017 (10); Jordan, et al., 2017 (47); Juárez, et al., 2018 (45); Rutherford, |

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| If a balance of interview, observation and recognised tools are used, alongside an assets-based approach, this will ensure a comprehensive and family-friendly diagnostic experience.<br>If the same Trust manages both community paediatrics and mental health services, this potentially allows for a seamless transition, avoids duplicate waits and enables families to see all relevant professionals at the same time. | et al., 2018 (35); Ahlers, et al., 2019 (70); Autistica, 2019 (38); Ford, et al., 2019 (68); Tollerfield and Pearce, 2020 (34). |
| **PT4 Diagnostic feedback**<br>If parents understand the diagnostic process and feel supported this can moderate parental expectations. Feedback should take an assets-based approach and management plans should be individualised, taking account of co-existing conditions. Reports should be timely and in a format that everyone finds helpful. | NICE, 2011 (1); RASDN, 2011 (52); Calzada, et al., 2012 (57); Carpenter, 2012 (39); Reed and Osborne, 2012 (67); Abbott, et al., 2013 (27); Karim, et al., 2014 (41); NICE, 2014a (55); The Scottish Government, 2014 (30); Halpin, 2016 (43); Healthcare Improvement Scotland, 2016 (51); Hennel, et al., 2016 (50); McKenzie, et al., 2016 (69); Reed, et al., 2016 (71); Rogers, et al., 2016 (44); Crane, et al., 2018 (53); The Scottish Government, 2018 (59); Autistica, 2019 (38); Hurt, et al., 2019 (29); Tollerfield and Pearce, 2020 (34). |
| **PTs 5-7: Cross-cutting programme theories affecting the diagnostic pathway** | |
| **PT5: Working in partnership with families**<br>If parents have a single point of contact, are provided explanations throughout and included in decision-making then diagnostic pathway may be less stressful. | Calzada, et al., 2012 (57); Abbott, et al., 2013 (27); Gregory, et al., 2013b (54); NICE, 2014a (55); Rogers, et al., 2016 (44); Healthcare Improvement Scotland, 2016 (51); Crane, et al., 2018 (53). |
| **PT6: Inter-agency working** | |

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| If “experts” including people with autism, carers, professionals and specialist organisations work in partnership and the knowledge generated is effectively embedded into local services, this will build capacity, improve parent/CYP satisfaction and support planning of services both locally and nationally. | NICE, 2011 (1); Calzada, et al., 2012 (57); Gregory, et al., 2013a (56); Gregory, et al., 2013b (54); Karim, et al., 2014 (41); NICE, 2014a (55); The Scottish Government, 2014 (30); Gray, et al., 2015 (42); Healthcare Improvement Scotland, 2016 (51); Rogers, et al., 2016 (44); Galliver, et al., 2017 (10); Hayes, et al., 2018 (72); The Scottish Government, 2018 (59); Williams et al., 2018 (73); Hurt, et al., 2019 (29); Tollerfield and Pearce, 2020 (34). |
| **PT7: Training, service development and evaluation**<br>If professionals have access to tailored training based on their needs, competencies and role, and services engage in service development and evaluation, this will increase the local skill set of people who regularly work with CYP who may have autism. | NICE, 2011 (1); Gregory, et al., 2013a (56); Autism ACHIEVE Alliance, 2014 (58); NHS Education for Scotland, 2014 (74); The Scottish Government, 2014 (30); Rutherford, et al., 2016 (31); RCPCH, 2017 (23); Rutherford, et al., 2018 (35); The Scottish Government, 2018 (59). |

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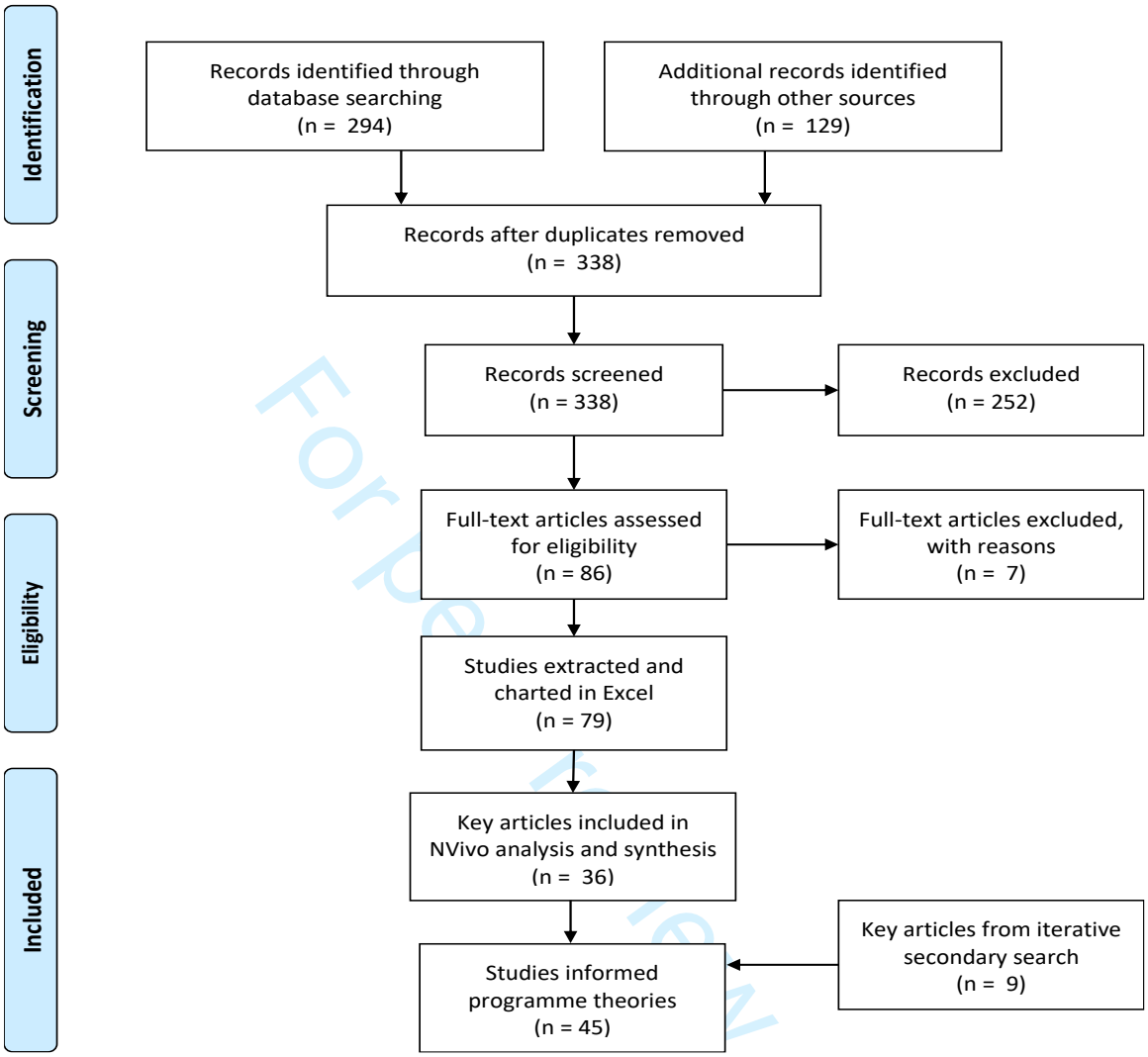

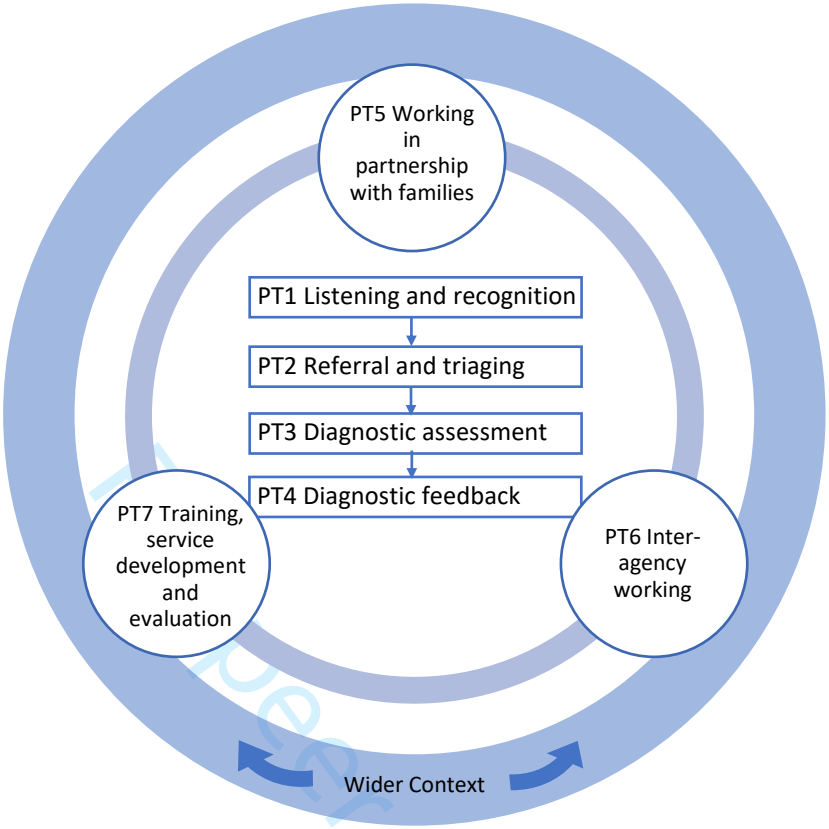

**Supplementary Document 1.** Database Search Strategies

**Number of databases searched**: 7

Medline (Ovid)
Embase (Ovid)
PsycINFO (Ovid)
Social Policy & Practice (Ovid)
CINAHL Plus (EBSCO)
Cochrane Library
Web of Science (Clarivate)

**Search limits:** 2011-current; English language; UK only

Literature search strategy used for **Medline** (search run on 25.11.19) is attached below. Additional search strategies available from the authors.

| | | |
|---|---|---|
| 1 | exp Autism Spectrum Disorder/di, ep, th [Diagnosis, Epidemiology, Therapy] | 10929 |
| 2 | (autism spectrum disorder* or ASD or autism).ti,kw. | 23890 |
| 3 | (asperger* syndrome or asperger*).ti,kw. | 1150 |
| 4 | 1 or 2 or 3 | 27668 |
| 5 | adolescent/ or child/ or child, preschool/ | 2937612 |
| 6 | (child or children* or pre-school child* or adolescent*).kw. | 70707 |
| 7 | 5 or 6 | 2940479 |
| 8 | 4 and 7 | 19625 |
| 9 | Community Mental Health Services/ | 18302 |
| 10 | ("child and adolescent mental health service*" or "child & adolescent mental health service*" or CAMHS).ti,ab,kw. | 491 |
| 11 | ("child and adolescent mental health team*" or child mental health service*).ti,ab. | 149 |
| 12 | child development clinic*.ti,ab. | 39 |
| 13 | 9 or 10 or 11 or 12 | 18873 |
| 14 | 8 and 13 | 69 |
| 15 | Diagnostic Services/ | 1916 |
| 16 | (diagnostic service model* or diagnostic assessment model* or diagnostic assessment or diagnostic process).ti,ab. | 6616 |
| 17 | (diagnostic pathway* or diagnostic evaluation or referral pathway*).ti,ab. | 8902 |
| 18 | early diagnosis/ or early intervention/ | 28062 |
| 19 | "Referral and Consultation"/ | 64435 |
| 20 | Critical Pathways/ | 6455 |
| 21 | ((multidisciplinary or multi-disciplinary or interprofessional or inter-professional or intraprofessional or intra-professional or interdisciplinary or inter-disciplinary) adj team*).ti,ab. | 18640 |

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| 22 | "delivery of health care, integrated"/ or health services accessibility/ or patient care team/ | 143724 |
| 23 | Professional-Family Relations/ | 14480 |
| 24 | (service delivery or diagnostic experience*).ti,ab. | 10451 |
| 25 | 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 | 283159 |
| 26 | 8 and 25 | 1254 |
| 27 | (cost-effectiveness or evaluation).ti,ab. | 1027879 |
| 28 | Efficiency, Organizational/ or Efficiency/ | 34521 |
| 29 | evaluation studies as topic/ or program evaluation/ or validation studies as topic/ | 183858 |
| 30 | "quality of health care"/ or "outcome and process assessment (health care)"/ | 95758 |
| 31 | Waiting Lists/ or Time Factors/ | 1175790 |
| 32 | (family experience or parent experience).ti,ab. | 365 |
| 33 | 27 or 28 or 29 or 30 or 31 or 32 | 2377747 |
| 34 | 14 or 26 | 1295 |
| 35 | limit 34 to (english language and yr="2011 - 2020") | 738 |
| 36 | 33 and 34 | 256 |
| 37 | limit 36 to (english language and yr="2011 - 2020") | 141 |
| 38 | remove duplicates from 35 | **736** |

**Supplementary Document 2.1 - Key papers from primary search and background search**

| **Author (year)** Green = key; Yellow = medium; Blue = nuggets. order is density of coding | **Country** | **Title** | **Settings/service types** (e.g. ASD, ASD & CAMHS) **& service models** | **Study type** | **Aims** | **Method** | **Sample size** | **Summary of findings relevant to programme theory** |
|---|---|---|---|---|---|---|---|---|
| Rutherford, et al., 2018 | Scotland | Improving efficiency and quality of the children's ASD diagnostic pathway: Lessons learned from practice | CCH/SLT, CCH/ CAMHS/SLT, a variety of ASD diagnostic assessment teams | mixed methods, quan&qual | a. Identify the baseline number of referrals and duration of ASD diagnostic assessment for children (aged 0–18) across a health board before a single evidence based ASD care pathway was in place<br>b. Describe the pathway development process and service changes implemented<br>c. Evaluate the effects of the new pathway for ASD diagnosis on knowledge of service demand, duration of assessment and waiting time. | The work reported comprised several steps: (a) baseline information gathering about current practice and national guidance; (b) development of an action plan (Fig. 2); (c) writing and achieving consensus to implement the new pathway (d) setting up a clinical database for recording and measuring involvement in the pathway for each child referred (e) statistical analysis of the data.<br><br>interviews, Case Note Analysis | 1 health board in Scotland- 4 local authority areas - Across all areas, 7 separate local teams were identified (teams 1–7).<br>One clinician from each team (n = 7) was interviewed about main aspects of the diagnostic services such as personnel involved and process followed.<br>telephone interview with a small number of families (n = 7) | it reports statistically significant reductions in waiting times for autism diagnostic assessment following a children's health service improvement programme. The average wait between referral and first appointment reduced from 14.2 to 10.4 weeks ($t(21) = 4.3$, $p < 0.05$) and between referral and diagnosis shared, reduced from 270 to 122.5 days, ($t(20) = 5.5$, $p < 0.05$). The proportion of girls identified increased from 5.6 to 2.7:1.<br>Methods reported include: local improvement action planning; evidence based pathways; systematic clinical data gathering and a training plan.<br>Model: see Fig 1 for all the steps including:<br>a) Comm Paed + SLT *OR* CAMHS,<br>b) specialist ASD Ax via triage,<br>c) Local abbrev Ax OR complex Ax OR request more information/decline |
| Rutherford, et al., 2016 | UK-Scotland | Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children | Child & adult services providing ASD diagnosis | sequential mixed methods design: Phase 1 quantitative data from the case notes & Phase 2 all sixteen services providing quantitative data were invited to participate in local focus groups.<br><br>*N.B. The study was part of the Scottish national Autism ACHIEVE Alliance study McKenzie et al. 2015 (Factors influencing waiting times...) which we have* | investigation from the perspective of diagnosing professional teams, of the reasons for delays, which also generates solutions.<br>Objectives:<br>- To explore the reasons clinicians give to explain long wait times for diagnosis for ASD.<br>- To identify clinicians views on the challenges and solutions to a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines.<br>- To develop **collaborative action plans** for improving the efficiency and quality of the process of ASD diagnosis in child and adult services. | Ninety five clinicians from 8 child and 8 adult ASD diagnostic services attended 16 focus groups to explore clinicians' views on a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines. During focus groups, quantitative data were fed back, used to frame discussions and facilitate solution focused action planning with each service. Sixteen local action plans were synthesised to create an ASD Action Plan for children and an ASD Action Plan for adults. | 95 clinicians | Key solutions are proposed to support the reduction of the wait for diagnostic assessment, through reducing non-attendance rates, reducing inappropriate referrals, developing efficient working and communication and improving the effectiveness of care pathways. These are presented in actions plans for use by clinical teams.<br><br>**Model: see Table 1** - 8 child ASD service, all **multi-disciplinary, specialist or general**, mix of profs<br><br>***See Table 4-5 & Fig 2 is good - check we've incorporate all in PTs*** |

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| The Scottish Government, 2014 | Scotland | Scottish Strategy **Mapping Report** | a broad range of autism services (for child/adult) across Scotland | Qualitative - workshops & quesionnaires - themes | The purpose of this report is as follows:<br>(i) to provide a 'snapshot' of autism services across Scotland, set out the key issues identified by people with autism and their carers, and provide an overview of how services are meeting their needs or where there may be gaps in services<br>(ii) set out the evidence gathered from the mapping project in order to inform local autism action plans and local decisions on autism service provision<br>(iii) inform future decisions on priorities for funding. | The project held 164 workshops and face-to-face meetings to accommodate individual needs. These equated to 35 multi-agency meetings, 68 carers meetings and 61 meetings with people with autism. | respondents number:<br>people with autism: 186 workshops & 237 questionnaires; parents and carers: 457 workshops & 719 questionnaires; multi-agency: 463 workshops & 595 questionnaires.<br><br>Overall 1106 workshops & 1106 questionnaires | single point referral for access (p7)<br>page 18-19: 'Indicator 6 - A **multi-agency** care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.'<br>page 22: 'Summary: Key Findings from the 10 indicators' p23 - distinguishes btwn co-ord/inclusion in individual vs inclusion/co-prod/PPI in service delivery which it criticises - and dissonance btwn what services say (we do include in service design) & pts who disagree.<br>page 32: appendix 1 - '3. Theme One: Diagnosis' - findings from survey p32, W/L so long, went private<br>page 64: Appendix 2-the experiences of service providers and statutory agencies. '2. Theme One: Service Provision and Assessment'<br>page 69: Appendix 2-the experiences of service providers and statutory agencies. '3. Theme Two: Joint Working and Referral'<br>Talks about **GIRFEC: getting it right for every child** - specific to Scotland. **Wider remit** than ASD.<br>**Model:** various. Note the ***distinction btwn multi-agency & multi-professional*** |
| Crane, et al., 2018 | UK | Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals | represented a number of geographical regions across the UK | part of a larger project exploring the autism diagnostic process in the UK.<br>In Phase One online survey: parents of children on the autism spectrum (Crane et al. 2016) and professionals involved in autism diagnosis (Rogers et al. 2016).<br>Phase Two (this paper) - Qualitative | to identify aspects of the diagnostic process that are working well, and areas in which improvements are needed. | qualitative: the views and experiences of ten autistic adults, ten parents of children on the autism spectrum, and ten professionals involved in autism diagnosis (three clinical psychologists, two paediatricians, one educational psychologist, one psychiatrist, one speech and language therapist, one specialist early years practitioner, and two educators). Seven professionals worked for the UK's National Health Service, two worked in the education sector, and one worked for a local authority. | 30 | Based on previous work, **six key factors** were predicted to **affect overall satisfaction** with the diagnostic process: **time taken** to diagnosis, age at diagnosis, **quality of information** provided at diagnosis, **manner** of professional giving diagnosis, **support post-**diagnosis & **stress** during the process. **Stress during the diagnostic process was the strongest predictor of overall satisfaction** with the diagnostic process. This was followed by satisfaction with the **support** offered post-diagnosis and satisfaction with the **manner** of the professional disclosing the diagnosis.<br>Three key themes were identified: the process of understanding and accepting autism; multiple barriers to satisfaction with the diagnostic process; and inadequate post-diagnostic support provision.<br><br>**Models: various types profs & services, not the focus/not specified**<br><br>**see Fig 1 summary of themes** |
| NICE, 2011 (updated in 2017) | UK | Autism spectrum disorder in under 19s: **recognition, referral and diagnosis** (CG128) | Autism spectrum disorder | guideline | This guideline covers recognising and diagnosing autism spectrum disorder in children and young people from birth up to 19 years. It also covers referral. It aims to improve the experience of children, young people and those who care for them. | NA | NA | page 5: '1.1 Local pathway for recognition, referral and diagnostic assessment of possible autism' section are all useful - 1.1.1 'A local autism **multi-agency strategy** group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.' and 1.1.2 'The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people.' and 1.1.3 'In each area a **multidisciplinary** group (the autism team) should be set up.'<br>***N.B. note multi-agency & multi-disc - does it stipulate more specifically than this?*** |

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| Rogers, et al., 2016 | UK | Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom | Services involved in ASD diagnostic process with children. | quantitative - on-line survey | conduct a review of diagnostic practice in the United Kingdom by exploring the experiences and perspectives of professionals involved in diagnosing ASD. | A heterogeneous sample of professionals who were clinically active in ASD diagnosis and assessment at the time of the survey, were invited to participate. To recruit the sample, services were collated via the National Autistic Society online directory, and Internet searches were conducted for ASD diagnostic services. 300 services were contacted. Additionally, approximately 3000 statutory and non-statutory ASD services listed in the NHS choices directory were contacted. A total of 126 multidisciplinary professionals completed the full questionnaire, but 10 professionals were excluded from the analysis as they were not clinically active at the time of the survey. Data collection ran from March 2012 to May 2013. Online questionnaire (4- & 5-point Likert scales) exploring their experiences and opinions of three key areas of service: accessibility, the diagnostic process and post-diagnostic support. open questions were analysed qualitatively, using a thematic analysis | 116 | Although professionals were largely satisfied with service accessibility, around 40% of services were failing to provide timely assessments. Standardised diagnostic tools were perceived as helpful and were used consistently, but concerns were raised about their validity in detecting atypical ASD presentations (e.g. females). Several challenges regarding giving ASD diagnoses were reported; these included making sure caregivers understood the diagnosis, pitching information at the correct level and managing distress. 76% of professionals acknowledged the practice of '**upgrading**' to a diagnosis of autism spectrum disorder in uncertain or complex cases and reasons for this varied widely. Professionals felt the need to streamline post-diagnostic support options, ensure the availability of long-term support and to ensure that the post-diagnostic support needs of under-served groups (e.g. women and girls; adults without learning disabilities) were not overlooked.<br><br>**Table 8** has explanations/**Ms** related to **accessibility** (in terms of ease of making referral & screening process), **diagnostic process** & **post-diagnostic support**<br><br>**Models: various types profs & services, not the focus/not specified** |
| Calzada, et al., 2012 | UK | High-functioning autism and Asperger's disorder: Utility and meaning for families | specialist clinic for the assessment of children and adolescents with a possible high-functioning PDD. | Qualitative, Semi-structured interviews | investigate the utility (how useful diagnosis is clinically) of pervasive developmental disorder (PDD) diagnoses & differentiating between AD & AsD. | interviewed 22 participants from 10 families. young people (aged 9–16 years) with highfunctioning autistic disorder (AD) and Asperger's disorder (AsD), and their parents. Framework analysis | Twenty two participants from ten families | Perceived advantages of AD and AsD diagnosis were increased understanding and practical support, and parental empowerment. Disadvantages included the effects of stigma and concerns about validity. The utility of AD and AsD depends upon both their validity and how these diagnoses are received in their cultural, economic and legislative context.<br>**Model: specialist clinic for the assessment of children and adolescents with a possible high-functioning PDD (pervasive developmental disorder).** *Not focus of article* |
| Hurt, et al., 2019 | **South Wales** | Understanding and improving the care pathway for children with autism | NHS MDT for NDCs<br>1) A NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8);<br><br>2) in education sector:<br>staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist, n= 8); | Qualitative mixed-methods approach using focus group discussions, creative writing workshops and visualisation using rich pictures | to describe current care pathways for children with autism including enablers and barriers, as experienced by health professionals, education professionals and families in South Wales, UK. | mixed-methods approach using focus group discussions, creative writing workshops and visualisation using rich pictures.<br>**Three workshops** were conducted in September 2015 with (see sample size):<br><br>During the workshops, we employed three methods to collect data. First, we used focus group discussions; Second, a graphic illustrator captured the discussions... enabled comparisons to be drawn across the three groups; Third, participants undertook creative writing exercises to express their experiences in narrative form. | (1) health professionals working within a NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8);<br>(2) staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist, n= 8); and<br>(3) parents of primary school children diagnosed with ASD (n= 7). | The **experiences of the care pathways** differed significantly across the three groups. Health professionals described the most rigidly structured pathways, with clear entry points and outcomes. "**Tier 2" pathway** catered for relatively **uncomplicated cases**, with **two assessment visits** and **one feedback** visit at which a **multi-disciplinary** team discuss the assessments with the family and decide on whether a diagnosis is necessary. The **"Tier 3" pathway** catered for **complicated** cases, and involved **more detailed assessments and discussion** before the feedback session with families. Both pathways were thought to take around **two to three months** to complete. Interaction with education was limited to **observations at school** and an invitation to educational professionals to **attend** the multi-disciplinary **feedback meeting**.<br>Education professionals and parents described more complex and confusing pathways, with **parents** assuming the responsibility of **coordinating** the **health and education** activity in a bid to link the two independent pathways. One school had an Additional Learning Needs Coordinator (**ALNCo**, a teacher) who **coordinated** the support for all children with an identified need before and/or after diagnosis & provided the link between the parents, teachers and any allied education professionals.<br>All three groups identified enablers, although these differed across the groups. The barriers were more consistent across the groups (e.g. poor communication, missing information, lack of transparency, limited post-diagnosis services and access to services based on diagnosis rather than need). In common with health professionals, the education professionals expressed dissatisfaction that many of the steps in the pathway required a **diagnosis,** rather than an examination of the child's **needs.**<br>**Model:** In autism care, there is recognition that holistic, **cross-agency and multi-disciplinary** working is essential (NICE, 2013)... 'In the refreshed ASD Strategic Action Plan, the Welsh Government (2016) commits to delivering a "**national integrated autism service**" by 2019. Whilst generic, high-level care pathways were suggested within the original strategy, it is **not understood how these work on the ground**, nor are there clear examples of good and poor practice to inform future service planning. **No revised pathway is provided** within the refreshed strategy to guide the delivery of the integrated service. |
| AUTISTICA, 2019. Embracing complexity in diagnosis: multi diagnostic pathways for NDCs. | UK | Embracing Complexity is a new coalition of 38 UK charities who support people with NDCs | Four exemplars, England & Wales | Report | Raise awareness of innovative models of care models for diagnosing NDCs | Interviews with professionals in the 4 pathways | No details | Outlines the **4 MDT models (Peterborough, Lambeth, Evelina, All Wales)** carrying out holistic assessment which can deliver multiple diagnoses of NDCs at the same time; lack of robust evidence or how best to reflect local needs. |

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| Tollerfield & Pearce, 2020. | England | Thinking Patterns in Autism Model: Innovating future-fit autism diagnostic assessment services. | the diagnostic service was incorporated into CAMHS, with diagnostic assessments completed by the SALT and consultant child and adolescent psychiatrist. | descriptive evaluation | to describe and retrospectively evaluate an autism diagnostic profiling model in a region of North England. | With reference to NICE (2017) guidelines, clinical service data, and a parent survey, the service model was retrospectively evaluated.<br>This retrospective study evaluated descriptive information about a service model that was trialled between November 2018 and May 2019. | 114 families attended for assessment during this six-month period. Parent information was sampled via SuveyMonkey.com (April 2019), and waiting list rates, staffing, means and ratios were calculated (November 2013 and November 2019). | Findings showed that positive changes over time resulted in an NHS service that was able to create high quality diagnostic profiles for every individual assessed. Findings further showed that the profiling assessments could be completed in less time; approximately 30% less speech and language therapy time and 70% less psychiatry time was needed. Positive parent comments suggested that diagnostic assessment profiling feedback was individualised, detailed and valuable. Central to achieving these outcomes was the use of standardised procedures and cost-effective skill mix for meeting NICE (2017) guidelines on gathering assessment information, communicating the results after the autism diagnostic assessment, and providing individual information on support (1.5; 1.8; 1.9). A model for understanding and explaining thinking patterns in autism was used as a structure for gathering information, for report writing, and for producing a simple visual designed to capture and communicate the complexity of autism as well as the unique context for each individual. It is suggested in this paper, that these innovations can support and inform the development of future-fit autism assessment services.<br>**Model of ASD**: Thinking Patterns in Autism (TPA) Profiling Model - with visual profiling.<br>**Diagnostic model**: By 2009, the diagnostic service was **incorporated into CAMHS**, with diagnostic assessments (12 per year) completed by the **SALT and consultant child and adolescent psychiatrist**. Funding associated with the waiting list initiatives led to increases in therapist time, but there were difficulties with funding and recruiting psychiatrists and psychologists. Consequently, a significant bottle-neck developed in the diagnostic pathway with families waiting extended times for psychiatry input following assessments. In response, the **therapist role was extended so that psychiatry time required per case was reduced.** |
| The Scottish Government, 2018 | Scotland | The Scottish Strategy for Autism - **Engagement Analysis** 2018 | NA | qualitative - online survey & engagement events | to gather in views on the final phase of the Scottish Strategy for Autism | From 18 October 2017 to 29 November 2017 we ran an online engagement exercise. we received 662 responses. Alongside our online questionnaire we held four engagement events, which were attended by more than 600 people. This means well over 1,000 people took part in our engagement activity.<br>As part of our engagement activity we held a number of engagement events, To ensure consistency, delegates who attended these events were asked the same questions as those who used the online engagement tool. Each event had two parts: a morning session for autistic people, their families and carers, and an afternoon session for professionals. | Of the 662 responses to our online questionnaire, 92 per cent were from individuals and the remaining eight per cent (n=56) from organisations. | page 9: '1.3 Referring children and young people to the autism team'<br>yes, p15-16 on training - public & profs<br>page 20: 'Training - Most participants agreed that raising awareness among professionals and services would only happen with more and better training.' - some quotes in this section touched about diagnosis time<br>page 23: 'Diagnosis and Post-Diagnostic Support'<br>page 85-86: 'Engagement Events – Afternoon Sessions' - 'Diagnosis, post-diagnostic support and services'<br><br>**Model:** not the focus/not specified |
| Karim, et al., 2014 | UK | Diagnosing autistic spectrum disorder in the age of austerity | Professionals from UK services including NHS, a primary care provider, and two local education authorities in East Midlands.<br><br>Model: In this area there is no specialist ASD clinic so children are seen by clinical professionals and educational psychologists. | qualitative | explore how diagnosis is managed in the real world by professionals. | semi-structured interviews were thematically analysed. *Doesn't say when interviews were done but paper was accepted* ***May 2012*** *, so prob 2011…* | **26 interviews**: child and adolescent psychiatrists (7), community paediatricians (9) and educational psychologists (10)- number updated by the author. | While there is some consistency across and within these groups there are also a number of variances, and several important issues are highlighted. These include the problem of time and resources, the issue of location for diagnosis, the value of diagnostic tools and schedules, the need for supporting information, the difficulty of multi-agency working, the relevance of a physical examination and the eventual diagnostic label.<br>Theme 1: time & resources - lack of is major difficulty for clinicians<br>Theme 2: setting medical staff seeing children often in outpatient environments where educational psychologists tend utilize the school setting. Important to see children in different settings - emphasizes the importance of multi-agency working.<br>Theme 3: **diagnostic tools vs clinical judgement**<br>Theme 4: use of supporting information for diagnosis - some professionals undertook their own observations, others delegated. Not problematic in itself.<br>Theme 5: **multi-professional/multi-agency or individual diagnosis?**<br>Theme 6: variations in physical examination - educ psychologists don't do this at all - need to be consistent with guidelines. [*Reflects medical vs educ orientation and how different ASD diagnosis is to other conditions* ] |
| Potter, et al., 2017 | UK | I received a leaflet and that is all': Father experiences of a diagnosis of autism | NA | qualitative | This study investigated father perspectives on a diagnosis of autism | investigated father perspectives on a diagnosis of autism, through an online survey. | The sample completing the survey were 306 fathers of children up to 19 years of age, with a diagnosis of autism, autism spectrum disorder or Asperger's syndrome and resident in the UK. 184 fathers (60% of the total) responded to the open-ended question concerning perspectives on diagnosis. | Thematic analysis of 184 replies to an open-ended question identified the following themes: strong initial emotional response and a range of immediate anxieties about the future, struggle to gain a diagnosis; anger in response to insensitive delivery of diagnosis together with insufficient information at the time and lack of support afterwards.<br><br>**Model**: not stated, assume various |

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| Gregory, et al., 2013 | UK | The development of a Child and Adolescent Mental Health Service for children with disabilities: rationale for the approach, method and techniques | CAMHS-Borough of Kensington & Chelsea | NA | explores the rationale for the practice and explains three different elements – approach, method and technique | This second paper explores the rationale for the practice and explains three different elements – approach, method and technique | NA | Page 77: Given other local pathways for assessment and diagnosis, as a team we focus on parent/network concerns and intervention relating to these and tend to avoid further diagnostic assessments, redirecting this work if the question arises. When we meet with families we create a set of goals together about our work with them which we then regularly review and amend throughout our involvement. This explicitly sets out our work as being collaborative and allows us to be transparent about our model and our position alongside the family as a partner in the work<br>page 79: In our team, having an **explicit model*** which informs our approach helps us to be clear about what we are doing and how this might be helpful to families. Thinking about how our methods and techniques fit with the overarching principles of our approach means that we can operate in a coherent way, mindful of the ideas we privilege and how these influence how we engage with and support parents and families.<br>**Parent Adviser Model** emphasises that in order to help and support families parents' views must be heard, understood and prioritised. ***Not really relevant to ASD - should we have excluded?!*** |
| SIGN, 2016 | Scotland | Assessment, diagnosis and interventions for autism spectrum disorders | A national clinical guideline in Scotland - multidisciplinary assessment recommended | A national clinical guideline | It is hoped that this update will contribute further to a reduction in variation in practice and improve services for people of all ages with ASD. | NA | NA | page 20: '1.8 Communicating the results from the autism diagnostic assessment'<br>'Research evidence on **multidisciplinary compared to single assessment** is limited.' But recommends (**model**):<br>'The use of **different professional groups** in the assessment process is recommended as it may identify different aspects of ASD and aid accurate diagnosis.<br>A diagnostic assessment, alongside a **profile of the individual's strengths and weaknesses**, carried out by a **multidisciplinary** team which has the skills and experience to undertake the assessments, should be considered as the optimum approach for individuals suspected of having ASD.' |
| Crane, et al., 2016 | UK (all regions) | Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom | NA | Phase One of above research - national survey | parents' experiences and opinions regarding the process of attaining a diagnosis of autism spectrum disorder for their children. | online survey based on **6 key factors** predicted to affect overall satisfaction with the diagnositic process. A total of 559 services providing information, support or assistance to parents of children with ASD were identified via a directory of autism-related services provided by the National Autistic Society (UK) and asked to forward survey information to their members. Data collection Mar 2012-May 2013. | 1047 parents (93% female, 95% White) | parents usually waited a year from when they first had concerns about their child's development before they sought professional help. On average, there was a delay of around 3.5 years from the point at which parents first approached a health professional with their concerns to the confirmation of an autism spectrum disorder diagnosis. Just over half of the parents surveyed were dissatisfied with the diagnostic process as a whole. Several factors predicted parents' overall levels of satisfaction with the diagnostic process, including the time taken to receive a diagnosis, satisfaction with the information provided at diagnosis, the manner of the diagnosing professional, the stress associated with the diagnostic process and satisfaction with post-diagnostic support.<br><br>**Model**: various/not clear & not the focus |
| Gregory, et al., 2013 | UK | The development of a Child and Adolescent Mental Health Service specifically for children with disabilities: reflections on the first four years | CAMHS-Borough of Kensington & Chelsea | NA | Describes the referrals received, the strengths of having a specialist team, and the arguments for and against setting up a specialist CAMHS service. | The first paper gave details on the nature of the referrals received, the strengths of having a specialist team, and the arguments for and against setting up a specialist CAMHS service. | NA | Describes the service, its development, remit & partnership working with other agencies/organisations and parents/PPI. Divides problems into development issues, challenging behaviours & impact on the family.<br><br>**Model: a team who set up a CAMHS specifically for children with disabilities, including those on the autism spectrum.;** multi-disciplinary but *not* part of generic **CAMHS team;** 'positioned (physically and strategically) alongside the Children with Disabilities Social Services team, within the Local Authority' - some split posts which assisted training colleagues in other services. |
| NICE, 2014 | UK | **QS 51** Autism Quality standard | NA | This standard is based on CG128, CG142 and CG170. | This quality standard covers autism in children, young people and adults, including both health and social care services.<br>The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. | NA | NA | covers health and social care services for adults, young people and children with autism. It includes assessment/diagnosis, care and support for people diagnosed with ASDIt describes high-quality care in priority areas for improvement.<br>Page 11: 'Statement 1. People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started **within 3 months** of their referral.' 'Rationale - There are several different routes by which someone with possible autism can be referred to an autism team for a diagnostic assessment. It is important that the assessment is conducted as soon as possible so that appropriate health and social care interventions, advice and support can be offered.'<br>page 12: 'What the quality statement means for service providers, health and social care practitioners, and commissioners' & 'What the quality statement means for service users and carers'<br>page 14: definition of Diagnostic assessment<br>page 17: 'Statement 2. People having a diagnostic assessment for autism are **also assessed for coexisting physical health conditions and mental health problems.**' 'Rationale - People with autism may have coexisting physical health conditions and/or mental health problems that, if unrecognised and untreated, will further impair the person's psychosocial functioning and could place additional pressure on families and carers.<br>page 18 'What the quality statement means for service providers, health and social care practitioners, and commissioners' & ...'for service users and carers'<br>page 33 'Quality statement 7: Assessing possible triggers for behaviour that challenges' |

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| O'Reilly, 2017 | UK | How parents build a case for autism spectrum disorder during initial assessments: 'We're fighting a losing battle' | CAMHS | qualitative conversation analysis | examine relevant issues in relation to the practitioner–family interactions that take place within the initial assessment context. | Each initial appointment typically lasted approximately 90 minutes, generating a corpus of 42 hours of video-recordings. **Participating families were seen by a minimum of two mental health professionals** from a **range of professional groups,** including consultants, staff-grade and trainee child and adolescent psychiatrists, clinical psychologists, assistant psychologists, community psychiatric nurses (CPNs), learning disabilities nurses, occupational therapists, psychotherapists, medical students and student nurses. Conversation analysis (CA) of video-recorded discussions between diagnosticians and families during pre-diagnosis triage screening within CAMHS. | 28 opportunistically sampled families attending their first assessment | Our findings illustrated that parents typically first raised the possibility of the presence of ASD diagnosis through 'building a case', which professionals were then able to ratify or negate. Found that the assessments unfolded sequentially and clinical decisions were typically reached through a distinctive pattern of interaction.<br><br>**Model:** Not clear & is **CAMHS** specific |
| Abbott, et al., 2013 | England | Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences | Community CAMHS (mental health & learning disability), North East England | Qualitative | Explore parents' experiences of receiving the news that their child warrants a diagnosis of Autism Spectrum Disorder (ASD). | Qualitative methodology was used to explore the experiences of the 'feedback session' (confirming the diagnosis) with nine sets of parents. General indictuve approach to analysis. | nine sets of parents with children aged 8-15. | page 13: '1.5 Autism diagnostic assessment for children and young people' autism case coordinator<br><br>**Model**: Not clear & is CAMHS specific |
| Gray, et al., 2015 | UK | Variable implementation of good practice recommendations for the assessment and management of UK children with neurodisability | All teams used a combination of assessment methods, with all reporting some level of single multidisciplinary team (MDT) assessment, an individual professional assessment followed by an MDT meeting and/or an individual assessment without an MDT meeting. | national surveys | to determine whether UK **child development teams (CDTs)** have implemented good practice recommendations for the co-ordinated assessment and support of children with neurodisability and to explore some of the factors associated with variations in good practice implementation. | Surveys were sent to every UK CDT in 2009/2010. Responses about CDT provision and ways of working were compared with good practice recommendations from national policy documents and professional organizations. The extent to which CDTs in England and Wales met 11 selected good practice recommendations was scored; teams in Scotland and Northern Ireland were given a score out of 9 to reflect the optional use of the common assessment framework and early support materials in these countries. | 225/240 (94%) UK CDTs responded.<br>37% of CDTs in England and Wales had implemented 9 or more of the 11 recommendations. 59% of teams in Scotland and 78% of those in N. Ireland met between six and nine recommendations of good working practice. | There was considerable variability in the degree to which CDTs implemented good practice recommendations for the diagnosis and management of children with neurodisability. Evidence about child and parent satisfaction, and the effectiveness of CDT practices and provision, is required, so policymakers, healthcare commissioners and clinicians can provide the most appropriate services to children with neurodisability and their families.<br><br>**Model:** All teams used a combination of assessment methods, with all reporting some level of single **multidisciplinary** team (MDT) assessment, an **individual professional** assessment followed by an **MDT meeting** and/or an **individual assessment without an MDT meeting**. |
| Dowden, 2018 | UK | Improving the diagnosis of autism spectrum disorder | NA | Opinion piece | assesses the scale of the problem and discusses possible reasons and solutions. | NA | NA | Barriers to receiving diagnosis include: organisatational complexities; professioansl not referring early enough or to the correct service or not even recognising symptoms; lack of capacity in services; parents needing to be 'pushy' without causing hostility with professionals. |
| Reed & Osborne, 2012 | UK | Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders | NA | review/opinion piece | Sets out existing theoretical and empirical knowledge concerning parental functioning and their child's ASD, including parental experiences of ASD diagnoses; general health and psychological functioning of parents of newly-diagnosed children with ASD; aspects of the diagnostic process impacting on parental functioning; and the relationship of parental functioning to child outcomes. | NA | NA | Discusses stress levels of parents & effectiveness of Rx for child - not related to diagnostic pathway but suggests this could be underlying mechanisms for effective Rx. Links this to importance of parental support important - possible **mechanism** for providing a management plan that parents find helpful (understanding/feeling supported). Makes good point about importance of parental trianing programmes also offering opportunity for families to explore the impact of the diagnosis & coming to terms with ASD diagnosis (coded under 7e). Suggests that issues such as the speed of diagnosis, the chain and coherence of referral through the diagnostic system, the help offered at the time of diagnosis and the communication styles of the professionals, both with the parents and with each other, may all be seen to be important in increasing parental satisfaction and establishing best diagnostic practice. |

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| Unigwe, et al., 2017 | UK | GPs' confidence in caring for their patients on the autism spectrum: an online self-report study | GPs across the UK - sample size 304 | quantitative - online survey | To understand GPs' perceived self-efficacy in identifying and managing their patients on the autism spectrum, and the factors affecting this. | An online self-report survey was developed for completion by GPs across the UK. GPs identified via the Royal College of General Practitioners (RCGP) and internet snowballing methods through social media. The survey collected responses on participants' background, training, and experience, both as a GP and with regard to autism, and included a 22-item knowledge of autism questionnaire, a 14-item self-efficacy scale targeting GPs' perceived confidence in identifying and managing their autistic patients, and an open question eliciting participants' experiences of working with autistic people. Data analysis: descriptive; correlational & regression analyses; thematic anaysis of open replies. | 304 | In total, 39.5% (n = 120) of GP participants reported never having received formal training in autism. Few responders (28.0%, n = 85) reported referring to the diagnostic criteria for autism and even fewer (19.1%, n = 58) reported using any screening instruments. Despite demonstrating good knowledge of its key features, participants reported limited confidence in their abilities to identify and manage autistic patients, with many citing a number of barriers that overwhelmingly focused on perceived failings of the current healthcare system (such as a lack of clarity around referral pathways and long delays from referral to diagnosis) and lack of support post-diagnosis. This confidence was related to greater experience with autism, including personal connections & prior training in autism.<br>Recommends improved local specialist service provision alongside clearer referral pathways for diagnosis. |
| Carpenter, 2012 | UK | Diagnosis and assessment in autism spectrum disorders | NA | Literature review | provide an overview of the current situation with diagnosis and assessment in autism spectrum disorders (ASD). | a review of literature combined with personal observation of practice | NA | Diagnosis cannot be determined by any one tool. It is a clinical judgement. A solo experienced clinician can make a diagnosis. Wider assessment is needed post diagnosis and needs a team.<br>Specialist multidisciplinary teams to assess people with ASD should be set up for adults as well as for children.<br>talks about different interpretations of diagnosis, DSM4, ICD10 & 'new draft' DSM5 (came out 2016). |
| Autism ACHIEVE Alliance, 2014 | Scotland | ASD: Waiting for Assessment - Executive Summary | a broad range of autism services (for child/adult) across Scotland<br><br>The child sample comprised 50% CAMHS services, 37% Child Development Centres or equivalent, and 13% joint service with input from both CAMHS and Child Development. All child services were provided through multi-disciplinary teams. | quantitative descriptive & case note analysis & focus groups | The Autism ACHIEVE Alliance was asked to investigate waiting times in the diagnosis of Autism Spectrum Disorder (ASD), as per the Scottish Strategy for Autism Recommendation 21: 'It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings'. | A telephone survey was conducted and 457 calls were made across Scotland to ascertain which services conduct diagnostic assessment of individuals with ASD.<br>This telephone survey resulted in a list of 94[1] services which conduct diagnostic assessment with 68% (64/94) of these being child services and 32% (30/94) adult services.<br><br>a retrospective case note analysis of 150 individuals diagnosed with ASD by these services.<br><br>focus groups -We conducted focus groups with each of the diagnostic services to review their specific data, co-examine their wait issues and co-identify specific solutions. | a random sample was conducted and the sampled services (n=16) were then invited to participate. The child sample comprised 50% CAMHS services, 37% Child Development Centres or equivalent, and 13% joint service with input from both CAMHS and Child Development. All child services were provided through multi-disciplinary teams. | For the child cases, the average total wait for diagnosis from referral to receiving the diagnosis was 331 days; however there was a wide range (30-1942 days).<br>Of the child cases, 74% took longer than 119 days, which is the recommended maximum time from referral to sharing the diagnosis (National Autism Plan for Children, NAP-C, 2003).<br>Children had a statistically significant longer wait between referral and first appointment, and a longer overall wait between referral and receiving the diagnosis, compared to adults.<br><br>Page 3: 'How long is the wait for diagnosis?'<br>Page 5: 'What affects the length of the wait? - Statistical analysis of the 150 cases illustrated:<br>? In child cases, having more information about the child prior to diagnosis was associated with shorter assessment durations.<br>? Adherence to the evidence-based guidelines (SIGN/NICE) or to the Quality Diagnostic Standard (QDS 2006) does not have a detrimental effect on the total wait for diagnosis.<br>? This suggests that a good quality service, as indicated by higher adherence, does not have to have a cost in terms of increased waiting times.<br>Child and adult service focus group discussions suggested frequent reasons for delays included:<br>? less efficient working and communication ? high non-attendance rates ? inappropriate referrals ? ineffective care pathways.<br>page 5-6: 'Are standardised diagnostic assessments used?'<br>page 6: 'To what extent do services adhere to the Quality Diagnostic Standard?'<br>page 6-7: 'What can be done to reduce delays?' 'These key solutions were identified by services as follows:<br>? To develop efficient working and communication by:...? To reduce non-attendance rates by:...? To reduce inappropriate referrals by:...? To improve effectiveness of care pathways by: |

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| Reed, et al., 2016 | Swansea, UK | Impact of Diagnostic Practices on the Self-Reported Health of Mothers of Recently Diagnosed Children with ASD | NA | quantitative, cross-sectional | examined the impact of different aspects of the diagnosis process on the self-reported mental health of mothers of children undergoing a diagnosis for ASD in a cross-sectional cohort design. | One-hundred-fifty-eight mothers of consequently diagnosed children with ASD participated. The severity of the children's ASD and their intellectual functioning was assessed within twelve months of the diagnosis, and the mothers completed a psychometric assessment battery including the Hospital Anxiety and Depression Scale, General Health Questionnaire, and Questionnaire on Resources and Stress. | 158 mothers | The actual time from first reporting a problem to obtaining a diagnosis, and the **speed of the diagnostic process** from first to last appointment, were both ***negatively*** related to parenting **stress**. In contrast, mothers' **perceptions of the speed and helpfulness of the process were *negatively* related to levels of anxiety and depression**. The **number of professionals involved** in the process and the perceived coherence of the diagnosis were also negatively related to aspects of mothers' functioning.<br><br>*bottom p6- p7: The perceived **speed of the process** and its **perceived helpfulness** were independently significant predictors.... The perceived helpfulness and interpersonal skills of the professional were the only independently significant predictors.. think relates to HR-QoL (GHQ)*<br><br>*The only two reliable associations being negative ones between the child's age at diagnosis and the perceived speed of the process (the **older the child at diagnosis the worse was the perceived speed**), and the number of professionals involved and the coherence of the process ( **the more professionals the less coherent the process appeared to the mother**). However, none of the associations reported in Table 2 were particularly large,*<br><br>*These findings suggest that, while an early diagnosis might lead to quicker access to services and beneficial earlier treatment for the child [2], it may also leave mothers unable to develop coping mechanisms for living with this diagnosis [14].could be possible **mechanism** ?*<br><br>*It may be that initially more anxious mothers are more dissatisfied with the diagnostic process, or that some third factor causes both anxiety and a lack of satisfaction with the events connected to the diagnosis* |
| Tryfona, et al., 2016 | UK | M-Health Solutions to Support the National Health Service in the Diagnosis and Monitoring of Autism Spectrum Disorders in Young Children | NA | opinion piece | consider the potential for user-behaviour analysis software on tablet computers or smart phones, along with other m-health solutions, to provide a cost- effective opportunity for the NHS to support the diagnostic process and to assist in the ongoing monitoring and development of children with ASD. | review/ opinion piece | NA | Whilst there are m-health solutions emerging to assist in the diagnosis and ongoing monitoring of autism in young children, there are also limitations associated with these approaches. In order for these software products to support the NHS, it is vital that the user-requirements elicitation and modelling processes effectively capture the unique and evolving needs of the various professionals working within a dynamic organization such as the NHS. This will also ensure that software can evolve to reflect changes in our understanding of ASDs. M-health solutions, however, do present an interesting oppor- tunity for health care professionals to make observations of children between appoint- ment times and within their home environment or familiar education setting, thus potentially speeding up the diagnosis process. |
| Halpin, 2016 | UK | What do nurses think they are doing in pre-school autism assessment? | group of nurses in one NHS trust (not named) where the child health teams assess pre-school children for possible autism. | qualitative - critical reflective inquiry research method | Asked 'what do nurses identify as their particular professional contribution to the assessment of pre-school children for autism?' | Used written reflective accounts and the transcripts of one-to-one and group discussions about practice. Participants reflected on the nursing beliefs and values they hold in common, and on their actions in practice. | all six qualified nurses currently working in preschool autism assessment in one NHS trust. | The study found that the beliefs and values held by these nurses, and their intention to offer holistic nursing delivered through a professional relationship of care, correlated with the kind of care that parents have said families need, and make a unique contribution to team assessment. |
| BACCH, 2019 | UK | A workforce strategy for community paediatrics | Community Child Health - the discussions are on neurodevelopmental conditions & community paediatricians in general, so ASD focused session is limited, but include helpful info on CCH services. | report | BACCH has put together a suite of deliverable initiatives below to improve recruitment and retention in the subspecialty, building on strategies adopted by other Colleges and the experience or members and departments on what is likely to be most productive and realistic. | report | NA | page 5: BACCH/RCPCH survey (2) in 2016 showed considerable pressure on CCH services: For autism spectrum disorder (ASD), 42.5% of services have a waiting time over 18 weeks for a first appointment, and a referral to treatment (RTT) time of 35.5 weeks, breaching the 18-week Referral to Treatment (RTT) rule in countries where it applies.<br>page 7: Better access to CCH services will shorten time to diagnosis for key conditions including ASD, ADHD, learning disability and other complex neurodevelopmental conditions. Early diagnosis enables better understanding by schools and families of how to best support children to manage their condition and to achieve their potential in society.<br>page 10: Community paediatricians already work with multidisciplinary and multiagency teams. They have been at the forefront of introducing skill mix in CCH e.g. supporting primary care GPs and nurses to take over the delivery of child health surveillance and immunisation programmes and audiological scientists in children's hearing services.<br>page 14: Clinical skill mix - The Covering All Bases (CAB) report shows that skill mix is gradually developing in CCH (Fig 10). ... However, there are currently no recognised role definitions or training pathways for other practitioners to develop Advanced Practice in CCH. These would need to be developed if skill mix is to be introduced safely and effectively.<br>page 14: Administrative support - The CAB survey (2) indicated that only 1 in 3 services had access to electronic records at all times when seeing patients. Many services estimated that nearly 10% of all available doctor time was spent doing non-medical tasks such as filing, photocopying and arranging meetings – all tasks that could be done more cheaply and more effectively by proper administrative support.<br><br>mostly about recruitment & retention - coded a little under 1b. Timely referral & Ax as it's an explanation (=M) for why even if referral is fast, Ax won't be |

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| Williams, et al., 2018 | Northampton, UK | Forty years of referrals and outcomes to a UK Child Development Centre (CDC): Has demand plateaued? | CDC at Northampton General Hospital | reviewing medical notes - descriptive quantitative | To explore 40 years of CDC activity and outcomes at Northampton General Hospital 1974–2014. | The study comprises 3 data sets: a published report from 1974 to 1999, an internal audit from 2001 to 2004, and more recent data collected from 2005 to 2014. The medical notes of all children who were assessed by the CDC in 2014 were reviewed, along with referral data collected by the CDC manager from this year and the preceding 10 years. This was compared with data previously collected from 1974 to 1999. | From January 1, 1974 to December 31, 2014, 3,786 children were assessed. | Covering 1974–2014, we demonstrate a clear increase in the number of referrals together with an increasing demand for assessments for social interaction and behavioural difficulties. This reflects the increased awareness of these neurodevelopmental difficulties and the changing diagnostic criteria which will now more likely result in an ASD diagnosis than previously. Together, these two features are most likely to have considerable implications for service development within Child Development Centres (CDCs) and Child Development Teams (CDTs).<br><br>Like other CDCs, they have experienced a **decrease in the number of AHPs** providing input into the assessment process. |
| Galliver, et al., 2017 | UK | Cost of assessing a child for possible autism spectrum disorder? An observational study of current practice in child development centres in the UK | CDCs - Three CDCs regularly provided long-term follow-up care for families with a new diagnosis. Two reported continued involvement only for specific issues such as need for medication. Another unit commented on its provision of short-term follow-up but experiencing increasing pressure to halt longer term follow-up. All centres could access other agencies for postdiagnosis input, for example, Early Bird programme. | online questionnaire | explore the number of hours of professional time required to complete such an assessment based on current practice in secondary care child development centres across the UK, and from this we calculate the cost of assessment. | An online questionnaire was sent to 20 child development centres asking them to retrospectively record team members involved at each stage of assessment and time taken, including report writing and administration for a typical assessment. Costs were estimated based on the hourly rate for each team member, including salary, on-costs and trust overheads | 20 questionnaires sent to CDCs, 12 returned (all in England & representing 7% of CDCs in the UK). | 10 centres adopted a two-stage approach to assessment with an initial 'screening' clinic determining whether the child needed to proceed to full multidisciplinary assessment. Median professional time involved was 13 hours (IQR 9.6– 15.5 hours). This resulted in a median cost of £809 ($1213, based on conversion rate £1 equal to US$1.5 (November 2015)), (IQR £684–£925) ($1026–$1388))<br>This study confirms that **multidisciplinary diagnostic assessment** of a child with possible autism requires significant professional time, with staff costs of approximately £800 ($1200) per child. This does not include costs of intervention, parent psychological education, investigation and assessment and management of comorbidities. If growing waiting times for diagnostic assessment are to be avoided, funding for diagnostic services needs to reflect the human resources required and the resulting costs of that assessment.<br><br>This would suggest that carrying out a **multidisciplinary assessment is a good practice** and allowing allied health professionals to carry out parts of the assessment not requiring doctor's skills, for example, observational assessment using ADOS, could **save costs**. |
| McKenzie, et al., 2016 | Scotland | The relationship between waiting times and 'adherence' to the Scottish Intercollegiate Guidelines Network 98 guideline in autism spectrum disorder diagnostic services in Scotland | child ASD diagnostic services in Scotland - 8 sampled services | Retrospective, cross sectional case note analysis<br><br>the 80 case notes in both, and 8 child services but 16 above incl adults. | explore the extent to which the Scottish Intercollegiate Guidelines Network 98 guidelines on the assessment and diagnosis of autism spectrum disorder were adhered to in child autism spectrum disorder diagnostic services in Scotland and whether there was a significant relationship between routine practice which more closely reflected these recommendations (increased adherence) and increased waiting times | Used various directories to compile list of possible services; carried out a telephone survey ascertain which services conducted diagnostic assessment of individuals with ASD. This resulted in a list of **64 child services, of which 53 routinely assessed for ASD. Of the 53 services, 23 were CAMHS, 15 were CDCs or equivalent and 15 were specialist ASD or communication teams.**<br>The inclusion criteria for the case notes were that the individual concerned had received a diagnosis of ASD from the participating service and was one of the 10 most recent cases where the individual had received a diagnosis of ASD. A total of 80 case notes were obtained from **eight services**. | 80 case notes. | the assessment and diagnostic practices were consistent with the relevant Scottish Intercollegiate Guidelines Network guideline recommendations. Increased adherence to the 19 included recommendations was not significantly related to increased total waiting times, indicating that the Scottish Intercollegiate Guidelines Network 98 recommendations have generally been integrated into practice, without a resultant increase in patient waits. |
| McKenzie, et al., 2015 | Scotland | Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults | 16 diagnosing services across Scotland (eight adult and eight child ASD diagnostic services) | a cross-sectional, retrospective case note study of eight adult and eight child ASD diagnostic services. | To identify the main factors predicting delays in diagnosis for Autism Spectrum Disorder (ASD) at three stages in the diagnostic process: wait for first appointment; assessment duration, and total wait for diagnosis. | Data were gathered from 150 case notes (**80 child** and 70 adult cases) from 16 diagnosing services across Scotland. | 150 case notes (80 child and 70 adult cases) | Within children's services, increasing the **amount of relevant information available pre-assessment** is likely to reduce total duration of the assessment process by reducing number of contacts required.<br>The results of the present study would suggest 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**.<br>It is also important that relevant information, which is collected by **services which are not necessarily specialists in relation to the diagnosis of ASD**, for example **generic general psychiatric services**, is communicated in a timely way to specialist services. This will help to ensure that diagnosis is not delayed because the individual is seen by numerous professionals before being referred to diagnostic services. |

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| RCPCH (Royal College of Paediatrics and Child Health), 2017 | UK | invited reviews the first four years (2012-2016) | paediatrics in general (not Autism focused) | Review | to provide a `state of play` of the service together with recommendations for future service design, workforce planning and support to our members and paediatrics in general. | The RCPCH provides a unique review service by bringing together clinical and policy expertise to work with local teams to identify and resolve issues of concern. The service launched over four years ago and has undertaken over 60 acute, community, neonatal, emergency and individual reviews.<br>The scope of a review can range from examining an individual case or doctor`s practice, to a theme, pathway, service or network of services.<br>Review teams comprise, as a minimum, two paediatricians and a staff administrator; they have agreed terms of reference and reviews are conducted with tact, diplomacy and discretion. Two additional reviewers provide a quality assurance review of the draft report; the client has a chance to comment on the draft and is encouraged to share the final report as widely as possible. | Over 75 RCPCH members have been involved with reviews alongside lay representatives and nominees from other clinical disciplines. | Emerging themes from the reviews to date include tackling clinical resistance to change, the integration of primary and secondary pathways and problems with covering Tier 2 medical rotas. It is important that clinicians are fully involved in the development of new ways of working, they must be clear about the benefits for children, and they must have confidence in clinical leadership.<br>Most reviews have recommended greater engagement with children and young people, involving them and their families in the design and operational policies of paediatric services. The establishment and assurance of adequate networks to support arrangements for escalating the care of very sick children must be prioritised.<br><br>Most are about **paediatrics in general**. Key info re autism:<br>Page 16 : 4.4 Community Paediatrics 'The changes to the assessment of children with special educational needs were rolled out in September 2014 under the Children and Families Act, resulting in increasing numbers of referrals from parents and schools seeking an autism assessment to identify resources for educational support. Each clinical commissioning group (CCG) is required to identify a Designated Health Officer for special educational needs, usually a senior community paediatrician, to support the contribution to the Education, Health and Care Plans.<br>Child and adolescent mental health services are increasingly pressured and with tight contracts many services are handling referrals for emotional and behavioural concerns through a 'single point of access' and against clear referral thresholds. This can lead to accepting only children and young people with the most severe symptoms or clear mental health need, referring any with suspected attention deficit hyperactivity disorder (ADHD) or autism (ASD) back to an already stretched paediatric team for initial assessment.'<br>and following highlighted findings |
| Ford, et al., 2019 | England | The agreement between the referrer, practitioner and research diagnosis of autistic spectrum conditions among children attending CAMHS over 2yrs | agreement about diagnoses between the **referrer**, **CAMHS practitioner** and a **research diagnosis**, as well as the stability of the practitioner's diagnosis over time | quantitative, secondary analysis | explore the levels of agreement about the diagnoses of Autistic Spectrum Conditions between the referrer, CAMHS practitioner and a research diagnosis, as well as the stability of the practitioner's diagnosis over time | secondary analysis of data from 302 children attending two Children's Team (Tier 3/secondary care), which provided **multidisciplinary treatments** to children up to the age of 16 and the Early Interventions Team (Tier 2/primary care) | 302 children aged 5–11 years recruited from 861 consecutive referrals accepted on the CAMHS waiting lists during the recruitment period (2006 and 2008) | Child health mapping suggests that one in every ten children utilising CAMHS has an ASC.<br>Their findings suggest that where practitioners are confident that a child definitely does or does not have an ASC, there was considerable agreement between practitioner and research diagnoses and clinical diagnoses were stable over time. However, for some children, initial diagnostic uncertainty led to confusing and prolonged fluctuations in practitioner assessments that may have undermined both engagement and intervention. **The use of standardised assessments and observations** might be particularly helpful for these children and could be evaluated further.<br><br>In this study, once assessed by CAMHS, most children with ASC receive a diagnosis within the first six months, which approximates to The National Autism Plan for Children recommendation that time from referral to diagnosis should not exceed 17 weeks. It also runs counter to reports of long delays and multiple assessments reported by others . We do not, however, have details on when these families first sought advice or which services they may have been in contact with prior to the index presentation to CAMHS. |

**Supplementary Document 2.2 - Key papers from secondary searches**

| **Author (year)** | **Country** | **Title** | **Settings/service types** (e.g. ASD, ASD & CAMHS) **& service models** | **Study type** | **Aims** | **Method** | **Sample size** | **Summary of findings relevant to programme theory** |
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| Ahlers, K., et al., 2019 | US | A pilot project using pediatricians as initial diagnosticians in multidisciplinary autism evaluations for young children please can we stick to UK spelling? | The University Developmental Assessment Clinics (UDAC) used a multidisciplinary team for autism spectrum disorder (ASD) evaluations, including psychologists (3), general pediatricians (4), developmental pediatrician (1), speech and language pathologists (SLPs; 2), occupational therapists (OTs; 2), and an audiologist. The UDAC is a clinical program operated by the Division of General Pediatrics at the University of Utah. | quantitative | to examine the feasibility of an alternative diagnostic model and evaluate the differences in wait time (to diagnosis) and fees charged for families whose children were evaluated for ASD in each of the 2 models. | Data were gathered through record extraction (n = 244) and parent questionnaire (n = 57). Authors compared time to diagnosis, charges, and parent satisfaction between traditional and alternative models. Agreement between paediatrician and psychologist diagnoses was examined for a subset (n = 18). | record extraction (n = 244); parent questionnaire (n = 57); Agreement between paediatrician and psychologist diagnoses was examined for a subset (n = 18). | Efficient use of available clinicians with additional training in Level 2 autism screening resulted in improvements in time to diagnosis and reduced charges for families. Coordination of multidisciplinary teams makes this possible, with strategic sequencing of patients through workflow. Flexibility was key to not only allowing paediatricians to refer uncertain cases to psychology for diagnosis but also allowing for diagnosis by a paediatrician when symptomatic presentation clearly met diagnostic criteria. However, there were concerns that the abbreviated pathways could lead to issues of inequality, with families receiving different outputs depending on their route. |
| Department for Education and Department of Health and Social Care, 2015 | England | Special educational needs and disability code of practice: 0 to 25 years. | Services for children and young people who have special educational needs or are disabled | staturory guidance - Code of Practice | Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities | The Code of Practice is the product of extensive consultation, and draws on the experience of pathfinder local authorities which have been piloting new approaches with local communities. | NA | This Code of Practice provides statutory guidance on duties, policies and procedures relating to Part 3 of the Children and Families Act 2014 and associated regulations and applies to England. It relates to children and young people with special educational needs (SEN) and disabled children and young people.<br>The aim is to identify special educational needs and disabilities at the earliest point with support routinely put in place. Relevant to programme theory 6b, the role of the SENco (SEN Co-ordinator). |

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| Hayes, et al., 2018 | UK | Clinical practice guidelines for diagnosis of autism spectrum disorder in adults and children in the UK: a narrative review | ASD services | narrative review | to consider how the content of clinical practice guidelines shapes diagnoses of Autism Spectrum Disorder in the UK; and investigate where, within those guidelines, social factors and influences are considered. | searched multiple databases (NICE Evidence Base; TRIP; Social Policy and Practice; US National Guidelines Clearinghouse; HMIC; The Cochrane Library; Embase; Global health; Ovid; PsychARTICLES; PsychINFO) and relevant web sources (government, professional and regional NHS websites) for clinical practice guidelines.<br>extracted details of key diagnostic elements such as assessment process and diagnostic tools.<br>A qualitative narrative analysis was conducted to identify social factors and influences. | Twenty-one documents were found and analysed. | Guidelines varied in recommendations for use of diagnostic tools and assessment procedures. Although multidisciplinary assessment was identified as the 'ideal' assessment, some guidelines suggested in practice one experienced healthcare professional was sufficient. Social factors in operational, interactional and contextual areas added complexity to guidelines but there were few concrete recommendations as to how these factors should be operationalized for best diagnostic outcomes.<br><br>Relevant to PT6a in terms of context of assessements; while supporting MDT assessements, it is unclear how disagreement is resolved; there is a lot of variation between guidelines which can sew confusion; the role of clinical judgement. |
| Hennel, S., et al., 2016 | Australia | Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice. | Australian Paediatric Research Network - members paediatricians who saw children with ASD - diverse clinics | Survey- quant & qual questions | 1) compare parents' experience and preferences with paediatrician report of (i) diagnosis delivery and (ii) information given at diagnosis and<br>2) identify types and usefulness of resources accessed by families post-diagnosis. | The design used for the study are parent and paediatrician surveys. Participants are parents of children aged 1.5–18 years, diagnosed with autism between 01 January 2010 and 30 September 2012 and their paediatricians who are members of the Australian Paediatric Research Network. Study-designed quantitative and qualitative questions about diagnosis delivery and information given at diagnosis (written and spoken vs. neither) and parent perceived importance and harms of information accessed post-diagnosis. | Paediatricians (53/198 (27%)) identified 1127 eligible families, of whom 404 (36%) participated. | Parents want more information than can be conveyed in a single diagnostic consultation. Developing a tailored 'autism action plan' with written materials could improve parents' understanding of and satisfaction with children's autism diagnoses.<br>Relevant to PT4a in terms of practical suggestions: clinicians should (i) encourage a support person to be present; (ii) provide information about school support, tailored therapy plans and choosing effective therapies either at diagnosis or afterwards; (iii) refer families to allied health professionals; and (iv)encourage families to explore evidence-based websites In addition to face-to-face clinical consultations, parents find written in- formation useful, particularly for understanding the diagnosis and explaining it to friends and family. |
| Jordan, E., Farr, W. & Male, I., 2017 | UK | Pirate adventure assessment software: a new tool to aid clinical assessment of children with possible autism. | UK based Child Development Centres | pilot - software in clinical assessment of children with possible autism | presents a computer based tool, developed by the research team, which early clinical experience suggests could provide additional information to the initial assessment. | The Pirate Adventure Autism Assessment software includes a number of psychometric tests adapted into a pirate adventure storyline.<br><br>The app has been piloted by paediatric consultants working in three local Child Development Centres, two at initial appointment, in one at a diagnostic clinic. | NA | Early experience, presented here, suggests the tool is a useful adjunct to parental history and school questionnaire obtained at initial clinic, in determining the need for the child to proceed to a full, time consuming, expensive, diagnostic assessment. |
| Juárez, et al., 2018 | US | Early identification of ASD through telemedicine: potential value for underserved populations. | Study 1: a diagnostic clinic at a university-affiliated medical centre due to early concerns about ASD.<br><br>Study 2: a regional health center serving a rural 23 county region, geographically distant from the urban diagnostic centers of our state. | Accuracy; Feasibility & acceptability | evaluate a telemedicine assessment procedure | 1) compared telediagnostic accuracy to blinded gold-standard evaluations (n = 20).<br>2) evaluated telediagnostic feasibility and acceptability in a rural catchment.<br>Children (n = 45) and caregivers completed the telemedicine procedure and provided feedback. | Study 1: Participants were 20 children (16 boys, 4 girls) between 20 and 34 months of age (mean = 26.65, SD = 4.49) and their caregivers.<br>Study 2: Participants were 45 children (mean age = 26.80 months, SD = 3.12, range 19–32; 35 boys, 10 girls) and their caregivers | Findings support preliminary feasibility, accuracy, and clinical utility of telemedicine-based assessment of ASD for young children. ASD cases identified via telemedicine were confirmed by in-person evaluation. However, 20% of children diagnosed with ASD in-person were not diagnosed via telemedicine.<br>Families indicated high levels of satisfaction. Remote diagnostic clinicians diagnosed 62% of children with ASD, but did not feel capable of ruling-in or out ASD in 13% of cases.<br>This pilot work demonstrated that a large percentage of children with ASD may be accurately diagnosed via remote observation of standardized assessment procedures, and many families and providers ascribe clinical value to the procedure. |

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| Male, Farr & Reddy, 2020 | UK | Should clinical services for children with possible ADHD, autism or related conditions be delivered in an integrated neurodevelopmental pathway? | two CDTs:<br>1- based in a large mixed urban–rural county, where there are three provider trusts, four CDTs and four CAMHS teams. While a newly commissioned, joint CAMHS/CDT complex cases clinic pilot is about to start, to assess children with diagnostic complexity, current commissioning and practice requires children with possible autism up to age 11 to be seen within CDTs, while children with possible ADHD and older children with possible autism are the remit of CAMHS.<br>2- a fully integrated CDT/CAMHS service, colocated in a single building, in a city organised as a unitary authority, facilitating close working between health, education, social care and child and family support services. | Viewpoint paper | We present the journeys of a typical primary school-aged child referred with a history suggestive of either autism and/or ADHD and the pathways they would follow in each service. This illustrates how the integrated and non-integrated approaches can affect the professional time involved, the resulting NHS costs and the patient journey. | Scenario<br>1) Diagnostic pathway experienced in the non-integrated approach;<br>2) Diagnostic pathway experienced in the integrated approach | NA | It's often a very inefficient and, for the parents, frustrating journey to a diagnostic conclusion for their child presenting with a mixture of difficulties in social communication, concentration and hyperactivity. Commissioning of separate autism and ADHD pathways, one with the CDT and the other with CAMHS, resulted in the child having to go through both pathways despite considerable overlap of assessment. The integrated approach, by running a single assessment process, cutting out this overlap, required less professional time (13 vs 20.75 hours), at a lower cost (£817 vs £1357), and reduced the time taken to reach a completed diagnostic formulation. Furthermore, the additional time and cost taken reduced the capacity of the first service to meet wider demand for assessment.<br><br>Why integrated pathways are still a novelty at secondary care level in neurodevelopmental services: CAMHS and CDTs often sit in different health trusts, who have been commissioned to deliver specific pathways; the separation of autism and ADHD in previous diagnostic coding systems; the current financial pressures on all NHS trusts.<br><br>moves toward running integrated CDT/ CAMHS services for children with potential neurodevelopmental and/or mental health conditions have the potential to improve efficiency of service delivery. |
| NHS Education for Scotland, 2014 | Scotland | The NHS Education for Scotland Autism Training Framework - Optimising Outcomes - A framework for all staff working with people with Autism Spectrum Disorders, their families and carers | various health and social care settings | Training Framework | The framework is not prescriptive, but its clarity and breadth of scope should facilitate individual employees, service providers and organisations to understand the knowledge and skills required and how this applies to their practice. | the framework developed was informed by:<br>-review of existing training frameworks (MacKay and Dunlop, 2004)<br>-evidence and best practice guidelines<br>-engagement with the autism community regarding experiences of contact with services<br>-Learning Needs Analysis amongst NHS staff<br>- Review of existing education and training in autism spectrum disorders<br>- consultation with professional bodies, thrid sector orgs and educational institutions<br>-consultation iwth the subgroups of the Scottish Strategy for Autism | NA | The NES Autism Training Framework has identified four Levels of Knowledge and Skills required, dpeending on the nature, extent and likely impact of contact during day-to-day work in the particular service, rather than defining levels specific to profession or position in a service. The Four levels: 1. Autism Informed Practice Level- for all professionals working with Autism in health and social care settings; 2. Autism Skilled Practice level- for all staff with direct and/or frequent contact with individuals with Autism or those who have a role with high impact on these individuals; 3. Autism enhanced Practice Level- for professionals with more regular or intense contact with individuals with Autism where their role focuses specifically on the condition and providing interventions, or service managers; 4. Expertise in autism Practice Level – for professionals who have a specialist role in the care, management and support of people with Autism.<br><br>. |
| RASDN, 2011 | Northern Ireland | Six Steps of Autism Care - for Children and Young People in Northern Ireland | various community settings, including GP, Autism services, social care & voluntary organisations | leaflet to parents/carers | to provide parents/carers with information about the new regional 'Six Steps of Autism Care' Pathway for children and young people in Northern Ireland. | NA | NA | This leaflet tells parents about the agreed journey child/ young person, and parents, will take through the integrated assessment, diagnosis and intervention process. It gives information about each step in the process about who will see the child/young person; which tests will take place; tell parents whether their child/young person has ASD, or not, and the follow up support that will be made available to the child/young person and family, with the following 6 steps (Page 4 flow diagram): 1. First appointment; 2. Integrated Multi-disciplinary Team Assessment; 3. Integrated Multi-disciplinary Team Formulation; 4. Family Feedback and Care Planning; 5. Integrated Family Intervention and Support Services Delivered Over Pre-Planned Sessions; and 6. Child and Family Care Plan Review at Regular Intervals. |

**Supplementary Document 3.** Programme theories with CMO configurations

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| **Programme theory 1 – Listening and recognition**<br><br>If frontline health and education professionals (e.g. GPs, teachers) are confident in recognising the signs and symptoms of autism, are cognisant of referral pathways and take parents/carers' concerns seriously then CYP will be referred to the appropriate service, in a timely manner, reducing parental frustration. | | |
| 1a. Parents/carers concerns are listened to and discussed | If frontline health and education professionals (e.g. GPs, teachers) take parents' concerns seriously (M), discuss and explain developmental behavioural concerns sensitively (M) and agree any actions to follow (M), then they will refer in a more timely manner (O) and parents will feel reassured with stress levels reduced (O).<br><br>Also, if professionals at nurseries and schools (teacher or others) make a difference in "pushing" for a diagnosis or a specific form of support (M), then this will lead to timelier referral (O) and improve parental satisfaction (O) with the referral pathway.<br><br>However, mis-diagnosis can be detrimental (C), so while parents should request referral for possible autism diagnosis (M) this has to be balanced against respecting professional expertise and enabling the development of a co-operative relationship (O). | NICE, 2011; Abbott, et al., 2013; The Scottish Government, 2014; Rogers, et al., 2016; O'Reilly, et al., 2017; Unigwe, et al., 2017; Crane, et al., 2018; Dowden, 2018; Rutherford, et al., 2018; Hurt, et al., 2019. |
| 1b. Frontline health and education professionals are cognisant of autism and referral pathways | If frontline health and education professionals (e.g., GPs, teachers) are trained in recognising the signs & symptoms of autism and referral routes (M), then their ability, confidence and skills in identifying children or young people (CYP) who need an autism diagnostic assessment will improve (O) and they will refer to the 'right' service in a timely manner (O).<br><br>If proportionately fewer CYP go through the full process (M) then accessibility of services will increase (O), and the risk of unnecessarily raising parental concern over autism when it is not present will reduce (O).<br><br>However, it is important to sensitively manage (M) a balance between supporting parents to accurately identify autism as early as possible, and not causing unnecessary concern amongst those who do not meet criteria for autism but may show some isolated Autistic-like features (O). | NICE, 2011; Reed and Osborne, 2012; Abbott, et al., 2013; The Scottish Government, 2014; Crane, et al., 2016; O'Reilly, et al., 2017; RCPCH, 2017; Potter, 2017; Dowden, 2018; Hurt, et al., 2019; Ford, et al., 2019. |
| **Programme theory 2 - Referral and triaging** | | |

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| If autism diagnostic services provide clear guidelines for referrers on what information is needed and how to refer, then time will be saved at the triaging stage and fewer CYP who do not have autism will go through the full process. | | |
| 2a. Referral process | Referrals often lack relevant information; this adds to waiting lists and clinician time, as they gather appropriate additional information, delaying the diagnostic process (C).<br><br>If referral is via a single point of access (for all neuro-developmental conditions and incorporating mental health expertise) (M) and referrers are provided with a systematic method of gathering relevant information from home and other settings preassessment (M) (e.g. proforma or digital assessment dashboard) and guidelines on how to do so (M), then referrers will know what information to gather, how to refer and what to expect following referral (O).<br><br>When referrals are declined, the referrer should be provided with an explanation (M), advice for improving the referral (M) and/or other appropriate services to refer to. Collectively, these measures will contribute to reducing the waiting list and low diagnostic yield (low numbers of positive diagnoses) (O). | NICE, 2011; Carpenter, 2012; The Scottish Government, 2014; MacKenzie, et al., 2015; Healthcare Improvement Scotland, 2016; Rutherford, et al., 2016; Rutherford, et al., 2018; Autistica, 2019; Tollerfield and Pearce, 2020. |
| 2b. Triage | Services that triage referrals depend on having the necessary information (C). Cross-organisational triaging (e.g. monthly meetings with a representative from CAMHS, CCH and SLT), while time intensive, has several benefits including improved joint working (M response); a forum to discuss complex cases (M); improved compliance with the care pathway (O); only referrals with adequate information are accepted and therefore clinicians will use their time well (O); and this avoids referrals bouncing between agencies (O).<br><br>Other approaches to triaging include an initial interview with an experienced clinician (M) who feels confident to identify CYP who clearly do, or do not, have autism; a community paediatrician carrying out a General Developmental Assessment/'Stage 1' Assessment, before referring to the MDT for further assessment, if needed (M).<br><br>Although triaging and referral management requires very clear guidance and training for staff (M) it results in proportionately fewer CYP going through the full process who do not have autism (O) which reduces the risk of unnecessarily raising parental concern over autism when it is not present (O). | NICE, 2011; The Scottish Government, 2014; MacKenzie, et al., 2015; Healthcare Improvement Scotland, 2016; Rutherford, et al., 2016; Rutherford, et al., 2018; Hurt, et al., 2019; Tollerfield and Pearce, 2020. |

| **Programme theory 3 - Diagnostic assessment**<br><br>There is wide variation in the model for autism diagnostic services and national staff shortages but these can be addressed with a structured and consistent approach, making best use of available staff and clinical expertise. | | |
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| 3a. Model & skills mix | Current services have different condition-specific remits and models (e.g. Autism only, all neuro-developmental conditions, and/or integrated with CAMHS), catchment areas and commissioning agreements which raises challenges around capacity, care pathways and funding (C). Streamlining (M) the autism diagnostic pathway requires a structured and consistent approach (M) so that the number of assessments per individual are minimised, alongside developing efficient working and communication (e.g. shared proformas for report writing; on-line reports) (M), thereby saving resources (O) and reducing waiting lists.<br><br>There is very little evidence to guide optimal service configuration (C) and the skills mix of diagnostic teams often relates to funding streams and the development of services over time (M). Core multi-disciplinary diagnostic teams are advisable (M) but there are national shortages of suitably trained professions including paediatricians and child psychiatrists who are the costliest members of the team (C).<br><br>However, the role of professions that are available locally (e.g. SALT) can be extended by training them to carry out aspects of the assessment not requiring medical expertise (e.g. observational assessment) (M) which will reduce costs (O). Similarly, incorporating questions previously undertaken by psychiatrists into the parent interview (M) will free up time for psychiatrists to focus on complex diagnoses (O).<br><br>Planning resources to meet need requires services to review their service configuration and skill mix (M) to accommodate demand within the available resources (O). Also recommended is ensuring that a core group of staff have dedicated autism time (M) and have shared skills for core aspects of autism assessment (M) to avoid overdependence on one clinician.<br><br>However, disadvantages of MDT diagnostic assessment are that it takes longer and different professions may disagree (C). To reduce this added stress on families, professionals sometimes make their diagnosis independently (O). | NICE, 2014; Karim, et al., 2014; Gray, et al., 2015; Halpin, 2016; Healthcare Improvement Scotland, 2016; MacKenzie, et al., 2016; Rogers, et al., 2016; Galliver, et al., 2017; Rutherford, et al., 2018. Ahlers, et al., 2019; Autistica, 2019; Tollerfield and Pearce, 2020. |

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| | Some CYP referred for autism diagnosis may require mental health expertise and when unavailable, have to return to the waiting list for CAMHS (C). If the same Trust manages both community paediatrics and mental health services (M), this potentially allows for a seamless transition, avoids duplicate waits and enables families to see all relevant professionals at the same time (O). | |
| 3b. Clinical judgement | Diagnosis should involve interview, observation and recognised tools (C). Less experienced clinicians appear to prefer using formal extended tools compared to their more experienced counterparts (C). However, standardised tests lack subtlety and children may not meet cut-offs (e.g. atypical presentations) to receive a positive diagnosis. Clinicians often use their clinical judgement (M) to 'upgrade' the diagnosis so that the child is entitled to support (O).<br><br>Many psychiatrists and paediatricians rely on the reports and observations of other professionals to inform their decisions while some, particularly educational psychologists, prefer to carry out their own observations within educational or home settings (C). This is valuable but time consuming; one solution (O) may be for professionals to only do observational assessment (M) if there are discrepancies between school and home reports.<br><br>It is not always possible to provide a child with an accurate diagnosis at an early stage (C). Diagnostic uncertainty can lead to confusing and prolonged assessments (M) that may undermine both engagement and intervention (O). Therefore, reassessment after a specified timeframe (M) is necessary and the use of standardised assessments and observations (M) might be particularly helpful to aid diagnosis (O). | Carpenter, 2012; Karim, et al., 2014; Crane, et al., 2016; Rogers, et al., 2016; Rutherford, et al., 2016; Healthcare Improvement Scotland, 2016; Ford, et al., 2019. |
| 3c. Digital technology | Children with autism sometimes feel an affinity for computing technology (C), as it is may be seen as a safe environment (M) to learn and practice skills that may be difficult in everyday life. The use of such technology in autism diagnosis is at an early stage (C) but shows potential, for example, using tablets/computers at school to collect observational data in a natural setting (M). If clinicians are able to access observations in advance (M), this would supplement other sources of data (O), save clinical time (O) and contribute to faster diagnosis (O). Telemedicine for autism screening &/or diagnosis is in the early stages of development (C) but shows some promise identifying individuals for further assessment (O) and early data suggest may be feasible and acceptable to parents and children (M). | Tryfona, et al., 2016; Jordan, et al., 2017; Juárez, et al., 2018. |

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| **Programme theory 4 – Diagnostic feedback**<br><br>If parents understand the diagnostic process and feel supported this can moderate parental expectations. Feedback should take an assets-based approach and the management plan should be individualised, taking account of co-existing conditions. Reports should be timely and in a format that everyone finds helpful. | | |
| 4a. Diagnostic feedback to parents and CYP | Parents can find the diagnostic process stressful, and may fear the stigma attached to diagnosis, but anticipate that a positive diagnosis will act as a gateway to individualised information, advice, support, services and/or treatment (C).<br><br>Receiving the diagnosis can affect parents' ability to absorb information but irrespective of the format (e.g. single professional or multi-disciplinary) (C) parents value: feedback that focuses on their child's strengths (asset based approach) (M) as this enables them to understand their child's needs (M), communicate these needs to others (O) and identify services to meet them (O); a structured and focused approach and the opportunity to ask questions (M); being put at their ease, listened to and given time to absorb information (M); and a positive and open parent-clinician relationship, established during the assessment process (M).<br><br>Parental satisfaction is further enhanced (O) when the diagnosis results in an individualised management plan that identifies co-existing conditions (M); support post-diagnosis is co-ordinated and tailored to need (M); and appropriate services are available (M).<br><br>Unintended consequences (O) include no autism or neurodevelopmental diagnosis which means parents may not be entitled to access condition specific services. Some CYP do not identify any benefits to diagnosis and fear being singled out as 'not normal' and subsequently stigmatised (O). | NICE 2011; NICE 2014, RASDN, 2011; Calzada, et al., 2012; Carpenter, 2012; Reed and Osborne 2012; Abbott, et al., 2013; Karim, et al., 2014; The Scottish Government, 2014; Halpin, 2016; Healthcare Improvement Scotland, 2016; Hennel, et al., 2016; Reed, et al., 2016; Rogers, et al., 2016; Crane, et al., 2018; The Scottish Government, 2018; Autistica, 2019; Hurt, et al., 2019; |
| 4b. Report format | A standardised template for report writing, using consistent terminology, visual tools, enabled professionals to collate reports in a timelier manner and in a format that all found helpful. | MacKenzie, et al., 2016; Tollerfield & Pearce, 2020. |
| **Programme theory 5 - Working in partnership with families**<br><br>Parents find the diagnostic pathway stressful so find it helpful to have a single point of contact; to be provided with explanations about the process; and to be included in decision-making. | | |

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| 5a. Parent/carer as co-experts in the diagnostic process | Contributing to the patient-professional tension is a debate around who is the expert (C). Parents expect to be listened to during the diagnostic process and their concerns taken seriously because they 'know' their child (C); if they feel belittled and/or do not understand the process or terminology (Ms), they will disengage from the process (M) and/or resist alternative diagnosis (O) which will have a detrimental impact on the parent-professional relationship (O). Professionals need to explain the diagnostic pathway and acknowledge that it is enhanced (O) when expertise is integrated with the perspectives of the individual and their family (M). Parents want to have a transparent and honest dialogue with professionals (M) and be involved in key decision-making (O). | Gregory, et al., 2013b; Rogers, 2016; Healthcare Improvement Scotland, 2016; Crane, et al., 2018. |
| 5b. Supporting parents/carers | Some parents perceive the system as poorly co-ordinated and feel it necessary to take charge of organising diagnostic and support processes. However, a consistent point of contact within the system would provide emotional support and enable parents to be kept up-to-date (O). When professionals explain the diagnostic process in advance and how long it will take (M), this improves parental satisfaction and can moderate expectations (O).<br><br>Non-attendance at appointments is frequent (C) and services need to have systems in place to reduce it, for example using reminders, opt-in systems and a support contact to facilitate attendance (M). By increasing attendance levels, this will reduce service costs and waiting times (O).<br><br>When contact with professionals during diagnosis has been perceived by parents as unsatisfactory, this may lead to subsequent treatments undertaken by the child being less effective than they otherwise might have been (C). Satisfaction can be improved by managing the process in a thoughtful and sensitive manner (M); clearly explaining the diagnosis (M); and demonstrating a high degree of knowledge and empathy (M). Also, if some professionals (e.g. nurses) provide advocacy for parents' views during assessment (M) and well-organised parent/carer groups are established (M), parents' concerns are more likely to be heard and parents will be empowered to speak up for themselves (O). | Calzada, et al., 2012; Abbott, et al., 2013; Gregory, et al., 2013b; NICE, 2014. |
| **Programme theory 6 - Inter-agency working**<br><br>If "experts" including people with autism, carers, professionals and specialist organisations work in partnership and the knowledge generated is effectively embedded into local services, this will build capacity, improve parent/CYP satisfaction and support planning of services both locally and nationally. | | |

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| 6a. Macro-Meso level | A multi-disciplinary, inter-agency and holistic approach is essential (M) given the subjective nature of diagnosis and the significant differences in presentation of CYP with autism (C). However, there are multiple barriers to inter-agency working at all levels, particularly a hierarchical relationship between education and health (C), with education practitioners delivering daily interventions but having to rely on healthcare professionals to issue diagnoses to release additional funding or support.<br><br>Macro-level approaches to ameliorate these barriers include: setting up a national 'whole life' autism strategy that co-ordinates multi-agency planning (M); a national approach to support school pupils with autism (M); clear standards of training and expertise (M) for all service providers offering services for those with autism, and access to specialist training; positioning (strategically and/or physically) autism services alongside other CYP's services (M), as this enables the development of a shared understanding which promotes effective joint-working (O) and is particularly useful where CYP are at risk; a more integrated care pathway with additional ringfenced funding (M).<br><br>If teams are supported to structure and deliver services in a flexible, creative, 'can do' approach at all levels from the clinician working on a day-to-day basis, to cross agency working, up through middle and senior management (M), then the experience of parents, children, clinicians and referrers would be improved (O).<br><br>If partnership working across organisations develops and consolidates a combined skill set (M), has mechanisms in place to share information (M) and holds regular networking and multi-agency professional meetings (M), then this will support the development of a shared understanding of CYP, their support needs and those of their parents (e.g. negotiating with the wider system) (O). | NICE, 2011; Gregory, et al., 2013a; Karim, et al., 2014; NICE, 2014; The Scottish Government, 2014; Gray, et al., 2015; Healthcare Improvement Scotland, 2016; Rogers, et al., 2016; Galliver, et al., 2017; Hayes, et al., 2018; The Scottish Government, 2018; Williams, et al., 2018; Hurt, et al., 2019; Tollerfield and Pearce, 2020. |
| 6b. Micro level | Multi-agency working (M) is designed to minimise variations and enhance the engagement of all services (C). Improved co-ordination between health, education and local authorities (M), at the level of individual diagnostic assessment would help reduce the time taken from referral to diagnosis, improve parental perceptions of support following diagnosis (O) and, with clear documentation (M), improve information flow between involved parties (O). | NICE, 2011; Calzada, et al., 2012; Gregory, et al., 2013b; The Scottish Government, 2014; Tollerfield and Pearce, 2020. |

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| | Opportunities to enhance multi-agency working include a "one stop shop" coordinator for children with ASD (M) and split posts for staff which can act as bridges between different parts of the system or different organisations (M), aiding understanding and communication (O). One opportunity to build links with relevant (voluntary) organisations (O) is to rent space, such as a community clinic, to carry out ASD assessments (M) but it needs to be an environment suited to the needs of children with ASD. However, when CDTs are based in a dedicated CDC (M), they are more likely to have implemented good practice recommendations including recommended team working and family communication standards (O).<br><br>If ASD diagnostic services establish clear pathways, including detailed data on the use of time and tools at each stage of the process (M), this will improve effectiveness in assessing, diagnosing and supporting children with autism (O). | |
| **Programme theory 7 – Training, service development and evaluation**<br><br>Based on their needs, skills and knowledge for autism diagnostic assessments and working with families, health and community professionals should have access to tailored training, service development and service evaluation. | | |
| 7a. Training for professionals working with CYP in community settings | Training in many organisations is "ad hoc", varies widely and may have low priority given financial constraints (C); multi-agency training is limited (C). Clinicians working with CYP with developmental delay, speech, language and communication impairments and mental health difficulties will come into regular contact with children with autism, as will frontline staff in generic children's services (e.g. nurseries) (C). If multi-agency training for professionals is provided (M), with a targeted and coordinated approach across organisations (M), a wide breadth of coverage of basic training can be achieved (M) and awareness and training geared to the needs of managers as well as front-line staff (M). This will increase the local skill set of people who regularly work with children who may have autism (O).<br><br>Another approach is to develop a detailed framework, mapping staff skills and knowledge for autism diagnostic assessment at different levels (informed, skilled, enhanced and expert practice levels) (M). The levels of skill required by different staff depend on the nature, extent and likely impact of daily contact with individuals with autism (M), rather than defining levels specific to profession or position in a service. The framework can be used by individuals, organisations or training providers to identify current or future training needs at different levels (O). | NICE, 2011; Gregory, et al., 2013a; NHS Education for Scotland, 2014; The Scottish Government, 2014; Rutherford, et al., 2016; Rutherford, et al., 2018; The Scottish Government, 2018. |

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| 7b. Training for health professionals working in autism services | Training budgets have been reduced (C). If professionals working in autism services are provided with crucial supports, including backing for training, funding for a specialist library and practical resources (M) as well as access to supervision, links with other experienced professionals, and an open team culture of sharing ideas (M), then they will be able to work with CYP in the most skilled and effective way (O). As above, training programmes need to be tailored to the level of competencies required (i.e. enhanced and expert practice levels) (M). Training activities could include observing in a (tertiary) autism clinic (M) to develop skills and confidence (O); 'buddy up' with more experienced staff (M); regular Continuing Professional Development sessions for the team to review training needs (M); developing an explicit plan for succession planning and training needs (M); and a national forum to share experiences and knowledge, including people with autism and their families (M). As more staff become better trained in, for example, the use of standardised autism assessment tools (O), there will be a higher degree of consistency between local and specialist teams (O). | Gregory, et al., 2013a; Autism ACHIEVE Alliance, 2014; Rutherford, et al., 2016; Rutherford, et al., 2018. |
| 7c. Service development & evaluation | Structural and organisational barriers impact on the effectiveness of the autism pathway (C) and as services have become increasingly overburdened, clinicians have little time to engage with service evaluation and development (C). If services plan resources to meet need, based on audit data, for example reviewing service configuration and skill mix to accommodate demand (M) and make efficient use of administrative support to free up the diagnostic team (M), then time allocation and quality of autism services will be protected within resources and available capacity (O).<br><br>Services should maintain or develop efficient systems of collecting information about referrals, waiting times and outcomes, for example using a guidelines checklist at the front of each patient file (M); data can be collated (M) for senior managers and commissioners to evidence shortcomings in staffing and resources (O).<br><br>Suggestions to help promote service development and embed changes into practice (O) include having one person to lead/champion change (M); generating research within clinical teams (M); encouraging practitioners to co-create contextually sensitive solutions (M) in a cyclical process of service evaluation and development; and drawing on 'experts' within the field, including people with autism, carers and specialist organisations who could support local service development if identified and connected into the process (M). | The Scottish Government, 2014; Rutherford, et al., 2016; RCPCH, 2017. |

**Checklist: List of items to be included when reporting a realist synthesis**
**From Wong et al. BMC Medicine 2013, RAMESES publication standards: realist syntheses11:21**
**http://www.biomedcentral.com/1741-7015/11/21**
**Page 4 of 14**

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| **TITLE** | | |
| 1 | In the title, identify the document as a realist synthesis or review | ✓ |
| **ABSTRACT** | | |
| 2 | While acknowledging publication requirements and house style, abstracts should ideally contain brief details of: the study's background, review question or objectives; search strategy; methods of selection, appraisal, analysis and synthesis of sources; main results; and implications for practice. | ✓ |
| **INTRODUCTION** | | |
| 3 | Rationale for review. Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area. | ✓ |
| 4 | Objectives and focus of review. State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review. | ✓ |
| **METHODS** | | |
| 5 | Changes in the review process. Any changes made to the review process that was initially planned should be briefly described and justified. | No changes necessary |
| 6 | Rationale for using realist synthesis. Explain why realist synthesis was considered the most appropriate method to use. | ✓ |
| 7 | Scoping the literature. Describe and justify the initial process of exploratory scoping of the literature. | ✓ |
| 8 | Searching processes. While considering specific requirements of the journal or other publication outlet, state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include, for example, name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected. | ✓ |
| 9 | Selection and appraisal of documents. Explain how judgements were made about including and excluding data from documents, and justify these. | ✓ |
| 10 | Data extraction. Describe and explain which data or information were extracted from the included documents and justify this selection. | ✓ |
| 11 | Analysis and synthesis processes. Describe the analysis and synthesis processes in detail. This section should include information on the constructs analyzed and describe the analytic process. | ✓ |
| **RESULTS** | | |
| 12 | Document flow diagram. Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example, from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification to suit the data) that are provided. | ✓ |

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| 13 | Document characteristics. Provide information on the characteristics of the documents included in the review. | ✓ |
| 14 | Main findings. Present the key findings with a specific focus on theory building and testing. | ✓ |
| **DISCUSSION** | | |
| 15 | Summary of findings. Summarize the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s). | ✓ |
| 16 | Strengths, limitations and future research directions. Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed. | ✓ |
| 17 | Comparison with existing literature. Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic. | ✓ |
| 18 | Conclusion and recommendations. List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice. | ✓ |
| 19 | Funding. Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers. | ✓ |

BMJ Open

# A Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD): Which diagnostic pathways work best, for whom and in what context? Findings from a rapid realist review.



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# A Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD): Which diagnostic pathways work best, for whom and in what context? Findings from a rapid realist review.

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# Abstract

**Objectives**

Waiting times in the UK for an autism diagnostic assessment have increased rapidly in the last five years. This review explored research (including 'grey' literature) to uncover the current evidence base about autism diagnostic pathways and what works best, for whom and in what circumstances, to deliver high quality and timely diagnosis.

**Design**

We performed a Rapid Realist Review (RRR) consistent with recognised standards for realist syntheses. We collected 129 grey literature and policy/guidelines and 220 articles from seven databases (Jan 2011-Dec 2019). We developed programme theories of how, why and in what contexts an intervention worked, based on cross-comparison and synthesis of evidence. The focus was on identifying factors that contributed to a clearly defined intervention (the diagnostic pathway), associated with specific outcomes (high quality and timely), within specific parameters (Autism diagnostic services in Paediatric and Child & Adolescent Mental Health services in the UK). Our Expert Stakeholder Group, including representatives from local parent forums, national advocacy groups and clinicians, was integral to the process.

**Results**

Based on 45 relevant articles, we identified seven programme theories that were integral to the process of diagnostic service delivery. Four were related to the clinical pathway: initial recognition of possible autism; referral and triaging; diagnostic model; and providing feedback to parents. Three programme theories were pertinent to all stages of the referral and diagnostic process: working in partnership with families; inter-agency working; and training, service evaluation and development.

**Conclusions**

This theory informed review of childhood autism diagnostic pathways identified important aspects that may contribute to efficient, high quality and family-friendly service delivery. The programme theories will be further tested through a national survey of current practice and in-depth longitudinal case studies of exemplar services.

**Trial registration number NCT04422483**.

**Strengths and limitations of this study**

- This realist review focussed on reviewing and synthesising recent evidence to determine what approaches to autism diagnostic assessment worked best, for whom and in what context. The approach is better suited than more empirical methods that assume there is one model to suit all situations.
- Our Expert Stakeholder Group and parent representatives engaged with all stages of the review and enabled an iterative approach to identifying relevant literature and refining our findings.
- As appropriate to our research question, we limited the search to UK literature but may have missed relevant literature from similar health systems. Although synthesis was based on UK literature, we have considered how this relates to relevant international literature.

# Introduction

The number of children and young people (CYP) diagnosed with autism spectrum disorder (autism) has increased significantly in recent years (1-3) with a median age for diagnosis of 55 months (4). This international phenomena is reflected in increasing pressures on diagnostic assessment and long waiting times in some services (5), with associated family dissatisfaction (6). The UK National Health Service (NHS) Long Term Plan (7) highlighted the need for research to identify the most effective ways to improve timely access to diagnosis whilst maintaining high-quality assessment.

Autism is characterised by persistent severe deficits in social interaction, social communication, and restricted, repetitive, inflexible patterns of behaviour and interests (8), although the level of symptoms varies considerably between individuals. It is commonly associated with other neurodevelopmental and mental health conditions, such as anxiety, ADHD and developmental language disorder (9-11), making reliable diagnosis a complex process. National guidelines for Autism in the UK (12) recommend multidisciplinary assessment, with the skills to consider both the presence of other neurodevelopmental and mental health conditions (for example, ADHD, anxiety disorders), and co-existing conditions (for example eating or sleeping related). However, this holistic assessment is time-consuming and costly (13, 14). There are significant variations between diagnostic pathways, which some have defined as 'complex interventions for mutual decision making, organisation and standardization of predictable care for a well-defined group of patients during a well-defined period' (15), and only limited evidence of which pathways work best, for whom and in what circumstances.

Although the formal research base is limited, some local providers have already reconfigured their services to address these issues (16-18). However, robust evidence is needed to identify which care

pathways, in which contexts, have the potential to meet the growing demand for diagnostic assessment in a timely, clinically valid, and family-friendly way. This Rapid Realist Review (RRR), the first step in a national Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD), aimed to explore how particular approaches aspired to deliver high quality and timely autism diagnostic services (19). High quality was defined as compliant with NICE guidelines (12). 'Timely' refers to diagnostic pathways that must be started within three months of referral, in-line with NICE guidelines (1), and last no more than one calendar year.

This study aimed to explore research evidence about autism diagnostic pathways to determine what works best, for whom and in what circumstances. The RRR aimed to use the literature to address the following questions:

1. How do various pathways of autism diagnostic and support services address the differing needs of different service user groups and what contexts and mechanisms affect their ability to do so?
2. How do different pathways of autism diagnostic and support services improve service user diagnostic experience?
3. What aspects of implementation, staffing and organisational context influence how care pathways for autism diagnostic and support services operate?

## Method

Autism diagnostic care pathways vary in terms of complex differences in local service configurations and settings, lending itself to realist review that can tease out contextual factors, resources and responses of those delivering and accessing the services. A systematic review may not be best matched to the heterogeneity of autism diagnostic services nor to capturing what is most helpful for policy decisions. Our focus was exploring solutions, so we did not focus on wider constraints, already widely documented, and incorporating chronic underfunding; increasing caseloads; reduced training budgets; and recruitment/retention issues, particularly paediatricians, child psychiatrists, clinical psychologists and SALTS (20, 21). Similarly, we did not focus on causes of service user dissatisfaction, rather ways of addressing it.

A RRR is a well-established approach to synthesising evidence within a compressed time period and the key steps are consistent with the RAMESES standards for realist syntheses (22); thus the difference is the timeframe, not the level of rigour. Additionally, RRR is explicitly designed to engage with stakeholders to accelerate the search process and validate findings (17). Our Expert Stakeholder

Group included clinicians (consultant paediatricians, child psychology, speech and language therapy (SALT)), policymakers and third sector advocacy groups (Council for Disabled Children and Autistica) who were involved in all stages of the process (19). Ethical approval was not required because stakeholders were acting as research advisers, not participants (23).

Realist reviews do not seek to compare interventions, rather they present evidence as programme theories (PTs) which are key features of the service and describe what appears to lead to certain outcomes (24), often phrased as 'if…. Then…' statements. PTs are supported by details of the context (C), mechanisms (M) and outcomes (O). These relationships are presented as CMO configurations (25). A realist approach requires starting with an initial PT of what should work and what outcomes are expected from a complex intervention; our PT was based on NICE 2011 guidance (12), the project team and Expert Stakeholder Group:

> *If there is a MDT assessment by a team with competencies in child neurodevelopment and mental health (context), then Autism will be recognised as a complex condition that relies on detailed history and observation across settings (mechanism) to diagnose it. This will lead to accurate diagnosis, recognition of associated co-occurring conditions such as ADHD and intellectual disability (outcome), and the ruling out of complex differential diagnoses. This will also create, whilst not an explicit part of this project, an accurate picture of a child's strengths and needs to inform individualised packages of support and intervention through health, education and social care (outcome).*

We worked backwards from the intended outcomes although we know in practice that complex interventions operating in different health and social care environments do not lead to the same outcomes across services because of differing contexts (for example, differences between services, ways of operationalizing and differences in recipient populations). Therefore, what is required is an understanding of what needs to be in place (circumstances or context), to trigger mechanisms (that can be responses or resources) that lead to the desired (intended) outcomes or other unintended outcomes.

## Changes to protocol

No changes to the review process proposed in the published protocol (https://bmjopen.bmj.com/content/10/7/e037846).

## Search methods

This RRR was carried out from 1 September 2019 to 30 June 2020 following RAMESES standards (24) for realist reviews. Through discussions within the RE-ASCeD project team and with our expert stakeholders, we confirmed and refined the research questions and scope; prioritised areas for

investigation; identified search terms; and collected grey literature, policy and guideline papers iteratively throughout the review.

Search terms were identified and developed with support from the RE-ASCeD project team and expert stakeholders. The primary search was conducted across Medline (Ovid), Embase (Ovid), PsycINFO (Ovid), Social Policy & Practice (Ovid), CINAHL Plus (EBSCO), Cochrane Library and Web of Science (Clarivate) limited by date (2011–2019), language (English) and country (UK only). Our focus was a clearly defined intervention (the diagnostic pathway, from receipt of referral to diagnosis), associated with specific outcomes (high quality and timely) within a particular set of parameters (autism/CAMHS services in the UK). All study types were included. The search strategy was created by an information specialist (AP) using a combination of free text and MeSH index terms after iterative pilots in Medline and adapted for each database. Search strings were based on a combination of terms covering "Children", AND "Autism" AND how they "Relate to diagnostic pathway OR assessment". For full search terms see Supplementary Document 1. Table 1 provides our inclusion/exclusion criteria.

Secondary searching was conducted iteratively throughout the review with input from our expert stakeholders. Two reviewers used papers identified in the primary and background search to look through reference lists for relevant articles; check forward citations; and search key authors and research teams to identify further literature, using Google scholar. Primary and background searches were restricted to UK only, given UK NHS context. On the advice of our expert stakeholders, we then reviewed high level national policy documents and guidelines and a few research articles from similar countries (USA, Canada, Australia, New Zealand) to help elucidate findings.

**Table 1 Inclusion/exclusion criteria**

| |
|---|
| Inclusion criteria:<br>• Children (preschool, primary or secondary school and adolescents) with Autism Spectrum Disorder or Autism spectrum condition<br>• UK healthcare system (England, Scotland, Wales and N. Ireland)<br>• Published 2011 onwards when the NICE guidelines for recognition, referral and diagnosis of autism in under 19s (2011) was published<br>• Relates to diagnostic pathway and model of service provision or relates to assessment process e.g. single discipline (paediatric consultant) or multidisciplinary |
| Primary exclusion criteria:<br>• Non-UK based literature<br>• Relates *only* to adult diagnostic pathway<br>• Relates *only* to *tertiary* services<br>• *Only* relates to treatment<br>• Relates to support services *only after* diagnosis. |
| Secondary exclusion criteria:<br>• Descriptive or irrelevant commentary on materials we already included; no added insights relevant to context or mechanisms |

- Specific tools in terms of assessment tools or psychometric properties e.g. reliability/validity of the tool
- Prevalence only studies
- Studies only related to symptoms or aetiology
- Articles about special needs in general, no mention of ASD (or ADHD)
- Duplicate material of Co-Is' previous research, excluded by Co-Is
- Conference paper with only abstract available
- The data collected or published on-line before 2011

## Article selection and appraisal

As shown in Figure 1, we collected 294 articles from the primary search , 129 grey literature records suggested by the RE-ASCeD project team members and our expert stakeholders, with overall 338 items once duplicates removed. Furthermore, 9 papers were collected via iterative secondary searches by searching all publications for key authors using Google Scholar and consulting our Expert Stakeholder Group. Two researchers (VA and WZ) carried out screening in two stages: an initial stage by title and abstract and second stage by full-text. Title-sifting of papers that deemed 'relevant' or 'maybe relevant' from both stages was also cross-checked by three team members (PW, WF and IM). Data extraction and appraisal were carried out by two researchers (VA and WZ) using a hybrid approach (26, 27): basic details from each included article (n=79) were recorded; appraisal of evidence was based on concepts of relevance, rigour and richness (26, 27), with highly relevant articles (n=45, including nine from iterative secondary search) coded in NVivo. For 20% of papers, a series of calibration exercises were undertaken by the RRR Lead (PW). When two reviewers were uncertain about the extraction or appraisal of a paper, this was discussed with the RRR Lead (PW). The quality and relevance of the selected papers were also assessed during the synthesis process by members from the RE-ASCeD project team.

Mapping the sources to test and develop PTs, we divided papers involved in NVivo analysis into three categories: 1) key papers that described a model of service delivery (e.g. integrated neuro-developmental service) in detail and were conceptually rich, 2) 'medium' papers that mentioned a model with some useful information but were not conceptually rich, 3) papers with a few 'nuggets' (28) relevant to PTs. This helped us focus on key and medium papers (Supplementary Document 2) that could contribute most to developing a conceptual framework (29) and refining PTs.

## Synthesis and refinement

Based on analysis of individual papers, we then conducted cross-evidence comparisons to build PTs and confirm/refute and refine CMO configurations; both synthesis and refining the evidence involved substantial discussion of 'contradictory' evidence, or unintended outcomes. We also consulted with our expert stakeholders iteratively during the review process and at a data interpretation workshop

in April 2020. Our expert stakeholders collectively reviewed the PTs, provided feedback and were invited to identify any omissions based on their clinical experience. We also asked them to suggest any further literature to help elucidate PTs. Based on feedback collected from the data interpretation workshop, two reviewers (VA and WZ) checked and added new papers suggested by our expert stakeholders; refined the programme theories and conceptual framework.

*Insert*: **Figure 1. Search and review flow diagram.**

## Patient and public involvement

Our co-investigators included a patient and public involvement (PPI) representative from a local parent organisation (West Sussex Parent Carer Forum) who was able to consult a wider group of families with lived experience and a parent who had previously managed Sussex Autism Support. Our PPI representatives were equal partners within the Expert Stakeholder Group. This helped focus the review on the questions they were most interested in answering and enabled the identification of salient grey or unpublished documents for review (30). PPI was embedded into the review protocol and was particularly helpful when synthesising and interpreting the data. A separate PPI Reference Group (all parents of CYP with autism), whose inception was delayed due to covid-19, is integral to the wider project.

# Results

We developed seven PTs, based on cross-comparison and synthesis of 45 highly relevant articles: the first four focused on referral and diagnostic process and the last three on cross-cutting themes (Table 2). Figure 2 summarises the interrelationship between these PTs, set in the wider context of structural and organisational barriers affecting autism diagnostic pathways. Full PTs with CMO configurations are provided as Supplementary Document 3.

*Insert*: **Figure 2. Programme theories for the autism diagnostic pathway**

*Insert*: **Table 2. Programme theories and sources**

## PT1: Listening and recognition

Professionals had to balance early referral with parents' concerns so that they felt listened to and taken seriously (6, 31, 32); parents were often the first to notice atypical patterns of development or behaviour in their child (6, 31-34). Managing parental expectations (35) and developing a co-operative relationship appeared to help manage this balance but 'was perceived to be particularly problematic because access to services is based on diagnosis, rather than an assessment of the child and family's

needs (35, p.215). From parents' perspective, one autism charity website suggested they "develop a talent for making a polite nuisance of themselves (more properly known as 'advocacy')" to traverse barriers to referral (34, p.29).

Additionally, greater autism awareness and training for frontline professionals, particularly general practitioners (GPs) and teachers, alongside training in how, when and who to refer to (6, 12, 31, 34, 36-38) was suggested as a strategy to improve early identification.

## PT2: Referral and triaging

Comprehensive information gathering pre-assessment reduced the number of contacts, assessment duration and total time taken to reach diagnosis (39). A systematic approach to information gathering (12, 37, 40) improved efficiency, but referrers also wanted feedback when referrals were declined (12, 37, 41).

Innovative approaches to triaging included: sufficient information gathering pre-assessment to enable same-day assessment in the context of tertiary services (42-44); initial interview with an experienced clinician (45); community/neurodevelopmental paediatrician carrying out a General Developmental Assessment (GDA) (41, 44, 46); assessment by CAMHS or a community paediatrician and SALT, then allocating to an abbreviated (local) or complex (specialist) pathway (41); triage meetings across CAMHS and CDS (41). However, whether these strategies constituted triaging or the first stage in the diagnostic pathway was arguable.

## PT3: Diagnostic assessment

Good practice in the UK (NICE) (12) recognises the importance of multidisciplinary assessment with use of information from parents, educational settings and direct observation/assessment of the child used as evidence alongside health professional assessment. However, services had different condition-specific remits, catchment areas and commissioning agreements. Where community paediatrics and mental health services, were integrated and collocated in the same organisation this allowed a seamless transition, avoiding duplicated waits and enabling families to see all relevant professionals at once (18, 44).

Few papers clearly delineated the service pathway (18, 35, 40, 41, 44, 47, 48) and within these were wide variations, including the balance of standardised assessments, observations and clinical judgement. As recommended by NICE (12), most services were multidisciplinary, and many offered a single point of access, bridging the autism-ADHD diagnostic divide (18, 44). For example,

Peterborough's integrated pathway provided assessments for ADHD and autism (18, 44) and combined a single point of access with a comprehensive skill mix, including access to therapies. This reduced the number of assessments per individual, saved time and money, and provided a better diagnostic experience (44). Another approach was to extend the role of available professions, for example, by training SALTs to carry out aspects of the assessment previously carried out by child psychiatrists (40). However, disadvantages of multidisciplinary assessment and/or multi-agency working included being labour intensive and costly (13); being negatively affected by the dissonance between medical and educational paradigms (47); and a 'perceived power differential' evidenced by the 'decision-making power of doctors and psychologists over other clinicians' (49, p.322).

Rutherford et al. (41) presented a multi-agency diagnostic pathway with an 'abbreviated' pathway when the signs and symptoms of autism were easily identified and a 'complex' pathway for CYP with, for example, co-existing conditions needing onward referral to a specialist team. This resulted in fewer CYP unnecessarily going through the full process, improving the timeliness of assessment (41).

An interesting theme within the literature considered the balance of clinical expertise against standardised assessments. Less experienced clinicians appeared to prefer using standardised tools, while more experienced clinicians expressed confidence in their clinical judgement (45). Some clinicians found diagnostic tools helpful, while others described them as 'very cumbersome and very time consuming' (47, p.118). Rogers et al. (50, p.824) referred to 'upgrading', whereby the majority of professionals (78 out of 116) erred on the side of a positive diagnosis when faced with uncertainty. The main reasons were to facilitate access to funding/support (n=17; 22%); enable individuals to get a statement of Special Educational Needs (n = 8; 10%); or differing opinions among colleagues in a team (n=32; 41%).

Finally, there was limited but positive literature around the use of technology. Aims included 'remote' observational assessments carried out by families during a short telehealth assessment to screen for autism in children under 3 years (51); using mobile technology to collect observational data in advance of formal assessment (52); educational games to assess risk of autism (52); an automated story ('A Pirates Adventure') scoring emotional cognition (53); and the use of computer-based Continuous Performance Tests (54). Our expert stakeholders also suggested that where the presence of ADHD is suspected, the use of Qbtest (54) may enable an objective measurement of attention, concentration, impulsivity and distractibility but the evidence is limited. Since carrying out the RRR, Lord (55) has provided guidance on adapting autism diagnostic assessment during social distancing, including the Autism Diagnostic Observation Schedule (ADOS) (although unvalidated), for remote use, demonstrating that the current covid-19 crisis has become a driver for telehealth approaches.

## PT4: Diagnostic feedback

Most parents regarded autism diagnosis as a gateway to services (50) but there was no consensus on best practice regarding feedback (48). Parents valued a sensitive approach and positive comments about their child and their parenting (32) but found it hard to absorb feedback (32, 56). Practical strategies included a structured approach; using consistent and straightforward terminology; opportunity to ask questions (including later); and recognising their child's skills/strengths (12, 32, 47, 56, 57). Guidelines recommended a needs-based and tailored management plan, co-developed with parents (12, 58).

Only one paper provided detailed information on the report format (40) and used a digital report-writing tool and visual profiling tool. Reports were available within a few days, enabling parents to review the content, improving partnership working. The visual profiling tool provided a concise visual aide for understanding, explaining, and communicating the abilities of each CYP.

## PT5: Working in partnership with families

The diagnostic process was enhanced by integrating 'expertise from several perspectives… that of the individual, their family, and the professionals' (59, p.3762) and acknowledging parents as co-experts. When parents understood the diagnostic process in advance, this improved satisfaction and helped moderate expectations (32, p.373). Open and honest dialogue involving parents in decision-making (50), helped promote engagement and manage differences of opinion (60). Having a named 'case coordinator' (12) or 'keyworker' (61) helped reduce stress and increase engagement (60). Parents offered support following diagnosis were, unsurprisingly, more satisfied than those who were not (59). A simple suggestion to improve satisfaction was to tailor links to relevant services and explore the full range of services that might prove useful (6). Another approach was to help parents develop strategies to manage difficulties, for example, meeting families wherever most convenient to reduce non-attendance (60, p.74).

## PT6: Inter-agency working

Integrating the pathways into a single assessment process potentially saved time and cost less (13, 18, 21) but we found little evidence of how to address macro-level constraints such as chronic underinvestment (34). Much appeared to rest on personal relationships at the micro-level (62) and/or parents co-ordinating services (35). While joint working was endorsed (63, p.240) suggestions to

promote it were limited to establishing clear pathways (64); creating opportunities to work in different teams, such as split posts or secondments (60); and an Additional Learning Needs Coordinator (a teacher at the school) (35).

### PT7: Training, service evaluation and development

Several papers identified the importance of training in improving the quality and efficiency of autism diagnostic services (36, 41). It was recommended that training should go beyond those working in autism services, include the educational sector (65) and be geared to the needs of managers as well as frontline staff (36) through multi-agency training (12).

Rutherford et al. (41) advocated a training framework with different skill levels, depending on the 'nature, extent and likely impact of daily contact with individuals with ASD' (41, p.1583) and now reflected in Health Education England recommendations (66). Other training suggestions included an opportunity to observe specialist autism services; buddying with experienced clinicians; regular review of training needs and succession planning; and a national forum to share experiences and knowledge (37, 64).

Finally, service evaluation was advocated to check adherence to standards/guidelines (20) and provide evidence for commissioners (37); one strategy was a guidelines checklist at the front of each patient file (37). Service development suggestions included having one person to champion change; generating research within clinical teams; encouraging practitioners to co-create contextually sensitive solutions (37); and drawing on the expertise of people with autism, carers and specialist organisations (36). Our stakeholders highlighted the importance of good quality national data to facilitate a whole system approach, with the current approach appearing somewhat fragmented (67).

## Discussion

This RRR explored diagnostic pathways that have been adopted across the UK, to determine what works best, for whom and in what circumstances. Four PTs related to the clinical pathway, addressing ways to improve initial recognition of possible autism, referral and triaging, the diagnostic model and post-diagnostic feedback. Whilst there were specific service delivery innovations of interest, such as adopting a broader neurodevelopmental approach to assessment, or the use of skill mix, there also appears to be scope to adapt stages within the process. For example, gathering information about a CYP's strengths/needs at the point of referral may enhance the process, regardless of the specific model. The three cross-cutting PTs centred on working in partnership with families; inter-agency working; and training, service evaluation and development. Collectively, these PTs evidence different

approaches that could contribute to a better experience for families, improved efficiency (and potentially cost savings) and shorter waiting lists.

Many of the issues identified in the RRR could be addressed by full adherence to NICE guidelines (12) and quality standards (68). However, a gap exists between guidelines and local interpretation, exacerbated by demand for assessment outstripping capacity and resourcing constraints. In particular, the guidelines indicate the need for a team with the competencies to deliver a broader neurodevelopmental and mental health assessment, producing a comprehensive description of a chid's strengths and needs, but some services appeared focused solely on autism diagnosis, partly reflecting resourcing constraints (36). A broader neurodevelopmental approach (38) may also ameliorate the concerns of those families whose child does not meet criteria for an autism diagnosis but has significant needs which may otherwise remain, or feel, unrecognised. This would be additionally aided by clinical teams resourcing the development of strengths and needs planning or working in consort with other agencies.

As previously noted, there may also be a trade-off between carrying out comprehensive assessments for all CYP with possible autism and 'providing a more streamlined approach that is tailored to the child's presentation' (69, p.526) which could reduce diagnostic validity. This mirrors feedback from our expert stakeholders – that there may need to be a discussion around the potential to increase investment in service delivery to enable high quality and timely approach versus the potential challenges associated with accepting lower quality and less timely diagnostic assessment. A similar approach delivering tiered assessment according to diagnostic complexity, has been recommended by recent Australian guidelines (70).

Whilst the study findings are based on UK literature that relates to the National Health Service where health oprovision is free at the point of care, and insurance-based health economies are different (69), the international literature was largely consistent with our findings. For example, recommendations to engage families in service design, and to produce a needs-based holistic assessment and report are mirrored internationally (70, 71). The seven PTs are echoed overall, for example in New Zealand recommendations (66), whilst international research also supports individual PTs, including improving knowledge and skills of referrers (72), improving information gathering to inform appropriateness of referral (72), and upskilling the diagnostic workforce (73, 74). These are also echoed in recommendations from NHS England published after completion of the RRR (75).

Internationally, digitally delivered training programmes such as ECHO (Extension for Community Healthcare Outcomes) have been developed to enable upskilling of a wider diagnostic workforce, for example community general paediatricians in US and Canada (74), whilst the World Health

Organisation has developed Caregiver Skills Training Programmes to train parents to support their children's development (76). Similarly, the need for social distancing during the Covid pandemic has acted as a driver to adopt digital technologies, although some of these had already been developed in response to geographical distancing between centralised specialist services and families living in widespread rural communities (45).

## Implication for practice and future research

From the PTs we identified six key areas that would benefit from further exploration. These were evaluation of: training and support materials available for non-specialist staff and parents/CYP accessing the diagnostic pathway which would increase early recognition that a child may need assessment and improve information gathering at the point of referral; training packages to upskill those working in autism services and the subsequent impact on workforce shortages; asset-based approaches to diagnosis, management and support; barriers and facilitators to comprehensive needs-led diagnostic assessment; approaches to integrating services dealing with autism; and increased use of technology in assessment that has already started in the context of COVID-19 (77).

## Strengths and limitations

The realist approach was well suited to examining and understanding the complexity of autism diagnostic assessment, and the challenges of delivering such services in different contexts. We developed systematic and focused search strategies, within the parameters of RRR (22), although not as extensive as a full realist review. Expert Stakeholder Engagement enhanced the search strategy, enabled an iterative approach to identifying relevant literature and was invaluable when synthesising the findings. Most papers had limited information on care pathway processes and contextual factors (which in realist terminology refers to any trigger that influences responses or resources), or more general sub-analysis by demographic/other characteristics, so PTs could only develop based on what was reported; this highlights the need for further empirical work which the next phase of this study will provide. Primary and background searches were restricted to UK only, given UK NHS context, but secondary searches included papers from countries with somewhat similar healthcare systems (USA, Canada, Australia, New Zealand) to help elucidate findings, as recommended by our expert stakeholders. However, we acknowledge that we may have missed literature from similar health systems that could have informed our PTs.

## Conclusion

In conclusion, this RRR identified important aspects that may contribute to more efficient, high quality and family-friendly service delivery. We will test the PTs and how service design could be further enhanced in the subsequent stages of the wider RE-ASCed study.

## AUTHORS' CONTRIBUTIONS:

VA & WZ: involved in all stages of the review and writing all drafts of this paper

PW: substantial contribution to writing protocol for the overall RE-ASCeD project, all stages of the review and commenting on all drafts of this paper

WF & IM: substantial contribution to writing protocol for the overall RE-ASCeD project, all stages of the review and commenting on drafts of this paper

JP: substantial contribution to writing protocol for the overall RE-ASCeD project, some stages of the review and commenting on a draft of this paper

VR: substantial contribution to writing protocol for the overall RE-ASCeD project, some stages of the review and commenting on a draft of this paper

AP: designing the search strategy and commenting on the methodology section of this paper

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## Ethics Statement:

Formal ethical review is not required for this review.

## Data sharing statement:

All data relevant to the study are included in the article or uploaded as supplementary information

**Figures:**

- **Figure 1. Search and review flow diagram.**
- **Figure 2. Programme theories for the autism diagnostic pathway.**

**Table 2: Programme theories and sources**

| PTs 1-4: Stage specific programme theories affecting the diagnostic assessment pathway | |
|---|---|
| **PT1 Listening and recognition** | |
| If frontline health and education professionals (e.g. GPs, teachers) are confident in recognising the signs and symptoms of autism, are cognisant of referral pathways and listen to parents, taking their concerns seriously then CYP will be referred to an appropriate service, in a timely manner, reducing parental frustration. | NICE, 2011 (12); Reed and Osborne, 2012 (78); Abbott, et al., 2013 (32); The Scottish Government, 2014 (36); Crane, et al., 2016 (6); Rogers, et al., 2016 (50); O'Reilly, et al., 2017 (31); RCPCH, 2017 (20); Potter, 2017 (33); Unigwe et al., 2017 (38); Crane, et al., 2018 (59); Dowden, 2018 (34); Rutherford, et al., 2018 (41); Ford, et al., 2019 (79); Hurt, et al., 2019 (35). |
| **PT2 Referral and triaging** | |
| If autism diagnostic services provide clear guidelines for referrers on what information is needed and how to refer, and referrers follow these guidelines, then time will be saved at the triaging stage and proportionately fewer CYP who do not have autism will go through the full process. | NICE, 2011 (12); Carpenter, 2012 (45); The Scottish Government, 2014 (36); McKenzie, et al., 2015 (39); Healthcare Improvement Scotland, 2016 (57); Rutherford, et al., 2016 (37); Rutherford, et al., 2018 (41); Autistica, 2019 (44); Hurt, et al., 2019 (35); Tollerfield and Pearce, 2020 (40). |
| **PT3 Diagnostic assessment** | |
| If a structured, consistent and multidisciplinary approach to service delivery is adopted, making best use of available staff and clinical expertise, then the number of assessments per individual may be reduced.<br>If a balance of interview, observation and recognised tools are used, alongside an assets-based approach, this will ensure a comprehensive and family-friendly diagnostic experience.<br>If the same Trust manages both community paediatrics and mental health services, this potentially allows for a seamless transition, avoids duplicate waits and enables families to see all relevant professionals at the same time. | Carpenter, 2012 (45); NICE, 2014a (61); Karim, et al., 2014 (47); Gray, et al., 2015 (48); Crane, et al., 2016 (6); Halpin, 2016 (49); Healthcare Improvement Scotland, 2016 (57); McKenzie, et al., 2016 (80); Rogers, et al., 2016 (50); Rutherford, et al., 2016 (37); Tryfona, et al., 2016 (52); Galliver, et al., 2017 (13); Jordan, et al., 2017 (53); Juárez, et al., 2018 (51); Rutherford, et al., 2018 (41); Ahlers, et al., 2019 (81); Autistica, 2019 (44); Ford, et al., 2019 (79); Tollerfield and Pearce, 2020 (40). |
| **PT4 Diagnostic feedback** | |

| | |
|---|---|
| If parents understand the diagnostic process and feel supported this can moderate parental expectations. Feedback should take an assets-based approach and management plans should be individualised, taking account of co-existing conditions. Reports should be timely and in a format that everyone finds helpful. | NICE, 2011 (12); RASDN, 2011 (58); Calzada, et al., 2012 (63); Carpenter, 2012 (45); Reed and Osborne, 2012 (78); Abbott, et al., 2013 (32); Karim, et al., 2014 (47); NICE, 2014a (61); The Scottish Government, 2014 (36); Halpin, 2016 (49); Healthcare Improvement Scotland, 2016 (57); Hennel, et al., 2016 (56); McKenzie, et al., 2016 (80); Reed, et al., 2016 (82); Rogers, et al., 2016 (50); Crane, et al., 2018 (59); The Scottish Government, 2018 (65); Autistica, 2019 (44); Hurt, et al., 2019 (35); Tollerfield and Pearce, 2020 (40). |
| **PTs 5-7: Cross-cutting programme theories affecting the diagnostic pathway** | |
| **PT5: Working in partnership with families** | |
| If parents have a single point of contact, are provided explanations throughout and included in decision-making then diagnostic pathway may be less stressful. | Calzada, et al., 2012 (63); Abbott, et al., 2013 (32); Gregory, et al., 2013b (60); NICE, 2014a (61); Rogers, et al., 2016 (50); Healthcare Improvement Scotland, 2016 (57); Crane, et al., 2018 (59). |
| **PT6: Inter-agency working** | |
| If "experts" including people with autism, carers, professionals and specialist organisations work in partnership and the knowledge generated is effectively embedded into local services, this will build capacity, improve parent/CYP satisfaction and support planning of services both locally and nationally. | NICE, 2011 (12); Calzada, et al., 2012 (63); Gregory, et al., 2013a (62); Gregory, et al., 2013b (60); Karim, et al., 2014 (47); NICE, 2014a (61); The Scottish Government, 2014 (36); Gray, et al., 2015 (48); Healthcare Improvement Scotland, 2016 (57); Rogers, et al., 2016 (50); Galliver, et al., 2017 (13); Hayes, et al., 2018 (83); The Scottish Government, 2018 (65); Williams et al., 2018 (84); Hurt, et al., 2019 (35); Tollerfield and Pearce, 2020 (40). |
| **PT7: Training, service development and evaluation** | |
| If professionals have access to tailored training based on their needs, competencies and role, and services engage in service development and evaluation, this will increase the local skill set of people who regularly work with CYP who may have autism. | NICE, 2011 (12); Gregory, et al., 2013a (62); Autism ACHIEVE Alliance, 2014 (64); NHS Education for Scotland, 2014 (85); The Scottish Government, 2014 (36); Rutherford, et al., 2016 (37); RCPCH, 2017 (20); Rutherford, et al., 2018 (41); The Scottish Government, 2018 (65). |

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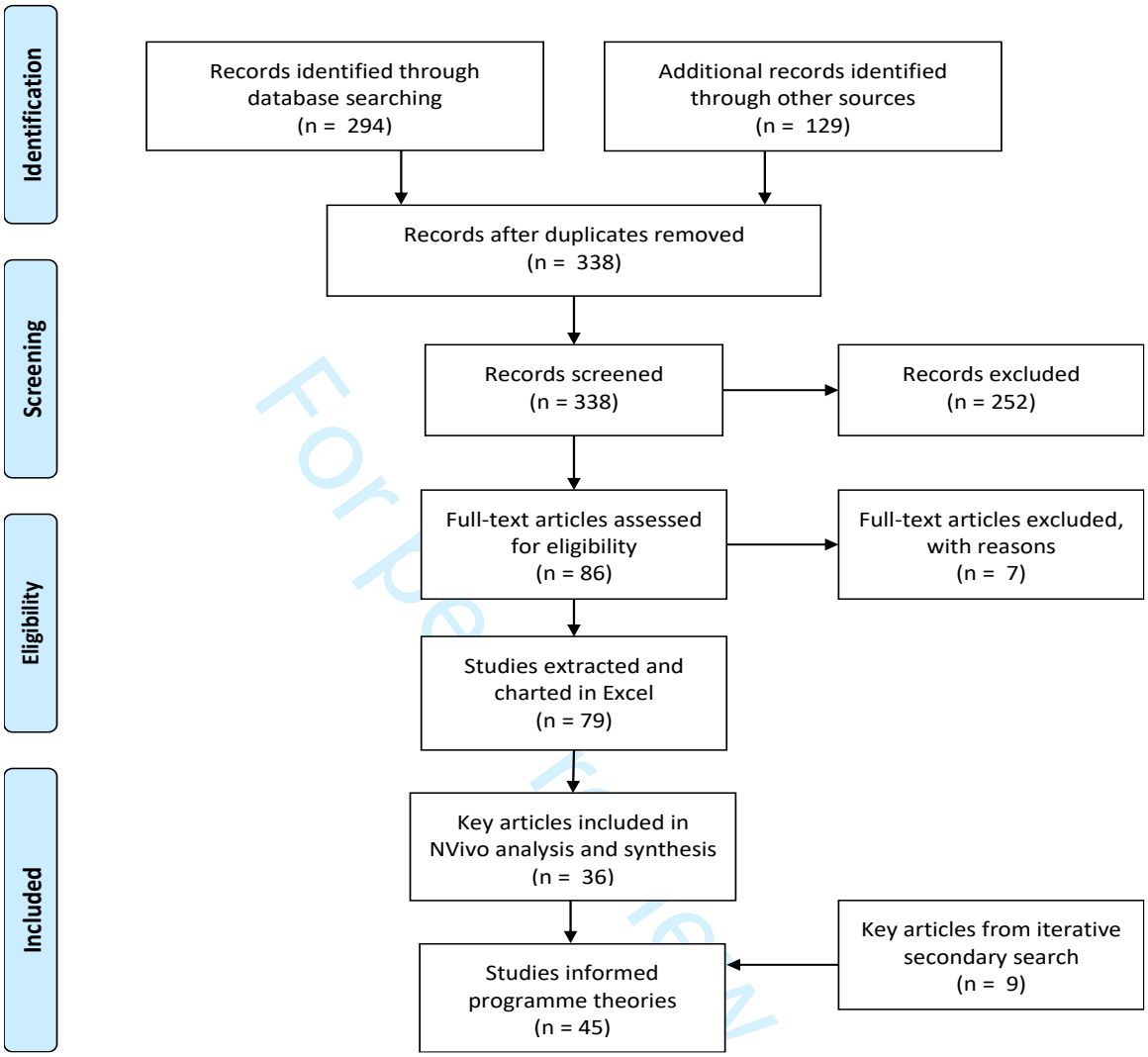

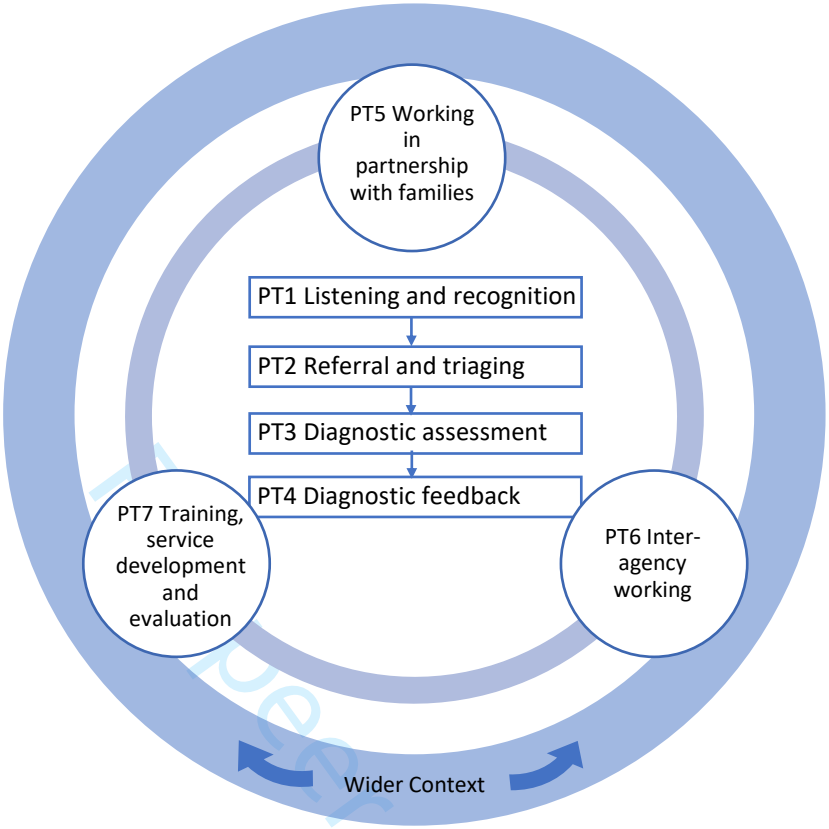

**Supplementary Document 1.** Database Search Strategies

**Number of databases searched**: 7

Medline (Ovid)
Embase (Ovid)
PsycINFO (Ovid)
Social Policy & Practice (Ovid)
CINAHL Plus (EBSCO)
Cochrane Library
Web of Science (Clarivate)

**Search limits:** 2011-current; English language; UK only

Note: We used 2020 date in the Medline search strategy because Medline includes a small number of in-process citations ahead of publication date (Medline in-Process & Other Non-indexed Citations).

Literature search strategy used for **Medline** (search run on 25.11.19) is attached below. Additional search strategies available from the authors.

| | | |
|---|---|---|
| 1 | exp Autism Spectrum Disorder/di, ep, th [Diagnosis, Epidemiology, Therapy] | 10929 |
| 2 | (autism spectrum disorder* or ASD or autism).ti,kw. | 23890 |
| 3 | (asperger* syndrome or asperger*).ti,kw. | 1150 |
| 4 | 1 or 2 or 3 | 27668 |
| 5 | adolescent/ or child/ or child, preschool/ | 2937612 |
| 6 | (child or children* or pre-school child* or adolescent*).kw. | 70707 |
| 7 | 5 or 6 | 2940479 |
| 8 | 4 and 7 | 19625 |
| 9 | Community Mental Health Services/ | 18302 |
| 10 | ("child and adolescent mental health service*" or "child & adolescent mental health service*" or CAMHS).ti,ab,kw. | 491 |
| 11 | ("child and adolescent mental health team*" or child mental health service*).ti,ab. | 149 |
| 12 | child development clinic*.ti,ab. | 39 |
| 13 | 9 or 10 or 11 or 12 | 18873 |
| 14 | 8 and 13 | 69 |
| 15 | Diagnostic Services/ | 1916 |
| 16 | (diagnostic service model* or diagnostic assessment model* or diagnostic assessment or diagnostic process).ti,ab. | 6616 |
| 17 | (diagnostic pathway* or diagnostic evaluation or referral pathway*).ti,ab. | 8902 |
| 18 | early diagnosis/ or early intervention/ | 28062 |
| 19 | "Referral and Consultation"/ | 64435 |

| | | |
|---|---|---|
| 20 | Critical Pathways/ | 6455 |
| 21 | ((multidisciplinary or multi-disciplinary or interprofessional or inter-professional or intraprofessional or intra-professional or interdisciplinary or inter-disciplinary) adj team*).ti,ab. | 18640 |
| 22 | "delivery of health care, integrated"/ or health services accessibility/ or patient care team/ | 143724 |
| 23 | Professional-Family Relations/ | 14480 |
| 24 | (service delivery or diagnostic experience*).ti,ab. | 10451 |
| 25 | 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 | 283159 |
| 26 | 8 and 25 | 1254 |
| 27 | (cost-effectiveness or evaluation).ti,ab. | 1027879 |
| 28 | Efficiency, Organizational/ or Efficiency/ | 34521 |
| 29 | evaluation studies as topic/ or program evaluation/ or validation studies as topic/ | 183858 |
| 30 | "quality of health care"/ or "outcome and process assessment (health care)"/ | 95758 |
| 31 | Waiting Lists/ or Time Factors/ | 1175790 |
| 32 | (family experience or parent experience).ti,ab. | 365 |
| 33 | 27 or 28 or 29 or 30 or 31 or 32 | 2377747 |
| 34 | 14 or 26 | 1295 |
| 35 | limit 34 to (english language and yr="2011 - 2020") | 738 |
| 36 | 33 and 34 | 256 |
| 37 | limit 36 to (english language and yr="2011 - 2020") | 141 |
| 38 | remove duplicates from 35 | **736** |

**Supplementary Document 2.1 - Key papers from primary search and background search**

| **Author (year)** Green = key; Yellow = medium; Blue = nuggets. order is density of coding | **Country** | **Title** | **Settings/service types** (e.g. ASD, ASD & CAMHS) **& service models** | **Study type** | **Aims** | **Method** | **Sample size** | **Summary of findings relevant to programme theory** |
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| Rutherford, et al., 2018 | Scotland | Improving efficiency and quality of the children's ASD diagnostic pathway: Lessons learned from practice | CCH/SLT, CCH/ CAMHS/SLT, a variety of ASD diagnostic assessment teams | mixed methods, quan&qual | a. Identify the baseline number of referrals and duration of ASD diagnostic assessment for children (aged 0–18) across a health board before a single evidence based ASD care pathway was in place<br>b. Describe the pathway development process and service changes implemented<br>c. Evaluate the effects of the new pathway for ASD diagnosis on knowledge of service demand, duration of assessment and waiting time. | The work reported comprised several steps: (a) baseline information gathering about current practice and national guidance; (b) development of an action plan (Fig. 2); (c) writing and achieving consensus to implement the new pathway (d) setting up a clinical database for recording and measuring involvement in the pathway for each child referred (e) statistical analysis of the data.<br><br>interviews, Case Note Analysis | 1 health board in Scotland- 4 local authority areas - Across all areas, 7 separate local teams were identified (teams 1–7).<br>One clinician from each team (n = 7) was interviewed about main aspects of the diagnostic services such as personnel involved and process followed.<br>telephone interview with a small number of families (n = 7) | it reports statistically significant reductions in waiting times for autism diagnostic assessment following a children's health service improvement programme. The average wait between referral and first appointment reduced from 14.2 to 10.4 weeks ($t(21) = 4.3$, $p < 0.05$) and between referral and diagnosis shared, reduced from 270 to 122.5 days, ($t(20) = 5.5$, $p < 0.05$). The proportion of girls identified increased from 5.6 to 2.7:1.<br>Methods reported include: local improvement action planning; evidence based pathways; systematic clinical data gathering and a training plan.<br>Model: see Fig 1 for all the steps including:<br>a) Comm Paed + SLT *OR* CAMHS,<br>b) specialist ASD Ax via triage,<br>c) Local abbrev Ax OR complex Ax OR request more information/decline |
| Rutherford, et al., 2016 | UK-Scotland | Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children | Child & adult services providing ASD diagnosis | sequential mixed methods design: Phase 1 quantitative data from the case notes & Phase 2 all sixteen services providing quantitative data were invited to participate in local focus groups.<br><br>*N.B. The study was part of the Scottish national Autism ACHIEVE Alliance study McKenzie et al. 2015 (Factors influencing waiting times...) which we have* | investigation from the perspective of diagnosing professional teams, of the reasons for delays, which also generates solutions.<br>Objectives:<br>- To explore the reasons clinicians give to explain long wait times for diagnosis for ASD.<br>- To identify clinicians views on the challenges and solutions to a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines.<br>- To develop **collaborative action plans** for improving the efficiency and quality of the process of ASD diagnosis in child and adult services. | Ninety five clinicians from 8 child and 8 adult ASD diagnostic services attended 16 focus groups to explore clinicians' views on a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines. During focus groups, quantitative data were fed back, used to frame discussions and facilitate solution focused action planning with each service. Sixteen local action plans were synthesised to create an ASD Action Plan for children and an ASD Action Plan for adults. | 95 clinicians | Key solutions are proposed to support the reduction of the wait for diagnostic assessment, through reducing non-attendance rates, reducing inappropriate referrals, developing efficient working and communication and improving the effectiveness of care pathways. These are presented in actions plans for use by clinical teams.<br><br>**Model: see Table 1** - 8 child ASD service, all **multi-disciplinary, specialist or general**, mix of profs<br><br>***See Table 4-5 & Fig 2 is good - check we've incorporate all in PTs*** |

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| The Scottish Government, 2014 | Scotland | Scottish Strategy **Mapping Report** | a broad range of autism services (for child/adult) across Scotland | Qualitative - workshops & quesionnaires - themes | The purpose of this report is as follows:<br>(i) to provide a 'snapshot' of autism services across Scotland, set out the key issues identified by people with autism and their carers, and provide an overview of how services are meeting their needs or where there may be gaps in services<br>(ii) set out the evidence gathered from the mapping project in order to inform local autism action plans and local decisions on autism service provision<br>(iii) inform future decisions on priorities for funding. | The project held 164 workshops and face-to-face meetings to accommodate individual needs. These equated to 35 multi-agency meetings, 68 carers meetings and 61 meetings with people with autism. | respondents number:<br>people with autism: 186 workshops & 237 questionnaires; parents and carers: 457 workshops & 719 questionnaires; multi-agency: 463 workshops & 595 questionnaires.<br><br>Overall 1106 workshops & 1106 questionnaires | single point referral for access (p7)<br>page 18-19: 'Indicator 6 - A **multi-agency** care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.'<br>page 22: 'Summary: Key Findings from the 10 indicators' p23 - distinguishes btwn co-ord/inclusion in individual vs inclusion/co-prod/PPI in service delivery which it criticises - and dissonance btwn what services say (we do include in service design) & pts who disagree.<br>page 32: appendix 1 - '3. Theme One: Diagnosis' - findings from survey p32, W/L so long, went private<br>page 64: Appendix 2-the experiences of service providers and statutory agencies. '2. Theme One: Service Provision and Assessment'<br>page 69: Appendix 2-the experiences of service providers and statutory agencies. '3. Theme Two: Joint Working and Referral'<br>Talks about **GIRFEC: getting it right for every child** - specific to Scotland. **Wider remit** than ASD.<br>**Model:** various. Note the ***distinction btwn multi-agency & multi-professional*** |
| Crane, et al., 2018 | UK | Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals | represented a number of geographical regions across the UK | part of a larger project exploring the autism diagnostic process in the UK.<br>In Phase One online survey: parents of children on the autism spectrum (Crane et al. 2016) and professionals involved in autism diagnosis (Rogers et al. 2016).<br>Phase Two (this paper) - Qualitative | to identify aspects of the diagnostic process that are working well, and areas in which improvements are needed. | qualitative: the views and experiences of ten autistic adults, ten parents of children on the autism spectrum, and ten professionals involved in autism diagnosis (three clinical psychologists, two paediatricians, one educational psychologist, one psychiatrist, one speech and language therapist, one specialist early years practitioner, and two educators). Seven professionals worked for the UK's National Health Service, two worked in the education sector, and one worked for a local authority. | 30 | Based on previous work, **six key factors** were predicted to **affect overall satisfaction** with the diagnostic process: **time taken** to diagnosis, age at diagnosis, **quality of information** provided at diagnosis, **manner** of professional giving diagnosis, **support post-**diagnosis & **stress** during the process. **Stress during the diagnostic process was the strongest predictor of overall satisfaction** with the diagnostic process. This was followed by satisfaction with the **support** offered post-diagnosis and satisfaction with the **manner** of the professional disclosing the diagnosis.<br>Three key themes were identified: the process of understanding and accepting autism; multiple barriers to satisfaction with the diagnostic process; and inadequate post-diagnostic support provision.<br><br>**Models: various types profs & services, not the focus/not specified**<br><br>**see Fig 1 summary of themes** |
| NICE, 2011 (updated in 2017) | UK | Autism spectrum disorder in under 19s: **recognition, referral and diagnosis** (CG128) | Autism spectrum disorder | guideline | This guideline covers recognising and diagnosing autism spectrum disorder in children and young people from birth up to 19 years. It also covers referral. It aims to improve the experience of children, young people and those who care for them. | NA | NA | page 5: '1.1 Local pathway for recognition, referral and diagnostic assessment of possible autism' section are all useful - 1.1.1 'A local autism **multi-agency strategy** group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.' and 1.1.2 'The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people.' and 1.1.3 'In each area a **multidisciplinary** group (the autism team) should be set up.'<br>***N.B. note multi-agency & multi-disc - does it stipulate more specifically than this?*** |

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| Rogers, et al., 2016 | UK | Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom | Services involved in ASD diagnostic process with children. | quantitative - on-line survey | conduct a review of diagnostic practice in the United Kingdom by exploring the experiences and perspectives of professionals involved in diagnosing ASD. | A heterogeneous sample of professionals who were clinically active in ASD diagnosis and assessment at the time of the survey, were invited to participate. To recruit the sample, services were collated via the National Autistic Society online directory, and Internet searches were conducted for ASD diagnostic services. 300 services were contacted. Additionally, approximately 3000 statutory and non-statutory ASD services listed in the NHS choices directory were contacted. A total of 126 multidisciplinary professionals completed the full questionnaire, but 10 professionals were excluded from the analysis as they were not clinically active at the time of the survey. Data collection ran from March 2012 to May 2013. Online questionnaire (4- & 5-point Likert scales) exploring their experiences and opinions of three key areas of service: accessibility, the diagnostic process and post-diagnostic support. open questions were analysed qualitatively, using a thematic analysis | 116 | Although professionals were largely satisfied with service accessibility, around 40% of services were failing to provide timely assessments. Standardised diagnostic tools were perceived as helpful and were used consistently, but concerns were raised about their validity in detecting atypical ASD presentations (e.g. females). Several challenges regarding giving ASD diagnoses were reported; these included making sure caregivers understood the diagnosis, pitching information at the correct level and managing distress. 76% of professionals acknowledged the practice of '**upgrading**' to a diagnosis of autism spectrum disorder in uncertain or complex cases and reasons for this varied widely. Professionals felt the need to streamline post-diagnostic support options, ensure the availability of long-term support and to ensure that the post-diagnostic support needs of under-served groups (e.g. women and girls; adults without learning disabilities) were not overlooked.<br><br>**Table 8** has explanations/**Ms** related to **accessibility** (in terms of ease of making referral & screening process), **diagnostic proces**s & **post-diagnostic support**<br><br>**Models: various types profs & services, not the focus/not specified** |
| Calzada, et al., 2012 | UK | High-functioning autism and Asperger's disorder: Utility and meaning for families | specialist clinic for the assessment of children and adolescents with a possible high-functioning PDD. | Qualitative, Semi-structured interviews | investigate the utility (how useful diagnosis is clinically) of pervasive developmental disorder (PDD) diagnoses & differentiating between AD & AsD. | interviewed 22 participants from 10 families. young people (aged 9–16 years) with highfunctioning autistic disorder (AD) and Asperger's disorder (AsD), and their parents. Framework analysis | Twenty two participants from ten families | Perceived advantages of AD and AsD diagnosis were increased understanding and practical support, and parental empowerment. Disadvantages included the effects of stigma and concerns about validity. The utility of AD and AsD depends upon both their validity and how these diagnoses are received in their cultural, economic and legislative context.<br>**Model: specialist clinic for the assessment of children and adolescents with a possible high-functioning PDD (pervasive developmental disorder).** *Not focus of article* |
| Hurt, et al., 2019 | **South Wales** | Understanding and improving the care pathway for children with autism | NHS MDT for NDCs<br>1) A NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8);<br><br>2) in education sector:<br>staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist, n= 8); | Qualitative mixed-methods approach using focus group discussions, creative writing workshops and visualisation using rich pictures | to describe current care pathways for children with autism including enablers and barriers, as experienced by health professionals, education professionals and families in South Wales, UK. | mixed-methods approach using focus group discussions, creative writing workshops and visualisation using rich pictures.<br>**Three workshops** were conducted in September 2015 with (see sample size):<br><br>During the workshops, we employed three methods to collect data. First, we used focus group discussions; Second, a graphic illustrator captured the discussions... enabled comparisons to be drawn across the three groups; Third, participants undertook creative writing exercises to express their experiences in narrative form. | (1) health professionals working within a NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8);<br>(2) staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist, n= 8); and<br>(3) parents of primary school children diagnosed with ASD (n= 7). | The **experiences of the care pathways** differed significantly across the three groups. Health professionals described the most rigidly structured pathways, with clear entry points and outcomes. "**Tier 2" pathway** catered for relatively **uncomplicated cases**, with **two assessment visits** and **one feedback** visit at which a **multi-disciplinary** team discuss the assessments with the family and decide on whether a diagnosis is necessary. The **"Tier 3" pathway** catered for **complicated** cases, and involved **more detailed assessments and discussion** before the feedback session with families. Both pathways were thought to take around **two to three months** to complete. Interaction with education was limited to **observations at school** and an invitation to educational professionals to **attend** the multi-disciplinary **feedback meeting**.<br>Education professionals and parents described more complex and confusing pathways, with **parents** assuming the responsibility of **coordinating** the **health and education** activity in a bid to link the two independent pathways. One school had an Additional Learning Needs Coordinator (**ALNCo**, a teacher) who **coordinated** the support for all children with an identified need before and/or after diagnosis & provided the link between the parents, teachers and any allied education professionals.<br>All three groups identified enablers, although these differed across the groups. The barriers were more consistent across the groups (e.g. poor communication, missing information, lack of transparency, limited post-diagnosis services and access to services based on diagnosis rather than need). In common with health professionals, the education professionals expressed dissatisfaction that many of the steps in the pathway required a **diagnosis,** rather than an examination of the child's **needs.**<br>**Model:** In autism care, there is recognition that holistic, **cross-agency and multi-disciplinary** working is essential (NICE, 2013)... 'In the refreshed ASD Strategic Action Plan, the Welsh Government (2016) commits to delivering a "**national integrated autism service**" by 2019. Whilst generic, high-level care pathways were suggested within the original strategy, it is **not understood how these work on the ground**, nor are there clear examples of good and poor practice to inform future service planning. **No revised pathway is provided** within the refreshed strategy to guide the delivery of the integrated service. |
| AUTISTICA, 2019. Embracing complexity in diagnosis: multi diagnostic pathways for NDCs. | UK | Embracing Complexity is a new coalition of 38 UK charities who support people with NDCs | Four exemplars, England & Wales | Report | Raise awareness of innovative models of care models for diagnosing NDCs | Interviews with professionals in the 4 pathways | No details | Outlines the **4 MDT models (Peterborough, Lambeth, Evelina, All Wales)** carrying out holistic assessment which can deliver multiple diagnoses of NDCs at the same time; lack of robust evidence or how best to reflect local needs. |

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| Tollerfield & Pearce, 2020. | England | Thinking Patterns in Autism Model: Innovating future-fit autism diagnostic assessment services. | the diagnostic service was incorporated into CAMHS, with diagnostic assessments completed by the SALT and consultant child and adolescent psychiatrist. | descriptive evaluation | to describe and retrospectively evaluate an autism diagnostic profiling model in a region of North England. | With reference to NICE (2017) guidelines, clinical service data, and a parent survey, the service model was retrospectively evaluated.<br>This retrospective study evaluated descriptive information about a service model that was trialled between November 2018 and May 2019. | 114 families attended for assessment during this six-month period. Parent information was sampled via SuveyMonkey.com (April 2019), and waiting list rates, staffing, means and ratios were calculated (November 2013 and November 2019). | Findings showed that positive changes over time resulted in an NHS service that was able to create high quality diagnostic profiles for every individual assessed. Findings further showed that the profiling assessments could be completed in less time; approximately 30% less speech and language therapy time and 70% less psychiatry time was needed. Positive parent comments suggested that diagnostic assessment profiling feedback was individualised, detailed and valuable. Central to achieving these outcomes was the use of standardised procedures and cost-effective skill mix for meeting NICE (2017) guidelines on gathering assessment information, communicating the results after the autism diagnostic assessment, and providing individual information on support (1.5; 1.8; 1.9). A model for understanding and explaining thinking patterns in autism was used as a structure for gathering information, for report writing, and for producing a simple visual designed to capture and communicate the complexity of autism as well as the unique context for each individual. It is suggested in this paper, that these innovations can support and inform the development of future-fit autism assessment services.<br>**Model of ASD**: Thinking Patterns in Autism (TPA) Profiling Model - with visual profiling.<br>**Diagnostic model**: By 2009, the diagnostic service was **incorporated into CAMHS**, with diagnostic assessments (12 per year) completed by the **SALT and consultant child and adolescent psychiatrist**. Funding associated with the waiting list initiatives led to increases in therapist time, but there were difficulties with funding and recruiting psychiatrists and psychologists. Consequently, a significant bottle-neck developed in the diagnostic pathway with families waiting extended times for psychiatry input following assessments. In response, the **therapist role was extended so that psychiatry time required per case was reduced.** |
| The Scottish Government, 2018 | Scotland | The Scottish Strategy for Autism - **Engagement Analysis** 2018 | NA | qualitative - online survey & engagement events | to gather in views on the final phase of the Scottish Strategy for Autism | From 18 October 2017 to 29 November 2017 we ran an online engagement exercise. we received 662 responses. Alongside our online questionnaire we held four engagement events, which were attended by more than 600 people. This means well over 1,000 people took part in our engagement activity.<br>As part of our engagement activity we held a number of engagement events, To ensure consistency, delegates who attended these events were asked the same questions as those who used the online engagement tool. Each event had two parts: a morning session for autistic people, their families and carers, and an afternoon session for professionals. | Of the 662 responses to our online questionnaire, 92 per cent were from individuals and the remaining eight per cent (n=56) from organisations. | page 9: '1.3 Referring children and young people to the autism team'<br>yes, p15-16 on training - public & profs<br>page 20: 'Training - Most participants agreed that raising awareness among professionals and services would only happen with more and better training.' - some quotes in this section touched about diagnosis time<br>page 23: 'Diagnosis and Post-Diagnostic Support'<br>page 85-86: 'Engagement Events – Afternoon Sessions' - 'Diagnosis, post-diagnostic support and services'<br><br>**Model:** not the focus/not specified |
| Karim, et al., 2014 | UK | Diagnosing autistic spectrum disorder in the age of austerity | Professionals from UK services including NHS, a primary care provider, and two local education authorities in East Midlands.<br><br>Model: In this area there is no specialist ASD clinic so children are seen by clinical professionals and educational psychologists. | qualitative | explore how diagnosis is managed in the real world by professionals. | semi-structured interviews were thematically analysed. *Doesn't say when interviews were done but paper was accepted* ***May 2012*** *, so prob 2011…* | **26 interviews**: child and adolescent psychiatrists (7), community paediatricians (9) and educational psychologists (10)- number updated by the author. | While there is some consistency across and within these groups there are also a number of variances, and several important issues are highlighted. These include the problem of time and resources, the issue of location for diagnosis, the value of diagnostic tools and schedules, the need for supporting information, the difficulty of multi-agency working, the relevance of a physical examination and the eventual diagnostic label.<br>Theme 1: time & resources - lack of is major difficulty for clinicians<br>Theme 2: setting medical staff seeing children often in outpatient environments where educational psychologists tend utilize the school setting. Important to see children in different settings - emphasizes the importance of multi-agency working.<br>Theme 3: **diagnostic tools vs clinical judgement**<br>Theme 4: use of supporting information for diagnosis - some professionals undertook their own observations, others delegated. Not problematic in itself.<br>Theme 5: **multi-professional/multi-agency or individual diagnosis?**<br>Theme 6: variations in physical examination - educ psychologists don't do this at all - need to be consistent with guidelines. [*Reflects medical vs educ orientation and how different ASD diagnosis is to other conditions* ] |
| Potter, et al., 2017 | UK | I received a leaflet and that is all': Father experiences of a diagnosis of autism | NA | qualitative | This study investigated father perspectives on a diagnosis of autism | investigated father perspectives on a diagnosis of autism, through an online survey. | The sample completing the survey were 306 fathers of children up to 19 years of age, with a diagnosis of autism, autism spectrum disorder or Asperger's syndrome and resident in the UK. 184 fathers (60% of the total) responded to the open-ended question concerning perspectives on diagnosis. | Thematic analysis of 184 replies to an open-ended question identified the following themes: strong initial emotional response and a range of immediate anxieties about the future, struggle to gain a diagnosis; anger in response to insensitive delivery of diagnosis together with insufficient information at the time and lack of support afterwards.<br><br>**Model**: not stated, assume various |

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| Gregory, et al., 2013 | UK | The development of a Child and Adolescent Mental Health Service for children with disabilities: rationale for the approach, method and techniques | CAMHS-Borough of Kensington & Chelsea | NA | explores the rationale for the practice and explains three different elements – approach, method and technique | This second paper explores the rationale for the practice and explains three different elements – approach, method and technique | NA | Page 77: Given other local pathways for assessment and diagnosis, as a team we focus on parent/network concerns and intervention relating to these and tend to avoid further diagnostic assessments, redirecting this work if the question arises. When we meet with families we create a set of goals together about our work with them which we then regularly review and amend throughout our involvement. This explicitly sets out our work as being collaborative and allows us to be transparent about our model and our position alongside the family as a partner in the work<br>page 79: In our team, having an **explicit model*** which informs our approach helps us to be clear about what we are doing and how this might be helpful to families. Thinking about how our methods and techniques fit with the overarching principles of our approach means that we can operate in a coherent way, mindful of the ideas we privilege and how these influence how we engage with and support parents and families.<br>**Parent Adviser Model** emphasises that in order to help and support families parents' views must be heard, understood and prioritised. ***Not really relevant to ASD - should we have excluded?!*** |
| SIGN, 2016 | Scotland | Assessment, diagnosis and interventions for autism spectrum disorders | A national clinical guideline in Scotland - multidisciplinary assessment recommended | A national clinical guideline | It is hoped that this update will contribute further to a reduction in variation in practice and improve services for people of all ages with ASD. | NA | NA | page 20: '1.8 Communicating the results from the autism diagnostic assessment'<br>'Research evidence on **multidisciplinary compared to single assessment** is limited.' But recommends (**model**):<br>'The use of **different professional groups** in the assessment process is recommended as it may identify different aspects of ASD and aid accurate diagnosis.<br>A diagnostic assessment, alongside a **profile of the individual's strengths and weaknesses**, carried out by a **multidisciplinary** team which has the skills and experience to undertake the assessments, should be considered as the optimum approach for individuals suspected of having ASD.' |
| Crane, et al., 2016 | UK (all regions) | Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom | NA | Phase One of above research - national survey | parents' experiences and opinions regarding the process of attaining a diagnosis of autism spectrum disorder for their children. | online survey based on **6 key factors** predicted to affect overall satisfaction with the diagnositic process. A total of 559 services providing information, support or assistance to parents of children with ASD were identified via a directory of autism-related services provided by the National Autistic Society (UK) and asked to forward survey information to their members. Data collection Mar 2012-May 2013. | 1047 parents (93% female, 95% White) | parents usually waited a year from when they first had concerns about their child's development before they sought professional help. On average, there was a delay of around 3.5 years from the point at which parents first approached a health professional with their concerns to the confirmation of an autism spectrum disorder diagnosis. Just over half of the parents surveyed were dissatisfied with the diagnostic process as a whole. Several factors predicted parents' overall levels of satisfaction with the diagnostic process, including the time taken to receive a diagnosis, satisfaction with the information provided at diagnosis, the manner of the diagnosing professional, the stress associated with the diagnostic process and satisfaction with post-diagnostic support.<br><br>**Model**: various/not clear & not the focus |
| Gregory, et al., 2013 | UK | The development of a Child and Adolescent Mental Health Service specifically for children with disabilities: reflections on the first four years | CAMHS-Borough of Kensington & Chelsea | NA | Describes the referrals received, the strengths of having a specialist team, and the arguments for and against setting up a specialist CAMHS service. | The first paper gave details on the nature of the referrals received, the strengths of having a specialist team, and the arguments for and against setting up a specialist CAMHS service. | NA | Describes the service, its development, remit & partnership working with other agencies/organisations and parents/PPI. Divides problems into development issues, challenging behaviours & impact on the family.<br><br>**Model: a team who set up a CAMHS specifically for children with disabilities, including those on the autism spectrum.;** multi-disciplinary but *not* part of generic **CAMHS team; '**positioned (physically and strategically) alongside the Children with Disabilities Social Services team, within the Local Authority' - some split posts which assisted training colleagues in other services. |
| NICE, 2014 | UK | **QS 51** Autism Quality standard | NA | This standard is based on CG128, CG142 and CG170. | This quality standard covers autism in children, young people and adults, including both health and social care services.<br>The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. | NA | NA | covers health and social care services for adults, young people and children with autism. It includes assessment/diagnosis, care and support for people diagnosed with ASDIt describes high-quality care in priority areas for improvement.<br>Page 11: 'Statement 1. People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started **within 3 months** of their referral.' 'Rationale - There are several different routes by which someone with possible autism can be referred to an autism team for a diagnostic assessment. It is important that the assessment is conducted as soon as possible so that appropriate health and social care interventions, advice and support can be offered.'<br>page 12: 'What the quality statement means for service providers, health and social care practitioners, and commissioners' & 'What the quality statement means for service users and carers'<br>page 14: definition of Diagnostic assessment<br>page 17: 'Statement 2. People having a diagnostic assessment for autism are **also assessed for coexisting physical health conditions and mental health problems.**' 'Rationale - People with autism may have coexisting physical health conditions and/or mental health problems that, if unrecognised and untreated, will further impair the person's psychosocial functioning and could place additional pressure on families and carers.<br>page 18 'What the quality statement means for service providers, health and social care practitioners, and commissioners' & ...'for service users and carers'<br>page 33 'Quality statement 7: Assessing possible triggers for behaviour that challenges' |

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| O'Reilly, 2017 | UK | How parents build a case for autism spectrum disorder during initial assessments: 'We're fighting a losing battle' | CAMHS | qualitative conversation analysis | examine relevant issues in relation to the practitioner–family interactions that take place within the initial assessment context. | Each initial appointment typically lasted approximately 90 minutes, generating a corpus of 42 hours of video-recordings. **Participating families were seen by a minimum of two mental health professionals** from a **range of professional groups,** including consultants, staff-grade and trainee child and adolescent psychiatrists, clinical psychologists, assistant psychologists, community psychiatric nurses (CPNs), learning disabilities nurses, occupational therapists, psychotherapists, medical students and student nurses. Conversation analysis (CA) of video-recorded discussions between diagnosticians and families during pre-diagnosis triage screening within CAMHS. | 28 opportunistically sampled families attending their first assessment | Our findings illustrated that parents typically first raised the possibility of the presence of ASD diagnosis through 'building a case', which professionals were then able to ratify or negate. Found that the assessments unfolded sequentially and clinical decisions were typically reached through a distinctive pattern of interaction.<br><br>**Model:** Not clear & is **CAMHS** specific |
| Abbott, et al., 2013 | England | Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences | Community CAMHS (mental health & learning disability), North East England | Qualitative | Explore parents' experiences of receiving the news that their child warrants a diagnosis of Autism Spectrum Disorder (ASD). | Qualitative methodology was used to explore the experiences of the 'feedback session' (confirming the diagnosis) with nine sets of parents. General indictuve approach to analysis. | nine sets of parents with children aged 8-15. | page 13: '1.5 Autism diagnostic assessment for children and young people' autism case coordinator<br><br>**Model**: Not clear & is CAMHS specific |
| Gray, et al., 2015 | UK | Variable implementation of good practice recommendations for the assessment and management of UK children with neurodisability | All teams used a combination of assessment methods, with all reporting some level of single multidisciplinary team (MDT) assessment, an individual professional assessment followed by an MDT meeting and/or an individual assessment without an MDT meeting. | national surveys | to determine whether UK **child development teams (CDTs)** have implemented good practice recommendations for the co-ordinated assessment and support of children with neurodisability and to explore some of the factors associated with variations in good practice implementation. | Surveys were sent to every UK CDT in 2009/2010. Responses about CDT provision and ways of working were compared with good practice recommendations from national policy documents and professional organizations. The extent to which CDTs in England and Wales met 11 selected good practice recommendations was scored; teams in Scotland and Northern Ireland were given a score out of 9 to reflect the optional use of the common assessment framework and early support materials in these countries. | 225/240 (94%) UK CDTs responded.<br>37% of CDTs in England and Wales had implemented 9 or more of the 11 recommendations. 59% of teams in Scotland and 78% of those in N. Ireland met between six and nine recommendations of good working practice. | There was considerable variability in the degree to which CDTs implemented good practice recommendations for the diagnosis and management of children with neurodisability. Evidence about child and parent satisfaction, and the effectiveness of CDT practices and provision, is required, so policymakers, healthcare commissioners and clinicians can provide the most appropriate services to children with neurodisability and their families.<br><br>**Model:** All teams used a combination of assessment methods, with all reporting some level of single **multidisciplinary** team (MDT) assessment, an **individual professional** assessment followed by an **MDT meeting** and/or an **individual assessment without an MDT meeting**. |
| Dowden, 2018 | UK | Improving the diagnosis of autism spectrum disorder | NA | Opinion piece | assesses the scale of the problem and discusses possible reasons and solutions. | NA | NA | Barriers to receiving diagnosis include: organisatational complexities; professioansl not referring early enough or to the correct service or not even recognising symptoms; lack of capacity in services; parents needing to be 'pushy' without causing hostility with professionals. |
| Reed & Osborne, 2012 | UK | Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders | NA | review/opinion piece | Sets out existing theoretical and empirical knowledge concerning parental functioning and their child's ASD, including parental experiences of ASD diagnoses; general health and psychological functioning of parents of newly-diagnosed children with ASD; aspects of the diagnostic process impacting on parental functioning; and the relationship of parental functioning to child outcomes. | NA | NA | Discusses stress levels of parents & effectiveness of Rx for child - not related to diagnostic pathway but suggests this could be underlying mechanisms for effective Rx. Links this to importance of parental support important - possible **mechanism** for providing a management plan that parents find helpful (understanding/feeling supported). Makes good point about importance of parental trianing programmes also offering opportunity for families to explore the impact of the diagnosis & coming to terms with ASD diagnosis (coded under 7e). Suggests that issues such as the speed of diagnosis, the chain and coherence of referral through the diagnostic system, the help offered at the time of diagnosis and the communication styles of the professionals, both with the parents and with each other, may all be seen to be important in increasing parental satisfaction and establishing best diagnostic practice. |

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| Unigwe, et al., 2017 | UK | GPs' confidence in caring for their patients on the autism spectrum: an online self-report study | GPs across the UK - sample size 304 | quantitative - online survey | To understand GPs' perceived self-efficacy in identifying and managing their patients on the autism spectrum, and the factors affecting this. | An online self-report survey was developed for completion by GPs across the UK. GPs identified via the Royal College of General Practitioners (RCGP) and internet snowballing methods through social media. The survey collected responses on participants' background, training, and experience, both as a GP and with regard to autism, and included a 22-item knowledge of autism questionnaire, a 14-item self-efficacy scale targeting GPs' perceived confidence in identifying and managing their autistic patients, and an open question eliciting participants' experiences of working with autistic people. Data analysis: descriptive; correlational & regression analyses; thematic anaysis of open replies. | 304 | In total, 39.5% (n = 120) of GP participants reported never having received formal training in autism. Few responders (28.0%, n = 85) reported referring to the diagnostic criteria for autism and even fewer (19.1%, n = 58) reported using any screening instruments.<br>Despite demonstrating good knowledge of its key features, participants reported limited confidence in their abilities to identify and manage autistic patients, with many citing a number of barriers that overwhelmingly focused on perceived failings of the current healthcare system (such as a lack of clarity around referral pathways and long delays from referral to diagnosis) and lack of support post-diagnosis. This confidence was related to greater experience with autism, including personal connections & prior training in autism.<br>Recommends improved local specialist service provision alongside clearer referral pathways for diagnosis. |
| Carpenter, 2012 | UK | Diagnosis and assessment in autism spectrum disorders | NA | Literature review | provide an overview of the current situation with diagnosis and assessment in autism spectrum disorders (ASD). | a review of literature combined with personal observation of practice | NA | Diagnosis cannot be determined by any one tool. It is a clinical judgement. A solo experienced clinician can make a diagnosis. Wider assessment is needed post diagnosis and needs a team.<br>Specialist multidisciplinary teams to assess people with ASD should be set up for adults as well as for children.<br>talks about different interpretations of diagnosis, DSM4, ICD10 & 'new draft' DSM5 (came out 2016). |
| Autism ACHIEVE Alliance, 2014 | Scotland | ASD: Waiting for Assessment - Executive Summary | a broad range of autism services (for child/adult) across Scotland<br><br>The child sample comprised 50% CAMHS services, 37% Child Development Centres or equivalent, and 13% joint service with input from both CAMHS and Child Development. All child services were provided through multi-disciplinary teams. | quantitative descriptive & case note analysis & focus groups | The Autism ACHIEVE Alliance was asked to investigate waiting times in the diagnosis of Autism Spectrum Disorder (ASD), as per the Scottish Strategy for Autism Recommendation 21: 'It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings'. | A telephone survey was conducted and 457 calls were made across Scotland to ascertain which services conduct diagnostic assessment of individuals with ASD.<br>This telephone survey resulted in a list of 94[1] services which conduct diagnostic assessment with 68% (64/94) of these being child services and 32% (30/94) adult services.<br><br>a retrospective case note analysis of 150 individuals diagnosed with ASD by these services.<br><br>focus groups -We conducted focus groups with each of the diagnostic services to review their specific data, co-examine their wait issues and co-identify specific solutions. | a random sample was conducted and the sampled services (n=16) were then invited to participate. The child sample comprised 50% CAMHS services, 37% Child Development Centres or equivalent, and 13% joint service with input from both CAMHS and Child Development. All child services were provided through multi-disciplinary teams. | For the child cases, the average total wait for diagnosis from referral to receiving the diagnosis was 331 days; however there was a wide range (30-1942 days).<br>Of the child cases, 74% took longer than 119 days, which is the recommended maximum time from referral to sharing the diagnosis (National Autism Plan for Children, NAP-C, 2003).<br>Children had a statistically significant longer wait between referral and first appointment, and a longer overall wait between referral and receiving the diagnosis, compared to adults.<br><br>Page 3: 'How long is the wait for diagnosis?'<br>Page 5: 'What affects the length of the wait? - Statistical analysis of the 150 cases illustrated:<br>? In child cases, having more information about the child prior to diagnosis was associated with shorter assessment durations.<br>? Adherence to the evidence-based guidelines (SIGN/NICE) or to the Quality Diagnostic Standard (QDS 2006) does not have a detrimental effect on the total wait for diagnosis.<br>? This suggests that a good quality service, as indicated by higher adherence, does not have to have a cost in terms of increased waiting times.<br>Child and adult service focus group discussions suggested frequent reasons for delays included:<br>? less efficient working and communication ? high non-attendance rates ? inappropriate referrals ? ineffective care pathways.<br>page 5-6: 'Are standardised diagnostic assessments used?'<br>page 6: 'To what extent do services adhere to the Quality Diagnostic Standard?'<br>page 6-7: 'What can be done to reduce delays?' 'These key solutions were identified by services as follows:<br>? To develop efficient working and communication by:...? To reduce non-attendance rates by:...? To reduce inappropriate referrals by:...? To improve effectiveness of care pathways by: |

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| Reed, et al., 2016 | Swansea, UK | Impact of Diagnostic Practices on the Self-Reported Health of Mothers of Recently Diagnosed Children with ASD | NA | quantitative, cross-sectional | examined the impact of different aspects of the diagnosis process on the self-reported mental health of mothers of children undergoing a diagnosis for ASD in a cross-sectional cohort design. | One-hundred-fifty-eight mothers of consequently diagnosed children with ASD participated. The severity of the children's ASD and their intellectual functioning was assessed within twelve months of the diagnosis, and the mothers completed a psychometric assessment battery including the Hospital Anxiety and Depression Scale, General Health Questionnaire, and Questionnaire on Resources and Stress. | 158 mothers | The actual time from first reporting a problem to obtaining a diagnosis, and the **speed of the diagnostic process** from first to last appointment, were both ***negatively*** related to parenting **stress**. In contrast, mothers' **perceptions of the speed and helpfulness of the process were *negatively* related to levels of anxiety and depression**. The **number of professionals involved** in the process and the perceived coherence of the diagnosis were also negatively related to aspects of mothers' functioning.<br><br>*bottom p6- p7: The perceived **speed of the process** and its **perceived helpfulness** were independently significant predictors.... The perceived helpfulness and interpersonal skills of the professional were the only independently significant predictors.. think relates to HR-QoL (GHQ)*<br><br>*The only two reliable associations being negative ones between the child's age at diagnosis and the perceived speed of the process (the **older the child at diagnosis the worse was the perceived speed**), and the number of professionals involved and the coherence of the process ( **the more professionals the less coherent the process appeared to the mother**). However, none of the associations reported in Table 2 were particularly large,*<br><br>*These findings suggest that, while an early diagnosis might lead to quicker access to services and beneficial earlier treatment for the child [2], it may also leave mothers unable to develop coping mechanisms for living with this diagnosis [14].could be possible **mechanism** ?*<br><br>*It may be that initially more anxious mothers are more dissatisfied with the diagnostic process, or that some third factor causes both anxiety and a lack of satisfaction with the events connected to the diagnosis* |
| Tryfona, et al., 2016 | UK | M-Health Solutions to Support the National Health Service in the Diagnosis and Monitoring of Autism Spectrum Disorders in Young Children | NA | opinion piece | consider the potential for user-behaviour analysis software on tablet computers or smart phones, along with other m-health solutions, to provide a cost- effective opportunity for the NHS to support the diagnostic process and to assist in the ongoing monitoring and development of children with ASD. | review/ opinion piece | NA | Whilst there are m-health solutions emerging to assist in the diagnosis and ongoing monitoring of autism in young children, there are also limitations associated with these approaches. In order for these software products to support the NHS, it is vital that the user-requirements elicitation and modelling processes effectively capture the unique and evolving needs of the various professionals working within a dynamic organization such as the NHS. This will also ensure that software can evolve to reflect changes in our understanding of ASDs. M-health solutions, however, do present an interesting oppor- tunity for health care professionals to make observations of children between appoint- ment times and within their home environment or familiar education setting, thus potentially speeding up the diagnosis process. |
| Halpin, 2016 | UK | What do nurses think they are doing in pre-school autism assessment? | group of nurses in one NHS trust (not named) where the child health teams assess pre-school children for possible autism. | qualitative - critical reflective inquiry research method | Asked 'what do nurses identify as their particular professional contribution to the assessment of pre-school children for autism?' | Used written reflective accounts and the transcripts of one-to-one and group discussions about practice. Participants reflected on the nursing beliefs and values they hold in common, and on their actions in practice. | all six qualified nurses currently working in preschool autism assessment in one NHS trust. | The study found that the beliefs and values held by these nurses, and their intention to offer holistic nursing delivered through a professional relationship of care, correlated with the kind of care that parents have said families need, and make a unique contribution to team assessment. |
| BACCH, 2019 | UK | A workforce strategy for community paediatrics | Community Child Health - the discussions are on neurodevelopmental conditions & community paediatricians in general, so ASD focused session is limited, but include helpful info on CCH services. | report | BACCH has put together a suite of deliverable initiatives below to improve recruitment and retention in the subspecialty, building on strategies adopted by other Colleges and the experience or members and departments on what is likely to be most productive and realistic. | report | NA | page 5: BACCH/RCPCH survey (2) in 2016 showed considerable pressure on CCH services: For autism spectrum disorder (ASD), 42.5% of services have a waiting time over 18 weeks for a first appointment, and a referral to treatment (RTT) time of 35.5 weeks, breaching the 18-week Referral to Treatment (RTT) rule in countries where it applies.<br>page 7: Better access to CCH services will shorten time to diagnosis for key conditions including ASD, ADHD, learning disability and other complex neurodevelopmental conditions. Early diagnosis enables better understanding by schools and families of how to best support children to manage their condition and to achieve their potential in society.<br>page 10: Community paediatricians already work with multidisciplinary and multiagency teams. They have been at the forefront of introducing skill mix in CCH e.g. supporting primary care GPs and nurses to take over the delivery of child health surveillance and immunisation programmes and audiological scientists in children's hearing services.<br>page 14: Clinical skill mix - The Covering All Bases (CAB) report shows that skill mix is gradually developing in CCH (Fig 10). ... However, there are currently no recognised role definitions or training pathways for other practitioners to develop Advanced Practice in CCH. These would need to be developed if skill mix is to be introduced safely and effectively.<br>page 14: Administrative support - The CAB survey (2) indicated that only 1 in 3 services had access to electronic records at all times when seeing patients. Many services estimated that nearly 10% of all available doctor time was spent doing non-medical tasks such as filing, photocopying and arranging meetings – all tasks that could be done more cheaply and more effectively by proper administrative support.<br><br>mostly about recruitment & retention - coded a little under 1b. Timely referral & Ax as it's an explanation (=M) for why even if referral is fast, Ax won't be |

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| Williams, et al., 2018 | Northampton, UK | Forty years of referrals and outcomes to a UK Child Development Centre (CDC): Has demand plateaued? | CDC at Northampton General Hospital | reviewing medical notes - descriptive quantitative | To explore 40 years of CDC activity and outcomes at Northampton General Hospital 1974–2014. | The study comprises 3 data sets: a published report from 1974 to 1999, an internal audit from 2001 to 2004, and more recent data collected from 2005 to 2014. The medical notes of all children who were assessed by the CDC in 2014 were reviewed, along with referral data collected by the CDC manager from this year and the preceding 10 years. This was compared with data previously collected from 1974 to 1999. | From January 1, 1974 to December 31, 2014, 3,786 children were assessed. | Covering 1974–2014, we demonstrate a clear increase in the number of referrals together with an increasing demand for assessments for social interaction and behavioural difficulties. This reflects the increased awareness of these neurodevelopmental difficulties and the changing diagnostic criteria which will now more likely result in an ASD diagnosis than previously. Together, these two features are most likely to have considerable implications for service development within Child Development Centres (CDCs) and Child Development Teams (CDTs).<br><br>Like other CDCs, they have experienced a **decrease in the number of AHPs** providing input into the assessment process. |
| Galliver, et al., 2017 | UK | Cost of assessing a child for possible autism spectrum disorder? An observational study of current practice in child development centres in the UK | CDCs - Three CDCs regularly provided long-term follow-up care for families with a new diagnosis. Two reported continued involvement only for specific issues such as need for medication. Another unit commented on its provision of short-term follow-up but experiencing increasing pressure to halt longer term follow-up. All centres could access other agencies for postdiagnosis input, for example, Early Bird programme. | online questionnaire | explore the number of hours of professional time required to complete such an assessment based on current practice in secondary care child development centres across the UK, and from this we calculate the cost of assessment. | An online questionnaire was sent to 20 child development centres asking them to retrospectively record team members involved at each stage of assessment and time taken, including report writing and administration for a typical assessment. Costs were estimated based on the hourly rate for each team member, including salary, on-costs and trust overheads | 20 questionnaires sent to CDCs, 12 returned (all in England & representing 7% of CDCs in the UK). | 10 centres adopted a two-stage approach to assessment with an initial 'screening' clinic determining whether the child needed to proceed to full multidisciplinary assessment. Median professional time involved was 13 hours (IQR 9.6– 15.5 hours). This resulted in a median cost of £809 ($1213, based on conversion rate £1 equal to US$1.5 (November 2015)), (IQR £684–£925) ($1026–$1388))<br>This study confirms that **multidisciplinary diagnostic assessment** of a child with possible autism requires significant professional time, with staff costs of approximately £800 ($1200) per child. This does not include costs of intervention, parent psychological education, investigation and assessment and management of comorbidities. If growing waiting times for diagnostic assessment are to be avoided, funding for diagnostic services needs to reflect the human resources required and the resulting costs of that assessment.<br><br>This would suggest that carrying out a **multidisciplinary assessment is a good practice** and allowing allied health professionals to carry out parts of the assessment not requiring doctor's skills, for example, observational assessment using ADOS, could **save costs**. |
| McKenzie, et al., 2016 | Scotland | The relationship between waiting times and 'adherence' to the Scottish Intercollegiate Guidelines Network 98 guideline in autism spectrum disorder diagnostic services in Scotland | child ASD diagnostic services in Scotland - 8 sampled services | Retrospective, cross sectional case note analysis<br><br>the 80 case notes in both, and 8 child services but 16 above incl adults. | explore the extent to which the Scottish Intercollegiate Guidelines Network 98 guidelines on the assessment and diagnosis of autism spectrum disorder were adhered to in child autism spectrum disorder diagnostic services in Scotland and whether there was a significant relationship between routine practice which more closely reflected these recommendations (increased adherence) and increased waiting times | Used various directories to compile list of possible services; carried out a telephone survey ascertain which services conducted diagnostic assessment of individuals with ASD. This resulted in a list of **64 child services, of which 53 routinely assessed for ASD. Of the 53 services, 23 were CAMHS, 15 were CDCs or equivalent and 15 were specialist ASD or communication teams.**<br>The inclusion criteria for the case notes were that the individual concerned had received a diagnosis of ASD from the participating service and was one of the 10 most recent cases where the individual had received a diagnosis of ASD. A total of 80 case notes were obtained from **eight services**. | 80 case notes. | the assessment and diagnostic practices were consistent with the relevant Scottish Intercollegiate Guidelines Network guideline recommendations. Increased adherence to the 19 included recommendations was not significantly related to increased total waiting times, indicating that the Scottish Intercollegiate Guidelines Network 98 recommendations have generally been integrated into practice, without a resultant increase in patient waits. |
| McKenzie, et al., 2015 | Scotland | Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults | 16 diagnosing services across Scotland (eight adult and eight child ASD diagnostic services) | a cross-sectional, retrospective case note study of eight adult and eight child ASD diagnostic services. | To identify the main factors predicting delays in diagnosis for Autism Spectrum Disorder (ASD) at three stages in the diagnostic process: wait for first appointment; assessment duration, and total wait for diagnosis. | Data were gathered from 150 case notes (**80 child** and 70 adult cases) from 16 diagnosing services across Scotland. | 150 case notes (80 child and 70 adult cases) | Within children's services, increasing the **amount of relevant information available pre-assessment** is likely to reduce total duration of the assessment process by reducing number of contacts required.<br>The results of the present study would suggest 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**.<br>It is also important that relevant information, which is collected by **services which are not necessarily specialists in relation to the diagnosis of ASD**, for example **generic general psychiatric services**, is communicated in a timely way to specialist services. This will help to ensure that diagnosis is not delayed because the individual is seen by numerous professionals before being referred to diagnostic services. |

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| RCPCH (Royal College of Paediatrics and Child Health), 2017 | UK | invited reviews the first four years (2012-2016) | paediatrics in general (not Autism focused) | Review | to provide a `state of play` of the service together with recommendations for future service design, workforce planning and support to our members and paediatrics in general. | The RCPCH provides a unique review service by bringing together clinical and policy expertise to work with local teams to identify and resolve issues of concern. The service launched over four years ago and has undertaken over 60 acute, community, neonatal, emergency and individual reviews.<br>The scope of a review can range from examining an individual case or doctor`s practice, to a theme, pathway, service or network of services.<br>Review teams comprise, as a minimum, two paediatricians and a staff administrator; they have agreed terms of reference and reviews are conducted with tact, diplomacy and discretion. Two additional reviewers provide a quality assurance review of the draft report; the client has a chance to comment on the draft and is encouraged to share the final report as widely as possible. | Over 75 RCPCH members have been involved with reviews alongside lay representatives and nominees from other clinical disciplines. | Emerging themes from the reviews to date include tackling clinical resistance to change, the integration of primary and secondary pathways and problems with covering Tier 2 medical rotas. It is important that clinicians are fully involved in the development of new ways of working, they must be clear about the benefits for children, and they must have confidence in clinical leadership.<br>Most reviews have recommended greater engagement with children and young people, involving them and their families in the design and operational policies of paediatric services. The establishment and assurance of adequate networks to support arrangements for escalating the care of very sick children must be prioritised.<br><br>Most are about **paediatrics in general**. Key info re autism:<br>Page 16 : 4.4 Community Paediatrics 'The changes to the assessment of children with special educational needs were rolled out in September 2014 under the Children and Families Act, resulting in increasing numbers of referrals from parents and schools seeking an autism assessment to identify resources for educational support. Each clinical commissioning group (CCG) is required to identify a Designated Health Officer for special educational needs, usually a senior community paediatrician, to support the contribution to the Education, Health and Care Plans.<br>Child and adolescent mental health services are increasingly pressured and with tight contracts many services are handling referrals for emotional and behavioural concerns through a 'single point of access' and against clear referral thresholds. This can lead to accepting only children and young people with the most severe symptoms or clear mental health need, referring any with suspected attention deficit hyperactivity disorder (ADHD) or autism (ASD) back to an already stretched paediatric team for initial assessment.'<br>and following highlighted findings |
| Ford, et al., 2019 | England | The agreement between the referrer, practitioner and research diagnosis of autistic spectrum conditions among children attending CAMHS over 2yrs | agreement about diagnoses between the **referrer**, **CAMHS practitioner** and a **research diagnosis**, as well as the stability of the practitioner's diagnosis over time | quantitative, secondary analysis | explore the levels of agreement about the diagnoses of Autistic Spectrum Conditions between the referrer, CAMHS practitioner and a research diagnosis, as well as the stability of the practitioner's diagnosis over time | secondary analysis of data from 302 children attending two Children's Team (Tier 3/secondary care), which provided **multidisciplinary treatments** to children up to the age of 16 and the Early Interventions Team (Tier 2/primary care) | 302 children aged 5–11 years recruited from 861 consecutive referrals accepted on the CAMHS waiting lists during the recruitment period (2006 and 2008) | Child health mapping suggests that one in every ten children utilising CAMHS has an ASC.<br>Their findings suggest that where practitioners are confident that a child definitely does or does not have an ASC, there was considerable agreement between practitioner and research diagnoses and clinical diagnoses were stable over time. However, for some children, initial diagnostic uncertainty led to confusing and prolonged fluctuations in practitioner assessments that may have undermined both engagement and intervention. **The use of standardised assessments and observations** might be particularly helpful for these children and could be evaluated further.<br><br>In this study, once assessed by CAMHS, most children with ASC receive a diagnosis within the first six months, which approximates to The National Autism Plan for Children recommendation that time from referral to diagnosis should not exceed 17 weeks. It also runs counter to reports of long delays and multiple assessments reported by others . We do not, however, have details on when these families first sought advice or which services they may have been in contact with prior to the index presentation to CAMHS. |

**Supplementary Document 2.2 - Key papers from secondary searches**

| **Author (year)** | **Country** | **Title** | **Settings/service types** (e.g. ASD, ASD & CAMHS) **& service models** | **Study type** | **Aims** | **Method** | **Sample size** | **Summary of findings relevant to programme theory** |
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| Ahlers, K., et al., 2019 | US | A pilot project using pediatricians as initial diagnosticians in multidisciplinary autism evaluations for young children please can we stick to UK spelling? | The University Developmental Assessment Clinics (UDAC) used a multidisciplinary team for autism spectrum disorder (ASD) evaluations, including psychologists (3), general pediatricians (4), developmental pediatrician (1), speech and language pathologists (SLPs; 2), occupational therapists (OTs; 2), and an audiologist. The UDAC is a clinical program operated by the Division of General Pediatrics at the University of Utah. | quantitative | to examine the feasibility of an alternative diagnostic model and evaluate the differences in wait time (to diagnosis) and fees charged for families whose children were evaluated for ASD in each of the 2 models. | Data were gathered through record extraction (n = 244) and parent questionnaire (n = 57). Authors compared time to diagnosis, charges, and parent satisfaction between traditional and alternative models. Agreement between paediatrician and psychologist diagnoses was examined for a subset (n = 18). | record extraction (n = 244); parent questionnaire (n = 57); Agreement between paediatrician and psychologist diagnoses was examined for a subset (n = 18). | Efficient use of available clinicians with additional training in Level 2 autism screening resulted in improvements in time to diagnosis and reduced charges for families. Coordination of multidisciplinary teams makes this possible, with strategic sequencing of patients through workflow. Flexibility was key to not only allowing paediatricians to refer uncertain cases to psychology for diagnosis but also allowing for diagnosis by a paediatrician when symptomatic presentation clearly met diagnostic criteria. However, there were concerns that the abbreviated pathways could lead to issues of inequality, with families receiving different outputs depending on their route. |
| Department for Education and Department of Health and Social Care, 2015 | England | Special educational needs and disability code of practice: 0 to 25 years. | Services for children and young people who have special educational needs or are disabled | staturory guidance - Code of Practice | Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities | The Code of Practice is the product of extensive consultation, and draws on the experience of pathfinder local authorities which have been piloting new approaches with local communities. | NA | This Code of Practice provides statutory guidance on duties, policies and procedures relating to Part 3 of the Children and Families Act 2014 and associated regulations and applies to England. It relates to children and young people with special educational needs (SEN) and disabled children and young people.<br>The aim is to identify special educational needs and disabilities at the earliest point with support routinely put in place. Relevant to programme theory 6b, the role of the SENco (SEN Co-ordinator). |

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| Hayes, et al., 2018 | UK | Clinical practice guidelines for diagnosis of autism spectrum disorder in adults and children in the UK: a narrative review | ASD services | narrative review | to consider how the content of clinical practice guidelines shapes diagnoses of Autism Spectrum Disorder in the UK; and investigate where, within those guidelines, social factors and influences are considered. | searched multiple databases (NICE Evidence Base; TRIP; Social Policy and Practice; US National Guidelines Clearinghouse; HMIC; The Cochrane Library; Embase; Global health; Ovid; PsychARTICLES; PsychINFO) and relevant web sources (government, professional and regional NHS websites) for clinical practice guidelines.<br>extracted details of key diagnostic elements such as assessment process and diagnostic tools.<br>A qualitative narrative analysis was conducted to identify social factors and influences. | Twenty-one documents were found and analysed. | Guidelines varied in recommendations for use of diagnostic tools and assessment procedures. Although multidisciplinary assessment was identified as the 'ideal' assessment, some guidelines suggested in practice one experienced healthcare professional was sufficient. Social factors in operational, interactional and contextual areas added complexity to guidelines but there were few concrete recommendations as to how these factors should be operationalized for best diagnostic outcomes.<br><br>Relevant to PT6a in terms of context of assessements; while supporting MDT assessements, it is unclear how disagreement is resolved; there is a lot of variation between guidelines which can sew confusion; the role of clinical judgement. |
| Hennel, S., et al., 2016 | Australia | Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice. | Australian Paediatric Research Network - members paediatricians who saw children with ASD - diverse clinics | Survey- quant & qual questions | 1) compare parents' experience and preferences with paediatrician report of (i) diagnosis delivery and (ii) information given at diagnosis and<br>2) identify types and usefulness of resources accessed by families post-diagnosis. | The design used for the study are parent and paediatrician surveys. Participants are parents of children aged 1.5–18 years, diagnosed with autism between 01 January 2010 and 30 September 2012 and their paediatricians who are members of the Australian Paediatric Research Network. Study-designed quantitative and qualitative questions about diagnosis delivery and information given at diagnosis (written and spoken vs. neither) and parent perceived importance and harms of information accessed post-diagnosis. | Paediatricians (53/198 (27%)) identified 1127 eligible families, of whom 404 (36%) participated. | Parents want more information than can be conveyed in a single diagnostic consultation. Developing a tailored 'autism action plan' with written materials could improve parents' understanding of and satisfaction with children's autism diagnoses.<br>Relevant to PT4a in terms of practical suggestions: clinicians should (i) encourage a support person to be present; (ii) provide information about school support, tailored therapy plans and choosing effective therapies either at diagnosis or afterwards; (iii) refer families to allied health professionals; and (iv)encourage families to explore evidence-based websites In addition to face-to-face clinical consultations, parents find written in- formation useful, particularly for understanding the diagnosis and explaining it to friends and family. |
| Jordan, E., Farr, W. & Male, I., 2017 | UK | Pirate adventure assessment software: a new tool to aid clinical assessment of children with possible autism. | UK based Child Development Centres | pilot - software in clinical assessment of children with possible autism | presents a computer based tool, developed by the research team, which early clinical experience suggests could provide additional information to the initial assessment. | The Pirate Adventure Autism Assessment software includes a number of psychometric tests adapted into a pirate adventure storyline.<br><br>The app has been piloted by paediatric consultants working in three local Child Development Centres, two at initial appointment, in one at a diagnostic clinic. | NA | Early experience, presented here, suggests the tool is a useful adjunct to parental history and school questionnaire obtained at initial clinic, in determining the need for the child to proceed to a full, time consuming, expensive, diagnostic assessment. |
| Juárez, et al., 2018 | US | Early identification of ASD through telemedicine: potential value for underserved populations. | Study 1: a diagnostic clinic at a university-affiliated medical centre due to early concerns about ASD.<br><br>Study 2: a regional health center serving a rural 23 county region, geographically distant from the urban diagnostic centers of our state. | Accuracy; Feasibility & acceptability | evaluate a telemedicine assessment procedure | 1) compared telediagnostic accuracy to blinded gold-standard evaluations (n = 20).<br>2) evaluated telediagnostic feasibility and acceptability in a rural catchment.<br>Children (n = 45) and caregivers completed the telemedicine procedure and provided feedback. | Study 1: Participants were 20 children (16 boys, 4 girls) between 20 and 34 months of age (mean = 26.65, SD = 4.49) and their caregivers.<br>Study 2: Participants were 45 children (mean age = 26.80 months, SD = 3.12, range 19–32; 35 boys, 10 girls) and their caregivers | Findings support preliminary feasibility, accuracy, and clinical utility of telemedicine-based assessment of ASD for young children. ASD cases identified via telemedicine were confirmed by in-person evaluation. However, 20% of children diagnosed with ASD in-person were not diagnosed via telemedicine.<br>Families indicated high levels of satisfaction. Remote diagnostic clinicians diagnosed 62% of children with ASD, but did not feel capable of ruling-in or out ASD in 13% of cases.<br>This pilot work demonstrated that a large percentage of children with ASD may be accurately diagnosed via remote observation of standardized assessment procedures, and many families and providers ascribe clinical value to the procedure. |

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| Male, Farr & Reddy, 2020 | UK | Should clinical services for children with possible ADHD, autism or related conditions be delivered in an integrated neurodevelopmental pathway? | two CDTs:<br>1- based in a large mixed urban–rural county, where there are three provider trusts, four CDTs and four CAMHS teams. While a newly commissioned, joint CAMHS/CDT complex cases clinic pilot is about to start, to assess children with diagnostic complexity, current commissioning and practice requires children with possible autism up to age 11 to be seen within CDTs, while children with possible ADHD and older children with possible autism are the remit of CAMHS.<br>2- a fully integrated CDT/CAMHS service, colocated in a single building, in a city organised as a unitary authority, facilitating close working between health, education, social care and child and family support services. | Viewpoint paper | We present the journeys of a typical primary school-aged child referred with a history suggestive of either autism and/or ADHD and the pathways they would follow in each service. This illustrates how the integrated and non-integrated approaches can affect the professional time involved, the resulting NHS costs and the patient journey. | Scenario<br>1) Diagnostic pathway experienced in the non-integrated approach;<br>2) Diagnostic pathway experienced in the integrated approach | NA | It's often a very inefficient and, for the parents, frustrating journey to a diagnostic conclusion for their child presenting with a mixture of difficulties in social communication, concentration and hyperactivity. Commissioning of separate autism and ADHD pathways, one with the CDT and the other with CAMHS, resulted in the child having to go through both pathways despite considerable overlap of assessment. The integrated approach, by running a single assessment process, cutting out this overlap, required less professional time (13 vs 20.75 hours), at a lower cost (£817 vs £1357), and reduced the time taken to reach a completed diagnostic formulation. Furthermore, the additional time and cost taken reduced the capacity of the first service to meet wider demand for assessment.<br><br>Why integrated pathways are still a novelty at secondary care level in neurodevelopmental services: CAMHS and CDTs often sit in different health trusts, who have been commissioned to deliver specific pathways; the separation of autism and ADHD in previous diagnostic coding systems; the current financial pressures on all NHS trusts.<br><br>moves toward running integrated CDT/ CAMHS services for children with potential neurodevelopmental and/or mental health conditions have the potential to improve efficiency of service delivery. |
| NHS Education for Scotland, 2014 | Scotland | The NHS Education for Scotland Autism Training Framework - Optimising Outcomes - A framework for all staff working with people with Autism Spectrum Disorders, their families and carers | various health and social care settings | Training Framework | The framework is not prescriptive, but its clarity and breadth of scope should facilitate individual employees, service providers and organisations to understand the knowledge and skills required and how this applies to their practice. | the framework developed was informed by:<br>-review of existing training frameworks (MacKay and Dunlop, 2004)<br>-evidence and best practice guidelines<br>-engagement with the autism community regarding experiences of contact with services<br>-Learning Needs Analysis amongst NHS staff<br>- Review of existing education and training in autism spectrum disorders<br>- consultation with professional bodies, thrid sector orgs and educational institutions<br>-consultation iwth the subgroups of the Scottish Strategy for Autism | NA | The NES Autism Training Framework has identified four Levels of Knowledge and Skills required, dpeending on the nature, extent and likely impact of contact during day-to-day work in the particular service, rather than defining levels specific to profession or position in a service. The Four levels: 1. Autism Informed Practice Level- for all professionals working with Autism in health and social care settings; 2. Autism Skilled Practice level- for all staff with direct and/or frequent contact with individuals with Autism or those who have a role with high impact on these individuals; 3. Autism enhanced Practice Level- for professionals with more regular or intense contact with individuals with Autism where their role focuses specifically on the condition and providing interventions, or service managers; 4. Expertise in autism Practice Level – for professionals who have a specialist role in the care, management and support of people with Autism.<br><br>. |
| RASDN, 2011 | Northern Ireland | Six Steps of Autism Care - for Children and Young People in Northern Ireland | various community settings, including GP, Autism services, social care & voluntary organisations | leaflet to parents/carers | to provide parents/carers with information about the new regional 'Six Steps of Autism Care' Pathway for children and young people in Northern Ireland. | NA | NA | This leaflet tells parents about the agreed journey child/ young person, and parents, will take through the integrated assessment, diagnosis and intervention process. It gives information about each step in the process about who will see the child/young person; which tests will take place; tell parents whether their child/young person has ASD, or not, and the follow up support that will be made available to the child/young person and family, with the following 6 steps (Page 4 flow diagram): 1. First appointment; 2. Integrated Multi-disciplinary Team Assessment; 3. Integrated Multi-disciplinary Team Formulation; 4. Family Feedback and Care Planning; 5. Integrated Family Intervention and Support Services Delivered Over Pre-Planned Sessions; and 6. Child and Family Care Plan Review at Regular Intervals. |

**Supplementary Document 3.** Programme theories with CMO configurations

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| **Programme theory 1 – Listening and recognition**<br><br>If frontline health and education professionals (e.g. GPs, teachers) are confident in recognising the signs and symptoms of autism, are cognisant of referral pathways and take parents/carers' concerns seriously then CYP will be referred to the appropriate service, in a timely manner, reducing parental frustration. | | |
| 1a. Parents/carers concerns are listened to and discussed | If frontline health and education professionals (e.g. GPs, teachers) take parents' concerns seriously (M), discuss and explain developmental behavioural concerns sensitively (M) and agree any actions to follow (M), then they will refer in a more timely manner (O) and parents will feel reassured with stress levels reduced (O).<br><br>Also, if professionals at nurseries and schools (teacher or others) make a difference in "pushing" for a diagnosis or a specific form of support (M), then this will lead to timelier referral (O) and improve parental satisfaction (O) with the referral pathway.<br><br>However, mis-diagnosis can be detrimental (C), so while parents should request referral for possible autism diagnosis (M) this has to be balanced against respecting professional expertise and enabling the development of a co-operative relationship (O). | NICE, 2011; Abbott, et al., 2013; The Scottish Government, 2014; Rogers, et al., 2016; O'Reilly, et al., 2017; Unigwe, et al., 2017; Crane, et al., 2018; Dowden, 2018; Rutherford, et al., 2018; Hurt, et al., 2019. |
| 1b. Frontline health and education professionals are cognisant of autism and referral pathways | If frontline health and education professionals (e.g., GPs, teachers) are trained in recognising the signs & symptoms of autism and referral routes (M), then their ability, confidence and skills in identifying children or young people (CYP) who need an autism diagnostic assessment will improve (O) and they will refer to the 'right' service in a timely manner (O).<br><br>If proportionately fewer CYP go through the full process (M) then accessibility of services will increase (O), and the risk of unnecessarily raising parental concern over autism when it is not present will reduce (O).<br><br>However, it is important to sensitively manage (M) a balance between supporting parents to accurately identify autism as early as possible, and not causing unnecessary concern amongst those who do not meet criteria for autism but may show some isolated Autistic-like features (O). | NICE, 2011; Reed and Osborne, 2012; Abbott, et al., 2013; The Scottish Government, 2014; Crane, et al., 2016; O'Reilly, et al., 2017; RCPCH, 2017; Potter, 2017; Dowden, 2018; Hurt, et al., 2019; Ford, et al., 2019. |
| **Programme theory 2 - Referral and triaging** | | |

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| If autism diagnostic services provide clear guidelines for referrers on what information is needed and how to refer, then time will be saved at the triaging stage and fewer CYP who do not have autism will go through the full process. | | |
| 2a. Referral process | Referrals often lack relevant information; this adds to waiting lists and clinician time, as they gather appropriate additional information, delaying the diagnostic process (C).<br><br>If referral is via a single point of access (for all neuro-developmental conditions and incorporating mental health expertise) (M) and referrers are provided with a systematic method of gathering relevant information from home and other settings preassessment (M) (e.g. proforma or digital assessment dashboard) and guidelines on how to do so (M), then referrers will know what information to gather, how to refer and what to expect following referral (O).<br><br>When referrals are declined, the referrer should be provided with an explanation (M), advice for improving the referral (M) and/or other appropriate services to refer to. Collectively, these measures will contribute to reducing the waiting list and low diagnostic yield (low numbers of positive diagnoses) (O). | NICE, 2011; Carpenter, 2012; The Scottish Government, 2014; MacKenzie, et al., 2015; Healthcare Improvement Scotland, 2016; Rutherford, et al., 2016; Rutherford, et al., 2018; Autistica, 2019; Tollerfield and Pearce, 2020. |
| 2b. Triage | Services that triage referrals depend on having the necessary information (C). Cross-organisational triaging (e.g. monthly meetings with a representative from CAMHS, CCH and SLT), while time intensive, has several benefits including improved joint working (M response); a forum to discuss complex cases (M); improved compliance with the care pathway (O); only referrals with adequate information are accepted and therefore clinicians will use their time well (O); and this avoids referrals bouncing between agencies (O).<br><br>Other approaches to triaging include an initial interview with an experienced clinician (M) who feels confident to identify CYP who clearly do, or do not, have autism; a community paediatrician carrying out a General Developmental Assessment/'Stage 1' Assessment, before referring to the MDT for further assessment, if needed (M).<br><br>Although triaging and referral management requires very clear guidance and training for staff (M) it results in proportionately fewer CYP going through the full process who do not have autism (O) which reduces the risk of unnecessarily raising parental concern over autism when it is not present (O). | NICE, 2011; The Scottish Government, 2014; MacKenzie, et al., 2015; Healthcare Improvement Scotland, 2016; Rutherford, et al., 2016; Rutherford, et al., 2018; Hurt, et al., 2019; Tollerfield and Pearce, 2020. |

| **Programme theory 3 - Diagnostic assessment**<br><br>There is wide variation in the model for autism diagnostic services and national staff shortages but these can be addressed with a structured and consistent approach, making best use of available staff and clinical expertise. | | |
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| 3a. Model & skills mix | Current services have different condition-specific remits and models (e.g. Autism only, all neuro-developmental conditions, and/or integrated with CAMHS), catchment areas and commissioning agreements which raises challenges around capacity, care pathways and funding (C). Streamlining (M) the autism diagnostic pathway requires a structured and consistent approach (M) so that the number of assessments per individual are minimised, alongside developing efficient working and communication (e.g. shared proformas for report writing; on-line reports) (M), thereby saving resources (O) and reducing waiting lists.<br><br>There is very little evidence to guide optimal service configuration (C) and the skills mix of diagnostic teams often relates to funding streams and the development of services over time (M). Core multi-disciplinary diagnostic teams are advisable (M) but there are national shortages of suitably trained professions including paediatricians and child psychiatrists who are the costliest members of the team (C).<br><br>However, the role of professions that are available locally (e.g. SALT) can be extended by training them to carry out aspects of the assessment not requiring medical expertise (e.g. observational assessment) (M) which will reduce costs (O). Similarly, incorporating questions previously undertaken by psychiatrists into the parent interview (M) will free up time for psychiatrists to focus on complex diagnoses (O).<br><br>Planning resources to meet need requires services to review their service configuration and skill mix (M) to accommodate demand within the available resources (O). Also recommended is ensuring that a core group of staff have dedicated autism time (M) and have shared skills for core aspects of autism assessment (M) to avoid overdependence on one clinician.<br><br>However, disadvantages of MDT diagnostic assessment are that it takes longer and different professions may disagree (C). To reduce this added stress on families, professionals sometimes make their diagnosis independently (O). | NICE, 2014; Karim, et al., 2014; Gray, et al., 2015; Halpin, 2016; Healthcare Improvement Scotland, 2016; MacKenzie, et al., 2016; Rogers, et al., 2016; Galliver, et al., 2017; Rutherford, et al., 2018. Ahlers, et al., 2019; Autistica, 2019; Tollerfield and Pearce, 2020. |

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| | Some CYP referred for autism diagnosis may require mental health expertise and when unavailable, have to return to the waiting list for CAMHS (C). If the same Trust manages both community paediatrics and mental health services (M), this potentially allows for a seamless transition, avoids duplicate waits and enables families to see all relevant professionals at the same time (O). | |
| 3b. Clinical judgement | Diagnosis should involve interview, observation and recognised tools (C). Less experienced clinicians appear to prefer using formal extended tools compared to their more experienced counterparts (C). However, standardised tests lack subtlety and children may not meet cut-offs (e.g. atypical presentations) to receive a positive diagnosis. Clinicians often use their clinical judgement (M) to 'upgrade' the diagnosis so that the child is entitled to support (O).<br><br>Many psychiatrists and paediatricians rely on the reports and observations of other professionals to inform their decisions while some, particularly educational psychologists, prefer to carry out their own observations within educational or home settings (C). This is valuable but time consuming; one solution (O) may be for professionals to only do observational assessment (M) if there are discrepancies between school and home reports.<br><br>It is not always possible to provide a child with an accurate diagnosis at an early stage (C). Diagnostic uncertainty can lead to confusing and prolonged assessments (M) that may undermine both engagement and intervention (O). Therefore, reassessment after a specified timeframe (M) is necessary and the use of standardised assessments and observations (M) might be particularly helpful to aid diagnosis (O). | Carpenter, 2012; Karim, et al., 2014; Crane, et al., 2016; Rogers, et al., 2016; Rutherford, et al., 2016; Healthcare Improvement Scotland, 2016; Ford, et al., 2019. |
| 3c. Digital technology | Children with autism sometimes feel an affinity for computing technology (C), as it is may be seen as a safe environment (M) to learn and practice skills that may be difficult in everyday life. The use of such technology in autism diagnosis is at an early stage (C) but shows potential, for example, using tablets/computers at school to collect observational data in a natural setting (M). If clinicians are able to access observations in advance (M), this would supplement other sources of data (O), save clinical time (O) and contribute to faster diagnosis (O). Telemedicine for autism screening &/or diagnosis is in the early stages of development (C) but shows some promise identifying individuals for further assessment (O) and early data suggest may be feasible and acceptable to parents and children (M). | Tryfona, et al., 2016; Jordan, et al., 2017; Juárez, et al., 2018. |

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| **Programme theory 4 – Diagnostic feedback**<br><br>If parents understand the diagnostic process and feel supported this can moderate parental expectations. Feedback should take an assets-based approach and the management plan should be individualised, taking account of co-existing conditions. Reports should be timely and in a format that everyone finds helpful. | | |
| 4a. Diagnostic feedback to parents and CYP | Parents can find the diagnostic process stressful, and may fear the stigma attached to diagnosis, but anticipate that a positive diagnosis will act as a gateway to individualised information, advice, support, services and/or treatment (C).<br><br>Receiving the diagnosis can affect parents' ability to absorb information but irrespective of the format (e.g. single professional or multi-disciplinary) (C) parents value: feedback that focuses on their child's strengths (asset based approach) (M) as this enables them to understand their child's needs (M), communicate these needs to others (O) and identify services to meet them (O); a structured and focused approach and the opportunity to ask questions (M); being put at their ease, listened to and given time to absorb information (M); and a positive and open parent-clinician relationship, established during the assessment process (M).<br><br>Parental satisfaction is further enhanced (O) when the diagnosis results in an individualised management plan that identifies co-existing conditions (M); support post-diagnosis is co-ordinated and tailored to need (M); and appropriate services are available (M).<br><br>Unintended consequences (O) include no autism or neurodevelopmental diagnosis which means parents may not be entitled to access condition specific services. Some CYP do not identify any benefits to diagnosis and fear being singled out as 'not normal' and subsequently stigmatised (O). | NICE 2011; NICE 2014, RASDN, 2011; Calzada, et al., 2012; Carpenter, 2012; Reed and Osborne 2012; Abbott, et al., 2013; Karim, et al., 2014; The Scottish Government, 2014; Halpin, 2016; Healthcare Improvement Scotland, 2016; Hennel, et al., 2016; Reed, et al., 2016; Rogers, et al., 2016; Crane, et al., 2018; The Scottish Government, 2018; Autistica, 2019; Hurt, et al., 2019; |
| 4b. Report format | A standardised template for report writing, using consistent terminology, visual tools, enabled professionals to collate reports in a timelier manner and in a format that all found helpful. | MacKenzie, et al., 2016; Tollerfield & Pearce, 2020. |
| **Programme theory 5 - Working in partnership with families**<br><br>Parents find the diagnostic pathway stressful so find it helpful to have a single point of contact; to be provided with explanations about the process; and to be included in decision-making. | | |

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| 5a. Parent/carer as co-experts in the diagnostic process | Contributing to the patient-professional tension is a debate around who is the expert (C). Parents expect to be listened to during the diagnostic process and their concerns taken seriously because they 'know' their child (C); if they feel belittled and/or do not understand the process or terminology (Ms), they will disengage from the process (M) and/or resist alternative diagnosis (O) which will have a detrimental impact on the parent-professional relationship (O). Professionals need to explain the diagnostic pathway and acknowledge that it is enhanced (O) when expertise is integrated with the perspectives of the individual and their family (M). Parents want to have a transparent and honest dialogue with professionals (M) and be involved in key decision-making (O). | Gregory, et al., 2013b; Rogers, 2016; Healthcare Improvement Scotland, 2016; Crane, et al., 2018. |
| 5b. Supporting parents/carers | Some parents perceive the system as poorly co-ordinated and feel it necessary to take charge of organising diagnostic and support processes. However, a consistent point of contact within the system would provide emotional support and enable parents to be kept up-to-date (O). When professionals explain the diagnostic process in advance and how long it will take (M), this improves parental satisfaction and can moderate expectations (O).<br><br>Non-attendance at appointments is frequent (C) and services need to have systems in place to reduce it, for example using reminders, opt-in systems and a support contact to facilitate attendance (M). By increasing attendance levels, this will reduce service costs and waiting times (O).<br><br>When contact with professionals during diagnosis has been perceived by parents as unsatisfactory, this may lead to subsequent treatments undertaken by the child being less effective than they otherwise might have been (C). Satisfaction can be improved by managing the process in a thoughtful and sensitive manner (M); clearly explaining the diagnosis (M); and demonstrating a high degree of knowledge and empathy (M). Also, if some professionals (e.g. nurses) provide advocacy for parents' views during assessment (M) and well-organised parent/carer groups are established (M), parents' concerns are more likely to be heard and parents will be empowered to speak up for themselves (O). | Calzada, et al., 2012; Abbott, et al., 2013; Gregory, et al., 2013b; NICE, 2014. |
| **Programme theory 6 - Inter-agency working**<br><br>If "experts" including people with autism, carers, professionals and specialist organisations work in partnership and the knowledge generated is effectively embedded into local services, this will build capacity, improve parent/CYP satisfaction and support planning of services both locally and nationally. | | |

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| 6a. Macro-Meso level | A multi-disciplinary, inter-agency and holistic approach is essential (M) given the subjective nature of diagnosis and the significant differences in presentation of CYP with autism (C). However, there are multiple barriers to inter-agency working at all levels, particularly a hierarchical relationship between education and health (C), with education practitioners delivering daily interventions but having to rely on healthcare professionals to issue diagnoses to release additional funding or support.<br><br>Macro-level approaches to ameliorate these barriers include: setting up a national 'whole life' autism strategy that co-ordinates multi-agency planning (M); a national approach to support school pupils with autism (M); clear standards of training and expertise (M) for all service providers offering services for those with autism, and access to specialist training; positioning (strategically and/or physically) autism services alongside other CYP's services (M), as this enables the development of a shared understanding which promotes effective joint-working (O) and is particularly useful where CYP are at risk; a more integrated care pathway with additional ringfenced funding (M).<br><br>If teams are supported to structure and deliver services in a flexible, creative, 'can do' approach at all levels from the clinician working on a day-to-day basis, to cross agency working, up through middle and senior management (M), then the experience of parents, children, clinicians and referrers would be improved (O).<br><br>If partnership working across organisations develops and consolidates a combined skill set (M), has mechanisms in place to share information (M) and holds regular networking and multi-agency professional meetings (M), then this will support the development of a shared understanding of CYP, their support needs and those of their parents (e.g. negotiating with the wider system) (O). | NICE, 2011; Gregory, et al., 2013a; Karim, et al., 2014; NICE, 2014; The Scottish Government, 2014; Gray, et al., 2015; Healthcare Improvement Scotland, 2016; Rogers, et al., 2016; Galliver, et al., 2017; Hayes, et al., 2018; The Scottish Government, 2018; Williams, et al., 2018; Hurt, et al., 2019; Tollerfield and Pearce, 2020. |
| 6b. Micro level | Multi-agency working (M) is designed to minimise variations and enhance the engagement of all services (C). Improved co-ordination between health, education and local authorities (M), at the level of individual diagnostic assessment would help reduce the time taken from referral to diagnosis, improve parental perceptions of support following diagnosis (O) and, with clear documentation (M), improve information flow between involved parties (O). | NICE, 2011; Calzada, et al., 2012; Gregory, et al., 2013b; The Scottish Government, 2014; Tollerfield and Pearce, 2020. |

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| | Opportunities to enhance multi-agency working include a "one stop shop" coordinator for children with ASD (M) and split posts for staff which can act as bridges between different parts of the system or different organisations (M), aiding understanding and communication (O). One opportunity to build links with relevant (voluntary) organisations (O) is to rent space, such as a community clinic, to carry out ASD assessments (M) but it needs to be an environment suited to the needs of children with ASD. However, when CDTs are based in a dedicated CDC (M), they are more likely to have implemented good practice recommendations including recommended team working and family communication standards (O).<br><br>If ASD diagnostic services establish clear pathways, including detailed data on the use of time and tools at each stage of the process (M), this will improve effectiveness in assessing, diagnosing and supporting children with autism (O). | |
| **Programme theory 7 – Training, service development and evaluation**<br><br>Based on their needs, skills and knowledge for autism diagnostic assessments and working with families, health and community professionals should have access to tailored training, service development and service evaluation. | | |
| 7a. Training for professionals working with CYP in community settings | Training in many organisations is "ad hoc", varies widely and may have low priority given financial constraints (C); multi-agency training is limited (C). Clinicians working with CYP with developmental delay, speech, language and communication impairments and mental health difficulties will come into regular contact with children with autism, as will frontline staff in generic children's services (e.g. nurseries) (C). If multi-agency training for professionals is provided (M), with a targeted and coordinated approach across organisations (M), a wide breadth of coverage of basic training can be achieved (M) and awareness and training geared to the needs of managers as well as front-line staff (M). This will increase the local skill set of people who regularly work with children who may have autism (O).<br><br>Another approach is to develop a detailed framework, mapping staff skills and knowledge for autism diagnostic assessment at different levels (informed, skilled, enhanced and expert practice levels) (M). The levels of skill required by different staff depend on the nature, extent and likely impact of daily contact with individuals with autism (M), rather than defining levels specific to profession or position in a service. The framework can be used by individuals, organisations or training providers to identify current or future training needs at different levels (O). | NICE, 2011; Gregory, et al., 2013a; NHS Education for Scotland, 2014; The Scottish Government, 2014; Rutherford, et al., 2016; Rutherford, et al., 2018; The Scottish Government, 2018. |

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| 7b. Training for health professionals working in autism services | Training budgets have been reduced (C). If professionals working in autism services are provided with crucial supports, including backing for training, funding for a specialist library and practical resources (M) as well as access to supervision, links with other experienced professionals, and an open team culture of sharing ideas (M), then they will be able to work with CYP in the most skilled and effective way (O). As above, training programmes need to be tailored to the level of competencies required (i.e. enhanced and expert practice levels) (M). Training activities could include observing in a (tertiary) autism clinic (M) to develop skills and confidence (O); 'buddy up' with more experienced staff (M); regular Continuing Professional Development sessions for the team to review training needs (M); developing an explicit plan for succession planning and training needs (M); and a national forum to share experiences and knowledge, including people with autism and their families (M). As more staff become better trained in, for example, the use of standardised autism assessment tools (O), there will be a higher degree of consistency between local and specialist teams (O). | Gregory, et al., 2013a; Autism ACHIEVE Alliance, 2014; Rutherford, et al., 2016; Rutherford, et al., 2018. |
| 7c. Service development & evaluation | Structural and organisational barriers impact on the effectiveness of the autism pathway (C) and as services have become increasingly overburdened, clinicians have little time to engage with service evaluation and development (C). If services plan resources to meet need, based on audit data, for example reviewing service configuration and skill mix to accommodate demand (M) and make efficient use of administrative support to free up the diagnostic team (M), then time allocation and quality of autism services will be protected within resources and available capacity (O).<br><br>Services should maintain or develop efficient systems of collecting information about referrals, waiting times and outcomes, for example using a guidelines checklist at the front of each patient file (M); data can be collated (M) for senior managers and commissioners to evidence shortcomings in staffing and resources (O).<br><br>Suggestions to help promote service development and embed changes into practice (O) include having one person to lead/champion change (M); generating research within clinical teams (M); encouraging practitioners to co-create contextually sensitive solutions (M) in a cyclical process of service evaluation and development; and drawing on 'experts' within the field, including people with autism, carers and specialist organisations who could support local service development if identified and connected into the process (M). | The Scottish Government, 2014; Rutherford, et al., 2016; RCPCH, 2017. |

**Checklist: List of items to be included when reporting a realist synthesis**
**From Wong et al. BMC Medicine 2013, RAMESES publication standards: realist syntheses11:21**
**http://www.biomedcentral.com/1741-7015/11/21**
**Page 4 of 14**

| | | |
|---|---|---|
| **TITLE** | | |
| 1 | In the title, identify the document as a realist synthesis or review | ✓ p1 |
| **ABSTRACT** | | |
| 2 | While acknowledging publication requirements and house style, abstracts should ideally contain brief details of: the study's background, review question or objectives; search strategy; methods of selection, appraisal, analysis and synthesis of sources; main results; and implications for practice. | ✓ p2 |
| **INTRODUCTION** | | |
| 3 | Rationale for review. Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area. | ✓ p3 |
| 4 | Objectives and focus of review. State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review. | ✓ p4 |
| **METHODS** | | |
| 5 | Changes in the review process. Any changes made to the review process that was initially planned should be briefly described and justified. | No changes p5 |
| 6 | Rationale for using realist synthesis. Explain why realist synthesis was considered the most appropriate method to use. | ✓p4 |
| 7 | Scoping the literature. Describe and justify the initial process of exploratory scoping of the literature. | ✓ p5 |
| 8 | Searching processes. While considering specific requirements of the journal or other publication outlet, state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include, for example, name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected. | ✓p5-6 |
| 9 | Selection and appraisal of documents. Explain how judgements were made about including and excluding data from documents, and justify these. | ✓p7 |
| 10 | Data extraction. Describe and explain which data or information were extracted from the included documents and justify this selection. | ✓ p7 |
| 11 | Analysis and synthesis processes. Describe the analysis and synthesis processes in detail. This section should include information on the constructs analyzed and describe the analytic process. | ✓p7-8 |
| **RESULTS** | | |
| 12 | Document flow diagram. Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example, from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification to suit the data) that are provided. | ✓ p8 |

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| 13 | Document characteristics. Provide information on the characteristics of the documents included in the review. | ✓p8 |
| 14 | Main findings. Present the key findings with a specific focus on theory building and testing. | ✓p8-12 |
| **DISCUSSION** | | |
| 15 | Summary of findings. Summarize the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s). | ✓p12-14 |
| 16 | Strengths, limitations and future research directions. Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed. | ✓ p14 |
| 17 | Comparison with existing literature. Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic. | ✓ p12-14 |
| 18 | Conclusion and recommendations. List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice. | ✓p14 |
| 19 | Funding. Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers. | ✓ p15 |

BMJ Open

# A Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD): Which diagnostic pathways work best, for whom and in what context? Findings from a rapid realist review.



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# A Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD): Which diagnostic pathways work best, for whom and in what context? Findings from a rapid realist review.

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# Abstract

**Objectives**

Waiting times in the UK for an autism diagnostic assessment have increased rapidly in the last five years. This review explored research (including 'grey' literature) to uncover the current evidence base about autism diagnostic pathways and what works best, for whom and in what circumstances, to deliver high quality and timely diagnosis.

**Design**

We performed a Rapid Realist Review (RRR) consistent with recognised standards for realist syntheses. We collected 129 grey literature and policy/guidelines and 220 articles from seven databases (Jan 2011-Dec 2019). We developed programme theories of how, why and in what contexts an intervention worked, based on cross-comparison and synthesis of evidence. The focus was on identifying factors that contributed to a clearly defined intervention (the diagnostic pathway), associated with specific outcomes (high quality and timely), within specific parameters (Autism diagnostic services in Paediatric and Child & Adolescent Mental Health services in the UK). Our Expert Stakeholder Group, including representatives from local parent forums, national advocacy groups and clinicians, was integral to the process.

**Results**

Based on 45 relevant articles, we identified seven programme theories that were integral to the process of diagnostic service delivery. Four were related to the clinical pathway: initial recognition of possible autism; referral and triaging; diagnostic model; and providing feedback to parents. Three programme theories were pertinent to all stages of the referral and diagnostic process: working in partnership with families; inter-agency working; and training, service evaluation and development.

**Conclusions**

This theory informed review of childhood autism diagnostic pathways identified important aspects that may contribute to efficient, high quality and family-friendly service delivery. The programme theories will be further tested through a national survey of current practice and in-depth longitudinal case studies of exemplar services.

**Trial registration number NCT04422483**.

**Strengths and limitations of this study**

- This realist review focussed on reviewing and synthesising recent evidence to determine what approaches to autism diagnostic assessment worked best, for whom and in what context. The approach is better suited than more empirical methods that assume there is one model to suit all situations.
- Our Expert Stakeholder Group and parent representatives engaged with all stages of the review and enabled an iterative approach to identifying relevant literature and refining our findings.
- As appropriate to our research question, we limited the search to UK literature but may have missed relevant literature from similar health systems. Although synthesis was based on UK literature, we have considered how this relates to relevant international literature.

# Introduction

The number of children and young people (CYP) diagnosed with autism spectrum disorder (autism) has increased significantly in recent years (1-3) with a median age for diagnosis of 55 months (4). This international phenomena is reflected in increasing pressures on diagnostic assessment and long waiting times in some services (5), with associated family dissatisfaction (6). The UK National Health Service (NHS) Long Term Plan (7) highlighted the need for research to identify the most effective ways to improve timely access to diagnosis whilst maintaining high-quality assessment for this service user group.

Autism is characterised by persistent severe deficits in social interaction, social communication, and restricted, repetitive, inflexible patterns of behaviour and interests (8), although the level of symptoms varies considerably between individuals. It is commonly associated with other neurodevelopmental and mental health conditions, such as anxiety, ADHD and developmental language disorder (9-11), making reliable diagnosis a complex process. National guidelines for Autism in the UK (12) recommend multidisciplinary assessment, with the skills to consider both the presence of other neurodevelopmental and mental health conditions (for example, ADHD, anxiety disorders), and co-existing conditions (for example eating or sleeping related). However, this holistic assessment is time-consuming and costly (13, 14). There are significant variations between diagnostic pathways, which some have defined as 'complex interventions for mutual decision making, organisation and standardization of predictable care for a well-defined group of patients during a well-defined period' (15), and only limited evidence of which pathways work best, for whom and in what circumstances.

Although the formal research base is limited, some local providers have already reconfigured their services to address these issues (16-18). However, robust evidence is needed to identify which care pathways, in which contexts, have the potential to meet the growing demand for diagnostic assessment in a timely, clinically valid, and family-friendly way. This Rapid Realist Review (RRR), the first step in a national Realist Evaluation of Autism ServiCe Delivery (RE-ASCeD), aimed to explore how particular approaches aspired to deliver high quality and timely autism diagnostic services (19). High quality was defined as compliant with NICE guidelines (12). 'Timely' refers to diagnostic pathways that must be started within three months of referral, in-line with NICE guidelines (1), and last no more than one calendar year.

This study aimed to explore research evidence about autism diagnostic pathways to determine what works best, for whom and in what circumstances. The RRR aimed to use the literature to address the following questions:

1. How do various pathways of autism diagnostic and support services address the differing needs of service users and what contexts and mechanisms affect their ability to do so?
2. How do different pathways of autism diagnostic and support services improve service user diagnostic experience?
3. What aspects of implementation, staffing and organisational context influence how care pathways for autism diagnostic and support services operate?

## Method

Autism diagnostic care pathways vary in terms of complex differences in local service configurations and settings, lending itself to realist review that can tease out contextual factors, resources and responses of those delivering and accessing the services. A systematic review may not be best matched to the heterogeneity of autism diagnostic services nor to capturing what is most helpful for policy decisions. Our focus was exploring solutions, so we did not focus on wider constraints, already widely documented, and incorporating chronic underfunding; increasing caseloads; reduced training budgets; and recruitment/retention issues, particularly paediatricians, child psychiatrists, clinical psychologists and SALTS (20, 21). Similarly, we did not focus on causes of service user dissatisfaction, rather ways of addressing it.

A RRR is a well-established approach to synthesising evidence within a compressed time period and the key steps are consistent with the RAMESES standards for realist syntheses (22); thus the difference is the timeframe, not the level of rigour. Additionally, RRR is explicitly designed to engage with

stakeholders to accelerate the search process and validate findings (17). Our Expert Stakeholder Group included clinicians (consultant paediatricians, child psychology, speech and language therapy (SALT)), policymakers and third sector advocacy groups (Council for Disabled Children and Autistica) who were involved in all stages of the process (19). Ethical approval was not required because stakeholders were acting as research advisers, not participants (23).

Realist reviews do not seek to compare interventions, rather they present evidence as programme theories (PTs) which are key features of the service and describe what appears to lead to certain outcomes (24), often phrased as 'if…. Then…' statements. PTs are supported by details of the context (C), mechanisms (M) and outcomes (O). These relationships are presented as CMO configurations (25). A realist approach requires starting with an initial PT of what should work and what outcomes are expected from a complex intervention; our PT was based on NICE 2011 guidance (12), the project team and Expert Stakeholder Group:

> *If there is a MDT assessment by a team with competencies in child neurodevelopment and mental health (context), then Autism will be recognised as a complex condition that relies on detailed history and observation across settings (mechanism) to diagnose it. This will lead to accurate diagnosis, recognition of associated co-occurring conditions such as ADHD and intellectual disability (outcome), and the ruling out of complex differential diagnoses. This will also create, whilst not an explicit part of this project, an accurate picture of a child's strengths and needs to inform individualised packages of support and intervention through health, education and social care (outcome).*

We worked backwards from the intended outcomes although we know in practice that complex interventions operating in different health and social care environments do not lead to the same outcomes across services because of differing contexts (for example, differences between services, ways of operationalizing and differences in recipient populations). Therefore, what is required is an understanding of what needs to be in place (circumstances or context), to trigger mechanisms (that can be responses or resources) that lead to the desired (intended) outcomes or other unintended outcomes.

## Changes to protocol

No changes to the review process proposed in the published protocol (https://bmjopen.bmj.com/content/10/7/e037846).

## Search methods

This RRR was carried out from 1 September 2019 to 30 June 2020 following RAMESES standards (24) for realist reviews. Through discussions within the RE-ASCeD project team and with our expert

stakeholders, we confirmed and refined the research questions and scope; prioritised areas for investigation; identified search terms; and collected grey literature, policy and guideline papers iteratively throughout the review.

Search terms were identified and developed with support from the RE-ASCeD project team and expert stakeholders. The primary search was conducted across Medline (Ovid), Embase (Ovid), PsycINFO (Ovid), Social Policy & Practice (Ovid), CINAHL Plus (EBSCO), Cochrane Library and Web of Science (Clarivate) limited by date (2011–2019), language (English) and country (UK only). Our focus was a clearly defined intervention (the diagnostic pathway, from receipt of referral to diagnosis), associated with specific outcomes (high quality and timely) within a particular set of parameters (autism/CAMHS services in the UK). All study types were included. The search strategy was created by an information specialist (AP) using a combination of free text and MeSH index terms after iterative pilots in Medline and adapted for each database. Search strings were based on a combination of terms covering "Children", AND "Autism" AND how they "Relate to diagnostic pathway OR assessment". For full search terms see Supplementary Document 1. Table 1 provides our inclusion/exclusion criteria.

Secondary searching was conducted iteratively throughout the review with input from our expert stakeholders. Two reviewers used papers identified in the primary and background search to look through reference lists for relevant articles; check forward citations; and search key authors and research teams to identify further literature, using Google scholar. Primary and background searches were restricted to UK only, given UK NHS context. On the advice of our expert stakeholders, we then reviewed high level national policy documents and guidelines and a few research articles from similar countries (USA, Canada, Australia, New Zealand) to help elucidate findings.

**Table 1 Inclusion/exclusion criteria**

| |
|---|
| Inclusion criteria:<br>• Children (preschool, primary or secondary school and adolescents) with Autism Spectrum Disorder or Autism spectrum condition<br>• UK healthcare system (England, Scotland, Wales and N. Ireland)<br>• Published 2011 onwards when the NICE guidelines for recognition, referral and diagnosis of autism in under 19s (2011) was published<br>• Relates to diagnostic pathway and model of service provision or relates to assessment process e.g. single discipline (paediatric consultant) or multidisciplinary |
| Primary exclusion criteria:<br>• Non-UK based literature<br>• Relates *only* to adult diagnostic pathway<br>• Relates *only* to *tertiary* services<br>• *Only* relates to treatment<br>• Relates to support services *only after* diagnosis. |
| Secondary exclusion criteria: |

- Descriptive or irrelevant commentary on materials we already included; no added insights relevant to context or mechanisms
- Specific tools in terms of assessment tools or psychometric properties e.g. reliability/validity of the tool
- Prevalence only studies
- Studies only related to symptoms or aetiology
- Articles about special needs in general, no mention of ASD (or ADHD)
- Duplicate material of Co-Is' previous research, excluded by Co-Is
- Conference paper with only abstract available
- The data collected or published on-line before 2011

## Article selection and appraisal

As shown in Figure 1, we collected 294 articles from the primary search , 129 grey literature records suggested by the RE-ASCeD project team members and our expert stakeholders, with overall 338 items once duplicates removed. Furthermore, 9 papers were collected via iterative secondary searches by searching all publications for key authors using Google Scholar and consulting our Expert Stakeholder Group. Two researchers (VA and WZ) carried out screening in two stages: an initial stage by title and abstract and second stage by full-text. Title-sifting of papers that deemed 'relevant' or 'maybe relevant' from both stages was also cross-checked by three team members (PW, WF and IM). Data extraction and appraisal were carried out by two researchers (VA and WZ) using a hybrid approach (26, 27): basic details from each included article (n=79) were recorded; appraisal of evidence was based on concepts of relevance, rigour and richness (26, 27), with highly relevant articles (n=45, including nine from iterative secondary search) coded in NVivo. For 20% of papers, a series of calibration exercises were undertaken by the RRR Lead (PW). When two reviewers were uncertain about the extraction or appraisal of a paper, this was discussed with the RRR Lead (PW). The quality and relevance of the selected papers were also assessed during the synthesis process by members from the RE-ASCeD project team.

Mapping the sources to test and develop PTs, we divided papers involved in NVivo analysis into three categories: 1) key papers that described a model of service delivery (e.g. integrated neuro-developmental service) in detail and were conceptually rich, 2) 'medium' papers that mentioned a model with some useful information but were not conceptually rich, 3) papers with a few 'nuggets' (28) relevant to PTs. This helped us focus on key and medium papers (Supplementary Document 2) that could contribute most to developing a conceptual framework (29) and refining PTs.

## Synthesis and refinement

Based on analysis of individual papers, we then conducted cross-evidence comparisons to build PTs and confirm/refute and refine CMO configurations; both synthesis and refining the evidence involved

substantial discussion of 'contradictory' evidence, or unintended outcomes. We also consulted with our expert stakeholders iteratively during the review process and at a data interpretation workshop in April 2020. Our expert stakeholders collectively reviewed the PTs, provided feedback and were invited to identify any omissions based on their clinical experience. We also asked them to suggest any further literature to help elucidate PTs. Based on feedback collected from the data interpretation workshop, two reviewers (VA and WZ) checked and added new papers suggested by our expert stakeholders; refined the programme theories and conceptual framework.

*Insert*: **Figure 1. Search and review flow diagram.**

## Patient and public involvement

Our co-investigators included a patient and public involvement (PPI) representative from a local parent organisation (West Sussex Parent Carer Forum) who was able to consult a wider group of families with lived experience and a parent who had previously managed Sussex Autism Support. Our PPI representatives were equal partners within the Expert Stakeholder Group. This helped focus the review on the questions they were most interested in answering and enabled the identification of salient grey or unpublished documents for review (30). PPI was embedded into the review protocol and was particularly helpful when synthesising and interpreting the data. A separate PPI Reference Group (all parents of CYP with autism), whose inception was delayed due to covid-19, is integral to the wider project.

# Results

We developed seven PTs, based on cross-comparison and synthesis of 45 highly relevant articles: the first four focused on referral and diagnostic process and the last three on cross-cutting themes (Table 2). Figure 2 summarises the interrelationship between these PTs, set in the wider context of structural and organisational barriers affecting autism diagnostic pathways. Full PTs with CMO configurations are provided as Supplementary Document 3.

*Insert*: **Figure 2. Programme theories for the autism diagnostic pathway**

*Insert*: **Table 2. Programme theories and sources**

**Table 2: Programme theories and sources**

| PTs 1-4: Stage specific programme theories affecting the diagnostic assessment pathway | |
|---|---|
| **PT1 Listening and recognition** | |
| If frontline health and education professionals (e.g. GPs, teachers) are confident in recognising the signs and symptoms of autism, are cognisant of referral pathways and listen to parents, taking their concerns seriously then CYP will be referred to an appropriate service, in a timely manner, reducing parental frustration. | NICE, 2011 (12); Reed and Osborne, 2012 (31); Abbott, et al., 2013 (32); The Scottish Government, 2014 (33); Crane, et al., 2016 (6); Rogers, et al., 2016 (34); O'Reilly, et al., 2017 (35); RCPCH, 2017 (20); Potter, 2017 (36); Unigwe et al., 2017 (37); Crane, et al., 2018 (38); Dowden, 2018 (39); Rutherford, et al., 2018 (40); Ford, et al., 2019 (41); Hurt, et al., 2019 (42). |
| **PT2 Referral and triaging** | |
| If autism diagnostic services provide clear guidelines for referrers on what information is needed and how to refer, and referrers follow these guidelines, then time will be saved at the triaging stage and proportionately fewer CYP who do not have autism will go through the full process. | NICE, 2011 (12); Carpenter, 2012 (43); The Scottish Government, 2014 (33); McKenzie, et al., 2015 (44); Healthcare Improvement Scotland, 2016 (45); Rutherford, et al., 2016 (46); Rutherford, et al., 2018 (40); Autistica, 2019 (47); Hurt, et al., 2019 (42); Tollerfield and Pearce, 2020 (48). |
| **PT3 Diagnostic assessment** | |
| If a structured, consistent and multidisciplinary approach to service delivery is adopted, making best use of available staff and clinical expertise, then the number of assessments per individual may be reduced.<br>If a balance of interview, observation and recognised tools are used, alongside an assets-based approach, this will ensure a comprehensive and family-friendly diagnostic experience.<br>If the same Trust manages both community paediatrics and mental health services, this potentially allows for a seamless transition, avoids duplicate waits and enables families to see all relevant professionals at the same time. | Carpenter, 2012 (43); NICE, 2014a (49); Karim, et al., 2014 (50); Gray, et al., 2015 (51); Crane, et al., 2016 (6); Halpin, 2016 (52); Healthcare Improvement Scotland, 2016 (45); McKenzie, et al., 2016 (53); Rogers, et al., 2016 (34); Rutherford, et al., 2016 (46); Tryfona, et al., 2016 (54); Galliver, et al., 2017 (13); Jordan, et al., 2017 (55); Juárez, et al., 2018 (56); Rutherford, et al., 2018 (40); Ahlers, et al., 2019 (57); Autistica, 2019 (47); Ford, et al., 2019 (41); Tollerfield and Pearce, 2020 (48). |
| **PT4 Diagnostic feedback** | |

| | |
|---|---|
| If parents understand the diagnostic process and feel supported this can moderate parental expectations. Feedback should take an assets-based approach and management plans should be individualised, taking account of co-existing conditions. Reports should be timely and in a format that everyone finds helpful. | NICE, 2011 (12); RASDN, 2011 (58); Calzada, et al., 2012 (59); Carpenter, 2012 (43); Reed and Osborne, 2012 (31); Abbott, et al., 2013 (32); Karim, et al., 2014 (50); NICE, 2014a (49); The Scottish Government, 2014 (33); Halpin, 2016 (52); Healthcare Improvement Scotland, 2016 (45); Hennel, et al., 2016 (60); McKenzie, et al., 2016 (53); Reed, et al., 2016 (61); Rogers, et al., 2016 (34); Crane, et al., 2018 (38); The Scottish Government, 2018 (62); Autistica, 2019 (47); Hurt, et al., 2019 (42); Tollerfield and Pearce, 2020 (48). |
| **PTs 5-7: Cross-cutting programme theories affecting the diagnostic pathway** | |
| **PT5: Working in partnership with families** | |
| If parents have a single point of contact, are provided explanations throughout and included in decision-making then diagnostic pathway may be less stressful. | Calzada, et al., 2012 (59); Abbott, et al., 2013 (32); Gregory, et al., 2013b (63); NICE, 2014a (49); Rogers, et al., 2016 (34); Healthcare Improvement Scotland, 2016 (45); Crane, et al., 2018 (38). |
| **PT6: Inter-agency working** | |
| If "experts" including people with autism, carers, professionals and specialist organisations work in partnership and the knowledge generated is effectively embedded into local services, this will build capacity, improve parent/CYP satisfaction and support planning of services both locally and nationally. | NICE, 2011 (12); Calzada, et al., 2012 (59); Gregory, et al., 2013a (64); Gregory, et al., 2013b (63); Karim, et al., 2014 (50); NICE, 2014a (49); The Scottish Government, 2014 (33); Gray, et al., 2015 (51); Healthcare Improvement Scotland, 2016 (45); Rogers, et al., 2016 (34); Galliver, et al., 2017 (13); Hayes, et al., 2018 (65); The Scottish Government, 2018 (62); Williams et al., 2018 (66); Hurt, et al., 2019 (42); Tollerfield and Pearce, 2020 (48). |
| **PT7: Training, service development and evaluation** | |
| If professionals have access to tailored training based on their needs, competencies and role, and services engage in service development and evaluation, this will increase the local skill set of people who regularly work with CYP who may have autism. | NICE, 2011 (12); Gregory, et al., 2013a (64); Autism ACHIEVE Alliance, 2014 (67); NHS Education for Scotland, 2014 (68); The Scottish Government, 2014 (33); Rutherford, et al., 2016 (46); RCPCH, 2017 (20); Rutherford, et al., 2018 (40); The Scottish Government, 2018 (62). |

## PT1: Listening and recognition

Professionals had to balance early referral with parents' concerns so that they felt listened to and taken seriously (6, 32, 35); parents were often the first to notice atypical patterns of development or behaviour in their child (6, 32, 35, 36, 39). Managing parental expectations (42) and developing a co-operative relationship appeared to help manage this balance but 'was perceived to be particularly problematic because access to services is based on diagnosis, rather than an assessment of the child and family's needs' (42, p.215). From parents' perspective, one autism charity website suggested they "develop a talent for making a polite nuisance of themselves (more properly known as 'advocacy')" to traverse barriers to referral (39, p.29).

Additionally, greater autism awareness and training for frontline professionals, particularly general practitioners (GPs) and teachers, alongside training in how, when and who to refer to (6, 12, 33, 35, 37, 39, 46) was suggested as a strategy to improve early identification.

## PT2: Referral and triaging

Comprehensive information gathering pre-assessment reduced the number of contacts, assessment duration and total time taken to reach diagnosis (44). A systematic approach to information gathering (12, 46, 48) improved efficiency, but referrers also wanted feedback when referrals were declined (12, 40, 46).

Innovative approaches to triaging included: sufficient information gathering pre-assessment to enable same-day assessment in the context of tertiary services (47, 69, 70); initial interview with an experienced clinician (43); community/neurodevelopmental paediatrician carrying out a General Developmental Assessment (GDA) (40, 47, 71); assessment by CAMHS or a community paediatrician and SALT, then allocating to an abbreviated (local) or complex (specialist) pathway (40); triage meetings across CAMHS and CDS (40). However, whether these strategies constituted triaging or the first stage in the diagnostic pathway was arguable.

## PT3: Diagnostic assessment

Good practice in the UK (NICE) (12) recognises the importance of multidisciplinary assessment with use of information from parents, educational settings and direct observation/assessment of the child used as evidence alongside health professional assessment. However, services had different condition-specific remits, catchment areas and commissioning agreements. Where community

paediatrics and mental health services, were integrated and collocated in the same organisation this allowed a seamless transition, avoiding duplicated waits and enabling families to see all relevant professionals at once (18, 47).

Few papers clearly delineated the service pathway (18, 40, 42, 47, 48, 50, 51) and within these were wide variations, including the balance of standardised assessments, observations and clinical judgement. As recommended by NICE (12), most services were multidisciplinary, and many offered a single point of access, bridging the autism-ADHD diagnostic divide (18, 47). For example, Peterborough's integrated pathway provided assessments for ADHD and autism (18, 47) and combined a single point of access with a comprehensive skill mix, including access to therapies. This reduced the number of assessments per individual, saved time and money, and provided a better diagnostic experience (47). Another approach was to extend the role of available professions, for example, by training SALTs to carry out aspects of the assessment previously carried out by child psychiatrists (48). However, disadvantages of multidisciplinary assessment and/or multi-agency working included being labour intensive and costly (13); being negatively affected by the dissonance between medical and educational paradigms (50); and a 'perceived power differential' evidenced by the 'decision-making power of doctors and psychologists over other clinicians' (52, p.322).

Rutherford et al. (40) presented a multi-agency diagnostic pathway with an 'abbreviated' pathway when the signs and symptoms of autism were easily identified and a 'complex' pathway for CYP with, for example, co-existing conditions needing onward referral to a specialist team. This resulted in fewer CYP unnecessarily going through the full process, improving the timeliness of assessment (40).

An interesting theme within the literature considered the balance of clinical expertise against standardised assessments. Less experienced clinicians appeared to prefer using standardised tools, while more experienced clinicians expressed confidence in their clinical judgement (43). Some clinicians found diagnostic tools helpful, while others described them as 'very cumbersome and very time consuming' (50, p.118). Rogers et al. (34, p.824) referred to 'upgrading', whereby the majority of professionals (78 out of 116) erred on the side of a positive diagnosis when faced with uncertainty. The main reasons were to facilitate access to funding/support (n=17; 22%); enable individuals to get a statement of Special Educational Needs (n = 8; 10%); or differing opinions among colleagues in a team (n=32; 41%).

Finally, there was limited but positive literature around the use of technology. Aims included 'remote' observational assessments carried out by families during a short telehealth assessment to screen for autism in children under 3 years (56); using mobile technology to collect observational data in advance of formal assessment (54); educational games to assess risk of autism (54); an automated story ('A

Pirates Adventure') scoring emotional cognition (55); and the use of computer-based Continuous Performance Tests (72). Our expert stakeholders also suggested that where the presence of ADHD is suspected, the use of Qbtest (72) may enable an objective measurement of attention, concentration, impulsivity and distractibility but the evidence is limited. Since carrying out the RRR, Lord (73) has provided guidance on adapting autism diagnostic assessment during social distancing, including the Autism Diagnostic Observation Schedule (ADOS) (although unvalidated), for remote use, demonstrating that the current covid-19 crisis has become a driver for telehealth approaches.

## PT4: Diagnostic feedback

Most parents regarded autism diagnosis as a gateway to services (34) but there was no consensus on best practice regarding feedback (51). Parents valued a sensitive approach and positive comments about their child and their parenting (32) but found it hard to absorb feedback (32, 60). Practical strategies included a structured approach; using consistent and straightforward terminology; opportunity to ask questions (including later); and recognising their child's skills/strengths (12, 32, 45, 50, 60). Guidelines recommended a needs-based and tailored management plan, co-developed with parents (12, p.15, 58).

Only one paper provided detailed information on the report format (48) and used a digital report-writing tool and visual profiling tool. Reports were available within a few days, enabling parents to review the content, improving partnership working. The visual profiling tool provided a concise visual aide for understanding, explaining, and communicating the abilities of each CYP.

## PT5: Working in partnership with families

The diagnostic process was enhanced by integrating 'expertise from several perspectives… that of the individual, their family, and the professionals' (38, p.3762) and acknowledging parents as co-experts. When parents understood the diagnostic process in advance, this improved satisfaction and helped moderate expectations (32, p.373). Open and honest dialogue involving parents in decision-making (34), helped promote engagement and manage differences of opinion (63). Having a named 'case coordinator' (12) or 'keyworker' (49) helped reduce stress and increase engagement (63). Parents offered support following diagnosis were, unsurprisingly, more satisfied than those who were not (38). A simple suggestion to improve satisfaction was to tailor links to relevant services and explore the full range of services that might prove useful (6). Another approach was to help parents develop strategies to manage difficulties, for example, meeting families wherever most convenient to reduce non-attendance (63, p.74).

### PT6: Inter-agency working

Integrating the pathways into a single assessment process potentially saved time and cost less (13, 18, 21) but we found little evidence of how to address macro-level constraints such as chronic underinvestment (39). Much appeared to rest on personal relationships at the micro-level (64) and/or parents co-ordinating services (42). While joint working was endorsed (59, p.240) suggestions to promote it were limited to establishing clear pathways (67); creating opportunities to work in different teams, such as split posts or secondments (63); and an Additional Learning Needs Coordinator (a teacher at the school) (42).

### PT7: Training, service evaluation and development

Several papers identified the importance of training in improving the quality and efficiency of autism diagnostic services (33, 40). It was recommended that training should go beyond those working in autism services, include the educational sector (62) and be geared to the needs of managers as well as frontline staff (33) through multi-agency training (12).

Rutherford et al. (40) advocated a training framework with different skill levels, depending on the 'nature, extent and likely impact of daily contact with individuals with ASD' (40, p.1583) and now reflected in Health Education England recommendations (74). Other training suggestions included an opportunity to observe specialist autism services; buddying with experienced clinicians; regular review of training needs and succession planning; and a national forum to share experiences and knowledge (46, 67).

Finally, service evaluation was advocated to check adherence to standards/guidelines (20) and provide evidence for commissioners (46); one strategy was a guidelines checklist at the front of each patient file (46). Service development suggestions included having one person to champion change; generating research within clinical teams; encouraging practitioners to co-create contextually sensitive solutions (46); and drawing on the expertise of people with autism, carers and specialist organisations (33). Our stakeholders highlighted the importance of good quality national data to facilitate a whole system approach, with the current approach appearing somewhat fragmented (75).

## Discussion

This RRR explored diagnostic pathways that have been adopted across the UK, to determine what works best, for whom and in what circumstances. Four PTs related to the clinical pathway, addressing ways to improve initial recognition of possible autism, referral and triaging, the diagnostic model and

post-diagnostic feedback. Whilst there were specific service delivery innovations of interest, such as adopting a broader neurodevelopmental approach to assessment, or the use of skill mix, there also appears to be scope to adapt stages within the process. For example, gathering information about a CYP's strengths/needs at the point of referral may enhance the process, regardless of the specific model. The three cross-cutting PTs centred on working in partnership with families; inter-agency working; and training, service evaluation and development. Collectively, these PTs evidence different approaches that could contribute to a better experience for families, improved efficiency (and potentially cost savings) and shorter waiting lists.

Many of the issues identified in the RRR could be addressed by full adherence to NICE guidelines (12) and quality standards (76). However, a gap exists between guidelines and local interpretation, exacerbated by demand for assessment outstripping capacity and resourcing constraints. In particular, the guidelines indicate the need for a team with the competencies to deliver a broader neurodevelopmental and mental health assessment, producing a comprehensive description of a chid's strengths and needs, but some services appeared focused solely on autism diagnosis, partly reflecting resourcing constraints (33). A broader neurodevelopmental approach (38) may also ameliorate the concerns of those families whose child does not meet criteria for an autism diagnosis but has significant needs which may otherwise remain, or feel, unrecognised. This would be additionally aided by clinical teams resourcing the development of strengths and needs planning or working in consort with other agencies.

As previously noted, there may also be a trade-off between carrying out comprehensive assessments for all CYP with possible autism and 'providing a more streamlined approach that is tailored to the child's presentation' (77, p.526) which could reduce diagnostic validity. This mirrors feedback from our expert stakeholders – that there may need to be a discussion around the potential to increase investment in service delivery to enable high quality and timely approach versus the potential challenges associated with accepting lower quality and less timely diagnostic assessment. A similar approach delivering tiered assessment according to diagnostic complexity, has been recommended by recent Australian guidelines (78).

Whilst the study findings are based on UK literature that relates to the National Health Service where health provision is free at the point of care, and insurance-based health economies are different (77), the international literature was largely consistent with our findings. For example, recommendations to engage families in service design, and to produce a needs-based holistic assessment and report are mirrored internationally (78, 79). The seven PTs are echoed overall, for example in New Zealand recommendations (66), whilst international research also supports individual PTs, including improving knowledge and skills of referrers (80), improving information gathering to inform appropriateness of

referral (72), and upskilling the diagnostic workforce (81, 82). These are also echoed in recommendations from NHS England published after completion of the RRR (83).

Internationally, digitally delivered training programmes such as ECHO (Extension for Community Healthcare Outcomes) have been developed to enable upskilling of a wider diagnostic workforce, for example community general paediatricians in US and Canada (82), whilst the World Health Organisation has developed Caregiver Skills Training Programmes to train parents to support their children's development (84). Similarly, the need for social distancing during the Covid pandemic has acted as a driver to adopt digital technologies, although some of these had already been developed in response to geographical distancing between centralised specialist services and families living in widespread rural communities (45).

## Implication for practice and future research

From the PTs we identified six key areas that would benefit from further exploration. These were evaluation of: training and support materials available for non-specialist staff and parents/CYP accessing the diagnostic pathway which would increase early recognition that a child may need assessment and improve information gathering at the point of referral; training packages to upskill those working in autism services and the subsequent impact on workforce shortages; asset-based approaches to diagnosis, management and support; barriers and facilitators to comprehensive needs-led diagnostic assessment; approaches to integrating services dealing with autism; and increased use of technology in assessment that has already started in the context of COVID-19 (85).

## Strengths and limitations

The realist approach was well suited to examining and understanding the complexity of autism diagnostic assessment, and the challenges of delivering such services in different contexts. We developed systematic and focused search strategies, within the parameters of RRR (22), although not as extensive as a full realist review. Expert Stakeholder Engagement enhanced the search strategy, enabled an iterative approach to identifying relevant literature and was invaluable when synthesising the findings. Most papers had limited information on care pathway processes and contextual factors (which in realist terminology refers to any trigger that influences responses or resources), or more general sub-analysis by demographic/other characteristics, so PTs could only develop based on what was reported; this highlights the need for further empirical work which the next phase of this study will provide. Primary and background searches were restricted to UK only, given UK NHS context, but secondary searches included papers from countries with somewhat similar healthcare systems (USA, Canada, Australia, New Zealand) to help elucidate findings, as recommended by our expert

stakeholders. However, we acknowledge that we may have missed literature from similar health systems that could have informed our PTs.

## Conclusion

In conclusion, this RRR identified important aspects that may contribute to more efficient, high quality and family-friendly service delivery. We will test the PTs and how service design could be further enhanced in the subsequent stages of the wider RE-ASCed study.

## AUTHORS' CONTRIBUTIONS:

VA & WZ: involved in all stages of the review and writing all drafts of this paper

PW: substantial contribution to writing protocol for the overall RE-ASCeD project, all stages of the review and commenting on all drafts of this paper

WF & IM: substantial contribution to writing protocol for the overall RE-ASCeD project, all stages of the review and commenting on drafts of this paper

JP: substantial contribution to writing protocol for the overall RE-ASCeD project, some stages of the review and commenting on a draft of this paper

VR: substantial contribution to writing protocol for the overall RE-ASCeD project, some stages of the review and commenting on a draft of this paper

AP: designing the search strategy and commenting on the methodology section of this paper

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## Ethics Statement:

Formal ethical review is not required for this review.

## Data sharing statement:

All data relevant to the study are included in the article or uploaded as supplementary information

**Figures:**

- **Figure 1. Search and review flow diagram.**
- **Figure 2. Programme theories for the autism diagnostic pathway.**

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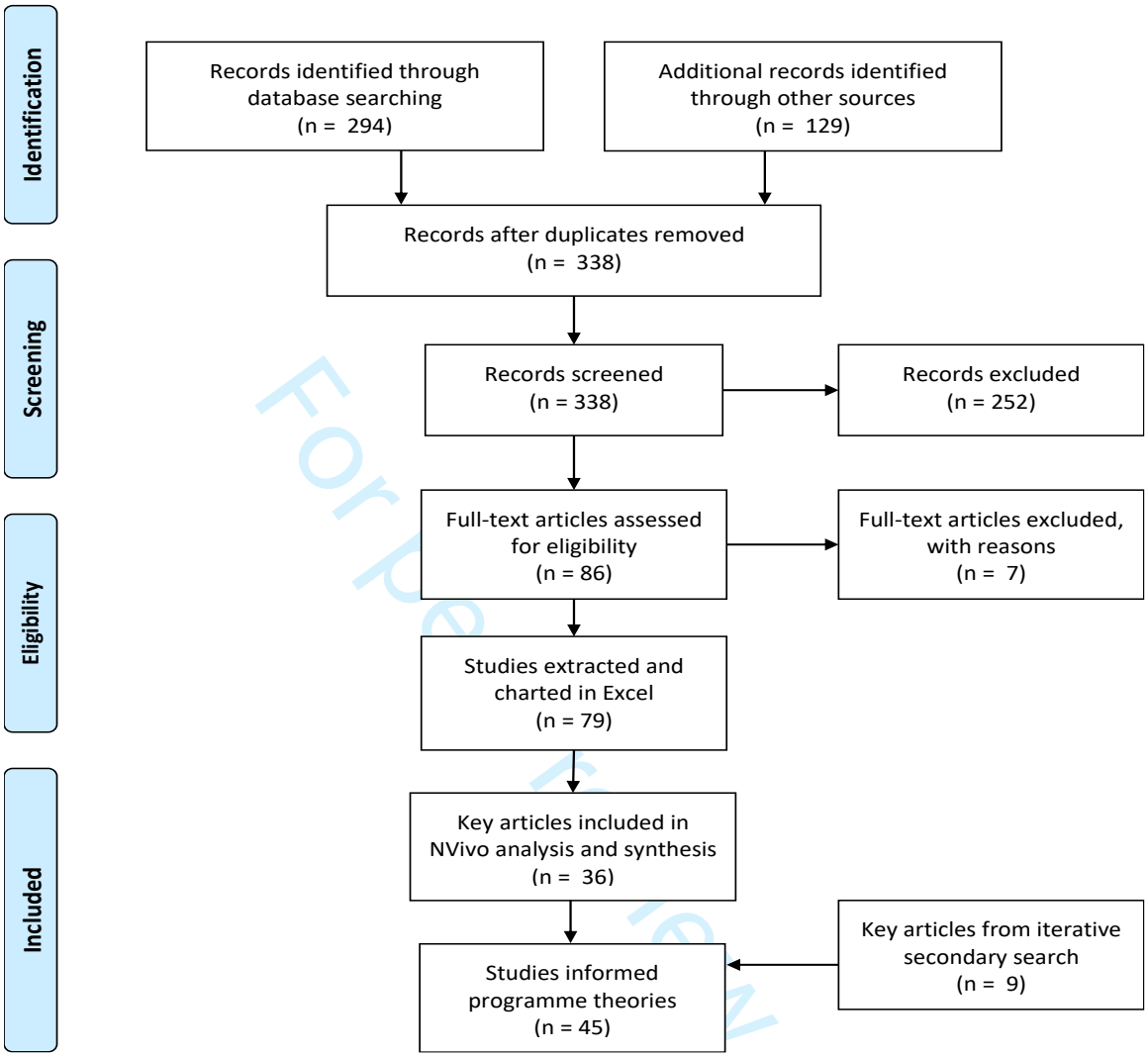

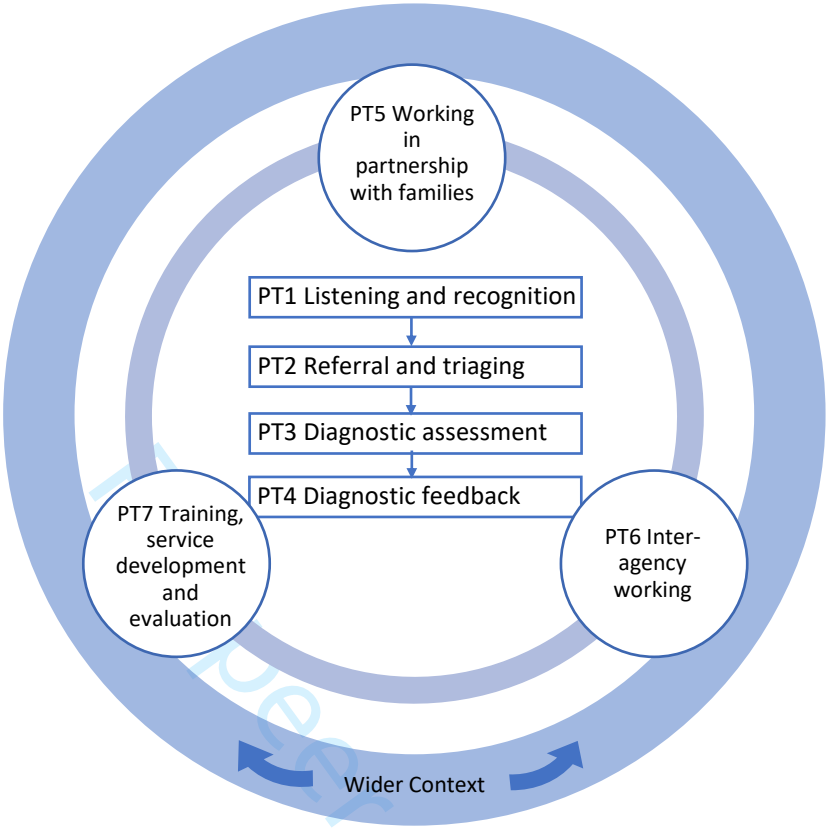

**Supplementary Document 1.** Database Search Strategies

**Number of databases searched**: 7

Medline (Ovid)
Embase (Ovid)
PsycINFO (Ovid)
Social Policy & Practice (Ovid)
CINAHL Plus (EBSCO)
Cochrane Library
Web of Science (Clarivate)

**Search limits:** 2011-current; English language; UK only

Note: We used 2020 date in the Medline search strategy because Medline includes a small number of in-process citations ahead of publication date (Medline in-Process & Other Non-indexed Citations).

Literature search strategy used for **Medline** (search run on 25.11.19) is attached below. Additional search strategies available from the authors.

| | | |
|---|---|---|
| 1 | exp Autism Spectrum Disorder/di, ep, th [Diagnosis, Epidemiology, Therapy] | 10929 |
| 2 | (autism spectrum disorder* or ASD or autism).ti,kw. | 23890 |
| 3 | (asperger* syndrome or asperger*).ti,kw. | 1150 |
| 4 | 1 or 2 or 3 | 27668 |
| 5 | adolescent/ or child/ or child, preschool/ | 2937612 |
| 6 | (child or children* or pre-school child* or adolescent*).kw. | 70707 |
| 7 | 5 or 6 | 2940479 |
| 8 | 4 and 7 | 19625 |
| 9 | Community Mental Health Services/ | 18302 |
| 10 | ("child and adolescent mental health service*" or "child & adolescent mental health service*" or CAMHS).ti,ab,kw. | 491 |
| 11 | ("child and adolescent mental health team*" or child mental health service*).ti,ab. | 149 |
| 12 | child development clinic*.ti,ab. | 39 |
| 13 | 9 or 10 or 11 or 12 | 18873 |
| 14 | 8 and 13 | 69 |
| 15 | Diagnostic Services/ | 1916 |
| 16 | (diagnostic service model* or diagnostic assessment model* or diagnostic assessment or diagnostic process).ti,ab. | 6616 |
| 17 | (diagnostic pathway* or diagnostic evaluation or referral pathway*).ti,ab. | 8902 |
| 18 | early diagnosis/ or early intervention/ | 28062 |
| 19 | "Referral and Consultation"/ | 64435 |

| | | |
|---|---|---|
| 20 | Critical Pathways/ | 6455 |
| 21 | ((multidisciplinary or multi-disciplinary or interprofessional or inter-professional or intraprofessional or intra-professional or interdisciplinary or inter-disciplinary) adj team*).ti,ab. | 18640 |
| 22 | "delivery of health care, integrated"/ or health services accessibility/ or patient care team/ | 143724 |
| 23 | Professional-Family Relations/ | 14480 |
| 24 | (service delivery or diagnostic experience*).ti,ab. | 10451 |
| 25 | 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 | 283159 |
| 26 | 8 and 25 | 1254 |
| 27 | (cost-effectiveness or evaluation).ti,ab. | 1027879 |
| 28 | Efficiency, Organizational/ or Efficiency/ | 34521 |
| 29 | evaluation studies as topic/ or program evaluation/ or validation studies as topic/ | 183858 |
| 30 | "quality of health care"/ or "outcome and process assessment (health care)"/ | 95758 |
| 31 | Waiting Lists/ or Time Factors/ | 1175790 |
| 32 | (family experience or parent experience).ti,ab. | 365 |
| 33 | 27 or 28 or 29 or 30 or 31 or 32 | 2377747 |
| 34 | 14 or 26 | 1295 |
| 35 | limit 34 to (english language and yr="2011 - 2020") | 738 |
| 36 | 33 and 34 | 256 |
| 37 | limit 36 to (english language and yr="2011 - 2020") | 141 |
| 38 | remove duplicates from 35 | **736** |

**Supplementary Document 2.1 - Key papers from primary search and background search**

| **Author (year)** Green = key; Yellow = medium; Blue = nuggets. order is density of coding | **Country** | **Title** | **Settings/service types** (e.g. ASD, ASD & CAMHS) **& service models** | **Study type** | **Aims** | **Method** | **Sample size** | **Summary of findings relevant to programme theory** |
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| Rutherford, et al., 2018 | Scotland | Improving efficiency and quality of the children's ASD diagnostic pathway: Lessons learned from practice | CCH/SLT, CCH/ CAMHS/SLT, a variety of ASD diagnostic assessment teams | mixed methods, quan&qual | a. Identify the baseline number of referrals and duration of ASD diagnostic assessment for children (aged 0–18) across a health board before a single evidence based ASD care pathway was in place<br>b. Describe the pathway development process and service changes implemented<br>c. Evaluate the effects of the new pathway for ASD diagnosis on knowledge of service demand, duration of assessment and waiting time. | The work reported comprised several steps: (a) baseline information gathering about current practice and national guidance; (b) development of an action plan (Fig. 2); (c) writing and achieving consensus to implement the new pathway (d) setting up a clinical database for recording and measuring involvement in the pathway for each child referred (e) statistical analysis of the data.<br><br>interviews, Case Note Analysis | 1 health board in Scotland- 4 local authority areas - Across all areas, 7 separate local teams were identified (teams 1–7).<br>One clinician from each team (n = 7) was interviewed about main aspects of the diagnostic services such as personnel involved and process followed.<br>telephone interview with a small number of families (n = 7) | it reports statistically significant reductions in waiting times for autism diagnostic assessment following a children's health service improvement programme. The average wait between referral and first appointment reduced from 14.2 to 10.4 weeks ($t(21) = 4.3$, $p < 0.05$) and between referral and diagnosis shared, reduced from 270 to 122.5 days, ($t(20) = 5.5$, $p < 0.05$). The proportion of girls identified increased from 5.6 to 2.7:1.<br>Methods reported include: local improvement action planning; evidence based pathways; systematic clinical data gathering and a training plan.<br>Model: see Fig 1 for all the steps including:<br>a) Comm Paed + SLT *OR* CAMHS,<br>b) specialist ASD Ax via triage,<br>c) Local abbrev Ax OR complex Ax OR request more information/decline |
| Rutherford, et al., 2016 | UK-Scotland | Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children | Child & adult services providing ASD diagnosis | sequential mixed methods design: Phase 1 quantitative data from the case notes & Phase 2 all sixteen services providing quantitative data were invited to participate in local focus groups.<br><br>*N.B. The study was part of the Scottish national Autism ACHIEVE Alliance study McKenzie et al. 2015 (Factors influencing waiting times...) which we have* | investigation from the perspective of diagnosing professional teams, of the reasons for delays, which also generates solutions.<br>Objectives:<br>- To explore the reasons clinicians give to explain long wait times for diagnosis for ASD.<br>- To identify clinicians views on the challenges and solutions to a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines.<br>- To develop **collaborative action plans** for improving the efficiency and quality of the process of ASD diagnosis in child and adult services. | Ninety five clinicians from 8 child and 8 adult ASD diagnostic services attended 16 focus groups to explore clinicians' views on a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines. During focus groups, quantitative data were fed back, used to frame discussions and facilitate solution focused action planning with each service. Sixteen local action plans were synthesised to create an ASD Action Plan for children and an ASD Action Plan for adults. | 95 clinicians | Key solutions are proposed to support the reduction of the wait for diagnostic assessment, through reducing non-attendance rates, reducing inappropriate referrals, developing efficient working and communication and improving the effectiveness of care pathways. These are presented in actions plans for use by clinical teams.<br><br>**Model: see Table 1** - 8 child ASD service, all **multi-disciplinary, specialist or general**, mix of profs<br><br>***See Table 4-5 & Fig 2 is good - check we've incorporate all in PTs*** |

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| The Scottish Government, 2014 | Scotland | Scottish Strategy **Mapping Report** | a broad range of autism services (for child/adult) across Scotland | Qualitative - workshops & quesionnaires - themes | The purpose of this report is as follows:<br>(i) to provide a 'snapshot' of autism services across Scotland, set out the key issues identified by people with autism and their carers, and provide an overview of how services are meeting their needs or where there may be gaps in services<br>(ii) set out the evidence gathered from the mapping project in order to inform local autism action plans and local decisions on autism service provision<br>(iii) inform future decisions on priorities for funding. | The project held 164 workshops and face-to-face meetings to accommodate individual needs. These equated to 35 multi-agency meetings, 68 carers meetings and 61 meetings with people with autism. | respondents number:<br>people with autism: 186 workshops & 237 questionnaires; parents and carers: 457 workshops & 719 questionnaires; multi-agency: 463 workshops & 595 questionnaires.<br><br>Overall 1106 workshops & 1106 questionnaires | single point referral for access (p7)<br>page 18-19: 'Indicator 6 - A **multi-agency** care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.'<br>page 22: 'Summary: Key Findings from the 10 indicators' p23 - distinguishes btwn co-ord/inclusion in individual vs inclusion/co-prod/PPI in service delivery which it criticises - and dissonance btwn what services say (we do include in service design) & pts who disagree.<br>page 32: appendix 1 - '3. Theme One: Diagnosis' - findings from survey p32, W/L so long, went private<br>page 64: Appendix 2-the experiences of service providers and statutory agencies. '2. Theme One: Service Provision and Assessment'<br>page 69: Appendix 2-the experiences of service providers and statutory agencies. '3. Theme Two: Joint Working and Referral'<br>Talks about **GIRFEC: getting it right for every child** - specific to Scotland. **Wider remit** than ASD.<br>**Model:** various. Note the ***distinction btwn multi-agency & multi-professional*** |
| Crane, et al., 2018 | UK | Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals | represented a number of geographical regions across the UK | part of a larger project exploring the autism diagnostic process in the UK.<br>In Phase One online survey: parents of children on the autism spectrum (Crane et al. 2016) and professionals involved in autism diagnosis (Rogers et al. 2016).<br>Phase Two (this paper) - Qualitative | to identify aspects of the diagnostic process that are working well, and areas in which improvements are needed. | qualitative: the views and experiences of ten autistic adults, ten parents of children on the autism spectrum, and ten professionals involved in autism diagnosis (three clinical psychologists, two paediatricians, one educational psychologist, one psychiatrist, one speech and language therapist, one specialist early years practitioner, and two educators). Seven professionals worked for the UK's National Health Service, two worked in the education sector, and one worked for a local authority. | 30 | Based on previous work, **six key factors** were predicted to **affect overall satisfaction** with the diagnostic process: **time taken** to diagnosis, age at diagnosis, **quality of information** provided at diagnosis, **manner** of professional giving diagnosis, **support post-**diagnosis & **stress** during the process. **Stress during the diagnostic process was the strongest predictor of overall satisfaction** with the diagnostic process. This was followed by satisfaction with the **support** offered post-diagnosis and satisfaction with the **manner** of the professional disclosing the diagnosis.<br>Three key themes were identified: the process of understanding and accepting autism; multiple barriers to satisfaction with the diagnostic process; and inadequate post-diagnostic support provision.<br><br>**Models: various types profs & services, not the focus/not specified**<br><br>**see Fig 1 summary of themes** |
| NICE, 2011 (updated in 2017) | UK | Autism spectrum disorder in under 19s: **recognition, referral and diagnosis** (CG128) | Autism spectrum disorder | guideline | This guideline covers recognising and diagnosing autism spectrum disorder in children and young people from birth up to 19 years. It also covers referral. It aims to improve the experience of children, young people and those who care for them. | NA | NA | page 5: '1.1 Local pathway for recognition, referral and diagnostic assessment of possible autism' section are all useful - 1.1.1 'A local autism **multi-agency strategy** group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and carer service users, and the voluntary sector.' and 1.1.2 'The local autism strategy group should appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people.' and 1.1.3 'In each area a **multidisciplinary** group (the autism team) should be set up.'<br>***N.B. note multi-agency & multi-disc - does it stipulate more specifically than this?*** |

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| Rogers, et al., 2016 | UK | Experiences of diagnosing autism spectrum disorder: A survey of professionals in the United Kingdom | Services involved in ASD diagnostic process with children. | quantitative - on-line survey | conduct a review of diagnostic practice in the United Kingdom by exploring the experiences and perspectives of professionals involved in diagnosing ASD. | A heterogeneous sample of professionals who were clinically active in ASD diagnosis and assessment at the time of the survey, were invited to participate. To recruit the sample, services were collated via the National Autistic Society online directory, and Internet searches were conducted for ASD diagnostic services. 300 services were contacted. Additionally, approximately 3000 statutory and non-statutory ASD services listed in the NHS choices directory were contacted. A total of 126 multidisciplinary professionals completed the full questionnaire, but 10 professionals were excluded from the analysis as they were not clinically active at the time of the survey. Data collection ran from March 2012 to May 2013. Online questionnaire (4- & 5-point Likert scales) exploring their experiences and opinions of three key areas of service: accessibility, the diagnostic process and post-diagnostic support. open questions were analysed qualitatively, using a thematic analysis | 116 | Although professionals were largely satisfied with service accessibility, around 40% of services were failing to provide timely assessments. Standardised diagnostic tools were perceived as helpful and were used consistently, but concerns were raised about their validity in detecting atypical ASD presentations (e.g. females). Several challenges regarding giving ASD diagnoses were reported; these included making sure caregivers understood the diagnosis, pitching information at the correct level and managing distress. 76% of professionals acknowledged the practice of '**upgrading**' to a diagnosis of autism spectrum disorder in uncertain or complex cases and reasons for this varied widely. Professionals felt the need to streamline post-diagnostic support options, ensure the availability of long-term support and to ensure that the post-diagnostic support needs of under-served groups (e.g. women and girls; adults without learning disabilities) were not overlooked.<br><br>**Table 8** has explanations/**Ms** related to **accessibility** (in terms of ease of making referral & screening process), **diagnostic proces**s & **post-diagnostic support**<br><br>**Models: various types profs & services, not the focus/not specified** |
| Calzada, et al., 2012 | UK | High-functioning autism and Asperger's disorder: Utility and meaning for families | specialist clinic for the assessment of children and adolescents with a possible high-functioning PDD. | Qualitative, Semi-structured interviews | investigate the utility (how useful diagnosis is clinically) of pervasive developmental disorder (PDD) diagnoses & differentiating between AD & AsD. | interviewed 22 participants from 10 families. young people (aged 9–16 years) with highfunctioning autistic disorder (AD) and Asperger's disorder (AsD), and their parents. Framework analysis | Twenty two participants from ten families | Perceived advantages of AD and AsD diagnosis were increased understanding and practical support, and parental empowerment. Disadvantages included the effects of stigma and concerns about validity. The utility of AD and AsD depends upon both their validity and how these diagnoses are received in their cultural, economic and legislative context.<br>**Model: specialist clinic for the assessment of children and adolescents with a possible high-functioning PDD (pervasive developmental disorder).** *Not focus of article* |
| Hurt, et al., 2019 | **South Wales** | Understanding and improving the care pathway for children with autism | NHS MDT for NDCs<br>1) A NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8);<br><br>2) in education sector:<br>staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist, n= 8); | Qualitative mixed-methods approach using focus group discussions, creative writing workshops and visualisation using rich pictures | to describe current care pathways for children with autism including enablers and barriers, as experienced by health professionals, education professionals and families in South Wales, UK. | mixed-methods approach using focus group discussions, creative writing workshops and visualisation using rich pictures.<br>**Three workshops** were conducted in September 2015 with (see sample size):<br><br>During the workshops, we employed three methods to collect data. First, we used focus group discussions; Second, a graphic illustrator captured the discussions... enabled comparisons to be drawn across the three groups; Third, participants undertook creative writing exercises to express their experiences in narrative form. | (1) health professionals working within a NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8);<br>(2) staff from a mainstream primary school in South Wales with two specialist ASD classes (including teachers, teaching assistants and a speech therapist, n= 8); and<br>(3) parents of primary school children diagnosed with ASD (n= 7). | The **experiences of the care pathways** differed significantly across the three groups. Health professionals described the most rigidly structured pathways, with clear entry points and outcomes. "**Tier 2" pathway** catered for relatively **uncomplicated cases**, with **two assessment visits** and **one feedback** visit at which a **multi-disciplinary** team discuss the assessments with the family and decide on whether a diagnosis is necessary. The **"Tier 3" pathway** catered for **complicated** cases, and involved **more detailed assessments and discussion** before the feedback session with families. Both pathways were thought to take around **two to three months** to complete. Interaction with education was limited to **observations at school** and an invitation to educational professionals to **attend** the multi-disciplinary **feedback meeting**.<br>Education professionals and parents described more complex and confusing pathways, with **parents** assuming the responsibility of **coordinating** the **health and education** activity in a bid to link the two independent pathways. One school had an Additional Learning Needs Coordinator (**ALNCo**, a teacher) who **coordinated** the support for all children with an identified need before and/or after diagnosis & provided the link between the parents, teachers and any allied education professionals.<br>All three groups identified enablers, although these differed across the groups. The barriers were more consistent across the groups (e.g. poor communication, missing information, lack of transparency, limited post-diagnosis services and access to services based on diagnosis rather than need). In common with health professionals, the education professionals expressed dissatisfaction that many of the steps in the pathway required a **diagnosis,** rather than an examination of the child's **needs.**<br>**Model:** In autism care, there is recognition that holistic, **cross-agency and multi-disciplinary** working is essential (NICE, 2013)... 'In the refreshed ASD Strategic Action Plan, the Welsh Government (2016) commits to delivering a "**national integrated autism service**" by 2019. Whilst generic, high-level care pathways were suggested within the original strategy, it is **not understood how these work on the ground**, nor are there clear examples of good and poor practice to inform future service planning. **No revised pathway is provided** within the refreshed strategy to guide the delivery of the integrated service. |
| AUTISTICA, 2019. Embracing complexity in diagnosis: multi diagnostic pathways for NDCs. | UK | Embracing Complexity is a new coalition of 38 UK charities who support people with NDCs | Four exemplars, England & Wales | Report | Raise awareness of innovative models of care models for diagnosing NDCs | Interviews with professionals in the 4 pathways | No details | Outlines the **4 MDT models (Peterborough, Lambeth, Evelina, All Wales)** carrying out holistic assessment which can deliver multiple diagnoses of NDCs at the same time; lack of robust evidence or how best to reflect local needs. |

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| Tollerfield & Pearce, 2020. | England | Thinking Patterns in Autism Model: Innovating future-fit autism diagnostic assessment services. | the diagnostic service was incorporated into CAMHS, with diagnostic assessments completed by the SALT and consultant child and adolescent psychiatrist. | descriptive evaluation | to describe and retrospectively evaluate an autism diagnostic profiling model in a region of North England. | With reference to NICE (2017) guidelines, clinical service data, and a parent survey, the service model was retrospectively evaluated.<br>This retrospective study evaluated descriptive information about a service model that was trialled between November 2018 and May 2019. | 114 families attended for assessment during this six-month period. Parent information was sampled via SuveyMonkey.com (April 2019), and waiting list rates, staffing, means and ratios were calculated (November 2013 and November 2019). | Findings showed that positive changes over time resulted in an NHS service that was able to create high quality diagnostic profiles for every individual assessed. Findings further showed that the profiling assessments could be completed in less time; approximately 30% less speech and language therapy time and 70% less psychiatry time was needed. Positive parent comments suggested that diagnostic assessment profiling feedback was individualised, detailed and valuable. Central to achieving these outcomes was the use of standardised procedures and cost-effective skill mix for meeting NICE (2017) guidelines on gathering assessment information, communicating the results after the autism diagnostic assessment, and providing individual information on support (1.5; 1.8; 1.9). A model for understanding and explaining thinking patterns in autism was used as a structure for gathering information, for report writing, and for producing a simple visual designed to capture and communicate the complexity of autism as well as the unique context for each individual. It is suggested in this paper, that these innovations can support and inform the development of future-fit autism assessment services.<br>**Model of ASD**: Thinking Patterns in Autism (TPA) Profiling Model - with visual profiling.<br>**Diagnostic model**: By 2009, the diagnostic service was **incorporated into CAMHS**, with diagnostic assessments (12 per year) completed by the **SALT and consultant child and adolescent psychiatrist**. Funding associated with the waiting list initiatives led to increases in therapist time, but there were difficulties with funding and recruiting psychiatrists and psychologists. Consequently, a significant bottle-neck developed in the diagnostic pathway with families waiting extended times for psychiatry input following assessments. In response, the **therapist role was extended so that psychiatry time required per case was reduced.** |
| The Scottish Government, 2018 | Scotland | The Scottish Strategy for Autism - **Engagement Analysis** 2018 | NA | qualitative - online survey & engagement events | to gather in views on the final phase of the Scottish Strategy for Autism | From 18 October 2017 to 29 November 2017 we ran an online engagement exercise. we received 662 responses. Alongside our online questionnaire we held four engagement events, which were attended by more than 600 people. This means well over 1,000 people took part in our engagement activity.<br>As part of our engagement activity we held a number of engagement events, To ensure consistency, delegates who attended these events were asked the same questions as those who used the online engagement tool. Each event had two parts: a morning session for autistic people, their families and carers, and an afternoon session for professionals. | Of the 662 responses to our online questionnaire, 92 per cent were from individuals and the remaining eight per cent (n=56) from organisations. | page 9: '1.3 Referring children and young people to the autism team'<br>yes, p15-16 on training - public & profs<br>page 20: 'Training - Most participants agreed that raising awareness among professionals and services would only happen with more and better training.' - some quotes in this section touched about diagnosis time<br>page 23: 'Diagnosis and Post-Diagnostic Support'<br>page 85-86: 'Engagement Events – Afternoon Sessions' - 'Diagnosis, post-diagnostic support and services'<br><br>**Model:** not the focus/not specified |
| Karim, et al., 2014 | UK | Diagnosing autistic spectrum disorder in the age of austerity | Professionals from UK services including NHS, a primary care provider, and two local education authorities in East Midlands.<br><br>Model: In this area there is no specialist ASD clinic so children are seen by clinical professionals and educational psychologists. | qualitative | explore how diagnosis is managed in the real world by professionals. | semi-structured interviews were thematically analysed. *Doesn't say when interviews were done but paper was accepted* ***May 2012*** *, so prob 2011…* | **26 interviews**: child and adolescent psychiatrists (7), community paediatricians (9) and educational psychologists (10)- number updated by the author. | While there is some consistency across and within these groups there are also a number of variances, and several important issues are highlighted. These include the problem of time and resources, the issue of location for diagnosis, the value of diagnostic tools and schedules, the need for supporting information, the difficulty of multi-agency working, the relevance of a physical examination and the eventual diagnostic label.<br>Theme 1: time & resources - lack of is major difficulty for clinicians<br>Theme 2: setting medical staff seeing children often in outpatient environments where educational psychologists tend utilize the school setting. Important to see children in different settings - emphasizes the importance of multi-agency working.<br>Theme 3: **diagnostic tools vs clinical judgement**<br>Theme 4: use of supporting information for diagnosis - some professionals undertook their own observations, others delegated. Not problematic in itself.<br>Theme 5: **multi-professional/multi-agency or individual diagnosis?**<br>Theme 6: variations in physical examination - educ psychologists don't do this at all - need to be consistent with guidelines. [*Reflects medical vs educ orientation and how different ASD diagnosis is to other conditions* ] |
| Potter, et al., 2017 | UK | I received a leaflet and that is all': Father experiences of a diagnosis of autism | NA | qualitative | This study investigated father perspectives on a diagnosis of autism | investigated father perspectives on a diagnosis of autism, through an online survey. | The sample completing the survey were 306 fathers of children up to 19 years of age, with a diagnosis of autism, autism spectrum disorder or Asperger's syndrome and resident in the UK. 184 fathers (60% of the total) responded to the open-ended question concerning perspectives on diagnosis. | Thematic analysis of 184 replies to an open-ended question identified the following themes: strong initial emotional response and a range of immediate anxieties about the future, struggle to gain a diagnosis; anger in response to insensitive delivery of diagnosis together with insufficient information at the time and lack of support afterwards.<br><br>**Model**: not stated, assume various |

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| Gregory, et al., 2013 | UK | The development of a Child and Adolescent Mental Health Service for children with disabilities: rationale for the approach, method and techniques | CAMHS-Borough of Kensington & Chelsea | NA | explores the rationale for the practice and explains three different elements – approach, method and technique | This second paper explores the rationale for the practice and explains three different elements – approach, method and technique | NA | Page 77: Given other local pathways for assessment and diagnosis, as a team we focus on parent/network concerns and intervention relating to these and tend to avoid further diagnostic assessments, redirecting this work if the question arises. When we meet with families we create a set of goals together about our work with them which we then regularly review and amend throughout our involvement. This explicitly sets out our work as being collaborative and allows us to be transparent about our model and our position alongside the family as a partner in the work<br>page 79: In our team, having an **explicit model*** which informs our approach helps us to be clear about what we are doing and how this might be helpful to families. Thinking about how our methods and techniques fit with the overarching principles of our approach means that we can operate in a coherent way, mindful of the ideas we privilege and how these influence how we engage with and support parents and families.<br>**Parent Adviser Model** emphasises that in order to help and support families parents' views must be heard, understood and prioritised. ***Not really relevant to ASD - should we have excluded?!*** |
| SIGN, 2016 | Scotland | Assessment, diagnosis and interventions for autism spectrum disorders | A national clinical guideline in Scotland - multidisciplinary assessment recommended | A national clinical guideline | It is hoped that this update will contribute further to a reduction in variation in practice and improve services for people of all ages with ASD. | NA | NA | page 20: '1.8 Communicating the results from the autism diagnostic assessment'<br>'Research evidence on **multidisciplinary compared to single assessment** is limited.' But recommends (**model**):<br>'The use of **different professional groups** in the assessment process is recommended as it may identify different aspects of ASD and aid accurate diagnosis.<br>A diagnostic assessment, alongside a **profile of the individual's strengths and weaknesses**, carried out by a **multidisciplinary** team which has the skills and experience to undertake the assessments, should be considered as the optimum approach for individuals suspected of having ASD.' |
| Crane, et al., 2016 | UK (all regions) | Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom | NA | Phase One of above research - national survey | parents' experiences and opinions regarding the process of attaining a diagnosis of autism spectrum disorder for their children. | online survey based on **6 key factors** predicted to affect overall satisfaction with the diagnositic process. A total of 559 services providing information, support or assistance to parents of children with ASD were identified via a directory of autism-related services provided by the National Autistic Society (UK) and asked to forward survey information to their members. Data collection Mar 2012-May 2013. | 1047 parents (93% female, 95% White) | parents usually waited a year from when they first had concerns about their child's development before they sought professional help. On average, there was a delay of around 3.5 years from the point at which parents first approached a health professional with their concerns to the confirmation of an autism spectrum disorder diagnosis. Just over half of the parents surveyed were dissatisfied with the diagnostic process as a whole. Several factors predicted parents' overall levels of satisfaction with the diagnostic process, including the time taken to receive a diagnosis, satisfaction with the information provided at diagnosis, the manner of the diagnosing professional, the stress associated with the diagnostic process and satisfaction with post-diagnostic support.<br><br>**Model**: various/not clear & not the focus |
| Gregory, et al., 2013 | UK | The development of a Child and Adolescent Mental Health Service specifically for children with disabilities: reflections on the first four years | CAMHS-Borough of Kensington & Chelsea | NA | Describes the referrals received, the strengths of having a specialist team, and the arguments for and against setting up a specialist CAMHS service. | The first paper gave details on the nature of the referrals received, the strengths of having a specialist team, and the arguments for and against setting up a specialist CAMHS service. | NA | Describes the service, its development, remit & partnership working with other agencies/organisations and parents/PPI. Divides problems into development issues, challenging behaviours & impact on the family.<br><br>**Model: a team who set up a CAMHS specifically for children with disabilities, including those on the autism spectrum.;** multi-disciplinary but *not* part of generic **CAMHS team; '**positioned (physically and strategically) alongside the Children with Disabilities Social Services team, within the Local Authority' - some split posts which assisted training colleagues in other services. |
| NICE, 2014 | UK | **QS 51** Autism Quality standard | NA | This standard is based on CG128, CG142 and CG170. | This quality standard covers autism in children, young people and adults, including both health and social care services.<br>The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. | NA | NA | covers health and social care services for adults, young people and children with autism. It includes assessment/diagnosis, care and support for people diagnosed with ASDIt describes high-quality care in priority areas for improvement.<br>Page 11: 'Statement 1. People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started **within 3 months** of their referral.' 'Rationale - There are several different routes by which someone with possible autism can be referred to an autism team for a diagnostic assessment. It is important that the assessment is conducted as soon as possible so that appropriate health and social care interventions, advice and support can be offered.'<br>page 12: 'What the quality statement means for service providers, health and social care practitioners, and commissioners' & 'What the quality statement means for service users and carers'<br>page 14: definition of Diagnostic assessment<br>page 17: 'Statement 2. People having a diagnostic assessment for autism are **also assessed for coexisting physical health conditions and mental health problems.**' 'Rationale - People with autism may have coexisting physical health conditions and/or mental health problems that, if unrecognised and untreated, will further impair the person's psychosocial functioning and could place additional pressure on families and carers.<br>page 18 'What the quality statement means for service providers, health and social care practitioners, and commissioners' & ...'for service users and carers'<br>page 33 'Quality statement 7: Assessing possible triggers for behaviour that challenges' |

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| O'Reilly, 2017 | UK | How parents build a case for autism spectrum disorder during initial assessments: 'We're fighting a losing battle' | CAMHS | qualitative conversation analysis | examine relevant issues in relation to the practitioner–family interactions that take place within the initial assessment context. | Each initial appointment typically lasted approximately 90 minutes, generating a corpus of 42 hours of video-recordings. **Participating families were seen by a minimum of two mental health professionals** from a **range of professional groups,** including consultants, staff-grade and trainee child and adolescent psychiatrists, clinical psychologists, assistant psychologists, community psychiatric nurses (CPNs), learning disabilities nurses, occupational therapists, psychotherapists, medical students and student nurses. Conversation analysis (CA) of video-recorded discussions between diagnosticians and families during pre-diagnosis triage screening within CAMHS. | 28 opportunistically sampled families attending their first assessment | Our findings illustrated that parents typically first raised the possibility of the presence of ASD diagnosis through 'building a case', which professionals were then able to ratify or negate. Found that the assessments unfolded sequentially and clinical decisions were typically reached through a distinctive pattern of interaction.<br><br>**Model:** Not clear & is **CAMHS** specific |
| Abbott, et al., 2013 | England | Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences | Community CAMHS (mental health & learning disability), North East England | Qualitative | Explore parents' experiences of receiving the news that their child warrants a diagnosis of Autism Spectrum Disorder (ASD). | Qualitative methodology was used to explore the experiences of the 'feedback session' (confirming the diagnosis) with nine sets of parents. General indictuve approach to analysis. | nine sets of parents with children aged 8-15. | page 13: '1.5 Autism diagnostic assessment for children and young people' autism case coordinator<br><br>**Model**: Not clear & is CAMHS specific |
| Gray, et al., 2015 | UK | Variable implementation of good practice recommendations for the assessment and management of UK children with neurodisability | All teams used a combination of assessment methods, with all reporting some level of single multidisciplinary team (MDT) assessment, an individual professional assessment followed by an MDT meeting and/or an individual assessment without an MDT meeting. | national surveys | to determine whether UK **child development teams (CDTs)** have implemented good practice recommendations for the co-ordinated assessment and support of children with neurodisability and to explore some of the factors associated with variations in good practice implementation. | Surveys were sent to every UK CDT in 2009/2010. Responses about CDT provision and ways of working were compared with good practice recommendations from national policy documents and professional organizations. The extent to which CDTs in England and Wales met 11 selected good practice recommendations was scored; teams in Scotland and Northern Ireland were given a score out of 9 to reflect the optional use of the common assessment framework and early support materials in these countries. | 225/240 (94%) UK CDTs responded.<br>37% of CDTs in England and Wales had implemented 9 or more of the 11 recommendations. 59% of teams in Scotland and 78% of those in N. Ireland met between six and nine recommendations of good working practice. | There was considerable variability in the degree to which CDTs implemented good practice recommendations for the diagnosis and management of children with neurodisability. Evidence about child and parent satisfaction, and the effectiveness of CDT practices and provision, is required, so policymakers, healthcare commissioners and clinicians can provide the most appropriate services to children with neurodisability and their families.<br><br>**Model:** All teams used a combination of assessment methods, with all reporting some level of single **multidisciplinary** team (MDT) assessment, an **individual professional** assessment followed by an **MDT meeting** and/or an **individual assessment without an MDT meeting**. |
| Dowden, 2018 | UK | Improving the diagnosis of autism spectrum disorder | NA | Opinion piece | assesses the scale of the problem and discusses possible reasons and solutions. | NA | NA | Barriers to receiving diagnosis include: organisatational complexities; professioansl not referring early enough or to the correct service or not even recognising symptoms; lack of capacity in services; parents needing to be 'pushy' without causing hostility with professionals. |
| Reed & Osborne, 2012 | UK | Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders | NA | review/opinion piece | Sets out existing theoretical and empirical knowledge concerning parental functioning and their child's ASD, including parental experiences of ASD diagnoses; general health and psychological functioning of parents of newly-diagnosed children with ASD; aspects of the diagnostic process impacting on parental functioning; and the relationship of parental functioning to child outcomes. | NA | NA | Discusses stress levels of parents & effectiveness of Rx for child - not related to diagnostic pathway but suggests this could be underlying mechanisms for effective Rx. Links this to importance of parental support important - possible **mechanism** for providing a management plan that parents find helpful (understanding/feeling supported). Makes good point about importance of parental trianing programmes also offering opportunity for families to explore the impact of the diagnosis & coming to terms with ASD diagnosis (coded under 7e). Suggests that issues such as the speed of diagnosis, the chain and coherence of referral through the diagnostic system, the help offered at the time of diagnosis and the communication styles of the professionals, both with the parents and with each other, may all be seen to be important in increasing parental satisfaction and establishing best diagnostic practice. |

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| Unigwe, et al., 2017 | UK | GPs' confidence in caring for their patients on the autism spectrum: an online self-report study | GPs across the UK - sample size 304 | quantitative - online survey | To understand GPs' perceived self-efficacy in identifying and managing their patients on the autism spectrum, and the factors affecting this. | An online self-report survey was developed for completion by GPs across the UK. GPs identified via the Royal College of General Practitioners (RCGP) and internet snowballing methods through social media. The survey collected responses on participants' background, training, and experience, both as a GP and with regard to autism, and included a 22-item knowledge of autism questionnaire, a 14-item self-efficacy scale targeting GPs' perceived confidence in identifying and managing their autistic patients, and an open question eliciting participants' experiences of working with autistic people. Data analysis: descriptive; correlational & regression analyses; thematic anaysis of open replies. | 304 | In total, 39.5% (n = 120) of GP participants reported never having received formal training in autism. Few responders (28.0%, n = 85) reported referring to the diagnostic criteria for autism and even fewer (19.1%, n = 58) reported using any screening instruments.<br>Despite demonstrating good knowledge of its key features, participants reported limited confidence in their abilities to identify and manage autistic patients, with many citing a number of barriers that overwhelmingly focused on perceived failings of the current healthcare system (such as a lack of clarity around referral pathways and long delays from referral to diagnosis) and lack of support post-diagnosis. This confidence was related to greater experience with autism, including personal connections & prior training in autism.<br>Recommends improved local specialist service provision alongside clearer referral pathways for diagnosis. |
| Carpenter, 2012 | UK | Diagnosis and assessment in autism spectrum disorders | NA | Literature review | provide an overview of the current situation with diagnosis and assessment in autism spectrum disorders (ASD). | a review of literature combined with personal observation of practice | NA | Diagnosis cannot be determined by any one tool. It is a clinical judgement. A solo experienced clinician can make a diagnosis. Wider assessment is needed post diagnosis and needs a team.<br>Specialist multidisciplinary teams to assess people with ASD should be set up for adults as well as for children.<br>talks about different interpretations of diagnosis, DSM4, ICD10 & 'new draft' DSM5 (came out 2016). |
| Autism ACHIEVE Alliance, 2014 | Scotland | ASD: Waiting for Assessment - Executive Summary | a broad range of autism services (for child/adult) across Scotland<br><br>The child sample comprised 50% CAMHS services, 37% Child Development Centres or equivalent, and 13% joint service with input from both CAMHS and Child Development. All child services were provided through multi-disciplinary teams. | quantitative descriptive & case note analysis & focus groups | The Autism ACHIEVE Alliance was asked to investigate waiting times in the diagnosis of Autism Spectrum Disorder (ASD), as per the Scottish Strategy for Autism Recommendation 21: 'It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings'. | A telephone survey was conducted and 457 calls were made across Scotland to ascertain which services conduct diagnostic assessment of individuals with ASD.<br>This telephone survey resulted in a list of 94[1] services which conduct diagnostic assessment with 68% (64/94) of these being child services and 32% (30/94) adult services.<br><br>a retrospective case note analysis of 150 individuals diagnosed with ASD by these services.<br><br>focus groups -We conducted focus groups with each of the diagnostic services to review their specific data, co-examine their wait issues and co-identify specific solutions. | a random sample was conducted and the sampled services (n=16) were then invited to participate. The child sample comprised 50% CAMHS services, 37% Child Development Centres or equivalent, and 13% joint service with input from both CAMHS and Child Development. All child services were provided through multi-disciplinary teams. | For the child cases, the average total wait for diagnosis from referral to receiving the diagnosis was 331 days; however there was a wide range (30-1942 days).<br>Of the child cases, 74% took longer than 119 days, which is the recommended maximum time from referral to sharing the diagnosis (National Autism Plan for Children, NAP-C, 2003).<br>Children had a statistically significant longer wait between referral and first appointment, and a longer overall wait between referral and receiving the diagnosis, compared to adults.<br><br>Page 3: 'How long is the wait for diagnosis?'<br>Page 5: 'What affects the length of the wait? - Statistical analysis of the 150 cases illustrated:<br>? In child cases, having more information about the child prior to diagnosis was associated with shorter assessment durations.<br>? Adherence to the evidence-based guidelines (SIGN/NICE) or to the Quality Diagnostic Standard (QDS 2006) does not have a detrimental effect on the total wait for diagnosis.<br>? This suggests that a good quality service, as indicated by higher adherence, does not have to have a cost in terms of increased waiting times.<br>Child and adult service focus group discussions suggested frequent reasons for delays included:<br>? less efficient working and communication ? high non-attendance rates ? inappropriate referrals ? ineffective care pathways.<br>page 5-6: 'Are standardised diagnostic assessments used?'<br>page 6: 'To what extent do services adhere to the Quality Diagnostic Standard?'<br>page 6-7: 'What can be done to reduce delays?' 'These key solutions were identified by services as follows:<br>? To develop efficient working and communication by:...? To reduce non-attendance rates by:...? To reduce inappropriate referrals by:...? To improve effectiveness of care pathways by: |

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| Reed, et al., 2016 | Swansea, UK | Impact of Diagnostic Practices on the Self-Reported Health of Mothers of Recently Diagnosed Children with ASD | NA | quantitative, cross-sectional | examined the impact of different aspects of the diagnosis process on the self-reported mental health of mothers of children undergoing a diagnosis for ASD in a cross-sectional cohort design. | One-hundred-fifty-eight mothers of consequently diagnosed children with ASD participated. The severity of the children's ASD and their intellectual functioning was assessed within twelve months of the diagnosis, and the mothers completed a psychometric assessment battery including the Hospital Anxiety and Depression Scale, General Health Questionnaire, and Questionnaire on Resources and Stress. | 158 mothers | The actual time from first reporting a problem to obtaining a diagnosis, and the **speed of the diagnostic process** from first to last appointment, were both ***negatively*** related to parenting **stress**. In contrast, mothers' **perceptions of the speed and helpfulness of the process were *negatively* related to levels of anxiety and depression**. The **number of professionals involved** in the process and the perceived coherence of the diagnosis were also negatively related to aspects of mothers' functioning.<br><br>*bottom p6- p7: The perceived **speed of the process** and its **perceived helpfulness** were independently significant predictors.... The perceived helpfulness and interpersonal skills of the professional were the only independently significant predictors.. think relates to HR-QoL (GHQ)*<br><br>*The only two reliable associations being negative ones between the child's age at diagnosis and the perceived speed of the process (the **older the child at diagnosis the worse was the perceived speed**), and the number of professionals involved and the coherence of the process ( **the more professionals the less coherent the process appeared to the mother**). However, none of the associations reported in Table 2 were particularly large,*<br><br>*These findings suggest that, while an early diagnosis might lead to quicker access to services and beneficial earlier treatment for the child [2], it may also leave mothers unable to develop coping mechanisms for living with this diagnosis [14].could be possible **mechanism** ?*<br><br>*It may be that initially more anxious mothers are more dissatisfied with the diagnostic process, or that some third factor causes both anxiety and a lack of satisfaction with the events connected to the diagnosis* |
| Tryfona, et al., 2016 | UK | M-Health Solutions to Support the National Health Service in the Diagnosis and Monitoring of Autism Spectrum Disorders in Young Children | NA | opinion piece | consider the potential for user-behaviour analysis software on tablet computers or smart phones, along with other m-health solutions, to provide a cost- effective opportunity for the NHS to support the diagnostic process and to assist in the ongoing monitoring and development of children with ASD. | review/ opinion piece | NA | Whilst there are m-health solutions emerging to assist in the diagnosis and ongoing monitoring of autism in young children, there are also limitations associated with these approaches. In order for these software products to support the NHS, it is vital that the user-requirements elicitation and modelling processes effectively capture the unique and evolving needs of the various professionals working within a dynamic organization such as the NHS. This will also ensure that software can evolve to reflect changes in our understanding of ASDs. M-health solutions, however, do present an interesting oppor- tunity for health care professionals to make observations of children between appoint- ment times and within their home environment or familiar education setting, thus potentially speeding up the diagnosis process. |
| Halpin, 2016 | UK | What do nurses think they are doing in pre-school autism assessment? | group of nurses in one NHS trust (not named) where the child health teams assess pre-school children for possible autism. | qualitative - critical reflective inquiry research method | Asked 'what do nurses identify as their particular professional contribution to the assessment of pre-school children for autism?' | Used written reflective accounts and the transcripts of one-to-one and group discussions about practice. Participants reflected on the nursing beliefs and values they hold in common, and on their actions in practice. | all six qualified nurses currently working in preschool autism assessment in one NHS trust. | The study found that the beliefs and values held by these nurses, and their intention to offer holistic nursing delivered through a professional relationship of care, correlated with the kind of care that parents have said families need, and make a unique contribution to team assessment. |
| BACCH, 2019 | UK | A workforce strategy for community paediatrics | Community Child Health - the discussions are on neurodevelopmental conditions & community paediatricians in general, so ASD focused session is limited, but include helpful info on CCH services. | report | BACCH has put together a suite of deliverable initiatives below to improve recruitment and retention in the subspecialty, building on strategies adopted by other Colleges and the experience or members and departments on what is likely to be most productive and realistic. | report | NA | page 5: BACCH/RCPCH survey (2) in 2016 showed considerable pressure on CCH services: For autism spectrum disorder (ASD), 42.5% of services have a waiting time over 18 weeks for a first appointment, and a referral to treatment (RTT) time of 35.5 weeks, breaching the 18-week Referral to Treatment (RTT) rule in countries where it applies.<br>page 7: Better access to CCH services will shorten time to diagnosis for key conditions including ASD, ADHD, learning disability and other complex neurodevelopmental conditions. Early diagnosis enables better understanding by schools and families of how to best support children to manage their condition and to achieve their potential in society.<br>page 10: Community paediatricians already work with multidisciplinary and multiagency teams. They have been at the forefront of introducing skill mix in CCH e.g. supporting primary care GPs and nurses to take over the delivery of child health surveillance and immunisation programmes and audiological scientists in children's hearing services.<br>page 14: Clinical skill mix - The Covering All Bases (CAB) report shows that skill mix is gradually developing in CCH (Fig 10). ... However, there are currently no recognised role definitions or training pathways for other practitioners to develop Advanced Practice in CCH. These would need to be developed if skill mix is to be introduced safely and effectively.<br>page 14: Administrative support - The CAB survey (2) indicated that only 1 in 3 services had access to electronic records at all times when seeing patients. Many services estimated that nearly 10% of all available doctor time was spent doing non-medical tasks such as filing, photocopying and arranging meetings – all tasks that could be done more cheaply and more effectively by proper administrative support.<br><br>mostly about recruitment & retention - coded a little under 1b. Timely referral & Ax as it's an explanation (=M) for why even if referral is fast, Ax won't be |

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| Williams, et al., 2018 | Northampton, UK | Forty years of referrals and outcomes to a UK Child Development Centre (CDC): Has demand plateaued? | CDC at Northampton General Hospital | reviewing medical notes - descriptive quantitative | To explore 40 years of CDC activity and outcomes at Northampton General Hospital 1974–2014. | The study comprises 3 data sets: a published report from 1974 to 1999, an internal audit from 2001 to 2004, and more recent data collected from 2005 to 2014. The medical notes of all children who were assessed by the CDC in 2014 were reviewed, along with referral data collected by the CDC manager from this year and the preceding 10 years. This was compared with data previously collected from 1974 to 1999. | From January 1, 1974 to December 31, 2014, 3,786 children were assessed. | Covering 1974–2014, we demonstrate a clear increase in the number of referrals together with an increasing demand for assessments for social interaction and behavioural difficulties. This reflects the increased awareness of these neurodevelopmental difficulties and the changing diagnostic criteria which will now more likely result in an ASD diagnosis than previously. Together, these two features are most likely to have considerable implications for service development within Child Development Centres (CDCs) and Child Development Teams (CDTs).<br><br>Like other CDCs, they have experienced a **decrease in the number of AHPs** providing input into the assessment process. |
| Galliver, et al., 2017 | UK | Cost of assessing a child for possible autism spectrum disorder? An observational study of current practice in child development centres in the UK | CDCs - Three CDCs regularly provided long-term follow-up care for families with a new diagnosis. Two reported continued involvement only for specific issues such as need for medication. Another unit commented on its provision of short-term follow-up but experiencing increasing pressure to halt longer term follow-up. All centres could access other agencies for postdiagnosis input, for example, Early Bird programme. | online questionnaire | explore the number of hours of professional time required to complete such an assessment based on current practice in secondary care child development centres across the UK, and from this we calculate the cost of assessment. | An online questionnaire was sent to 20 child development centres asking them to retrospectively record team members involved at each stage of assessment and time taken, including report writing and administration for a typical assessment. Costs were estimated based on the hourly rate for each team member, including salary, on-costs and trust overheads | 20 questionnaires sent to CDCs, 12 returned (all in England & representing 7% of CDCs in the UK). | 10 centres adopted a two-stage approach to assessment with an initial 'screening' clinic determining whether the child needed to proceed to full multidisciplinary assessment. Median professional time involved was 13 hours (IQR 9.6– 15.5 hours). This resulted in a median cost of £809 ($1213, based on conversion rate £1 equal to US$1.5 (November 2015)), (IQR £684–£925) ($1026–$1388))<br>This study confirms that **multidisciplinary diagnostic assessment** of a child with possible autism requires significant professional time, with staff costs of approximately £800 ($1200) per child. This does not include costs of intervention, parent psychological education, investigation and assessment and management of comorbidities. If growing waiting times for diagnostic assessment are to be avoided, funding for diagnostic services needs to reflect the human resources required and the resulting costs of that assessment.<br><br>This would suggest that carrying out a **multidisciplinary assessment is a good practice** and allowing allied health professionals to carry out parts of the assessment not requiring doctor's skills, for example, observational assessment using ADOS, could **save costs**. |
| McKenzie, et al., 2016 | Scotland | The relationship between waiting times and 'adherence' to the Scottish Intercollegiate Guidelines Network 98 guideline in autism spectrum disorder diagnostic services in Scotland | child ASD diagnostic services in Scotland - 8 sampled services | Retrospective, cross sectional case note analysis<br><br>the 80 case notes in both, and 8 child services but 16 above incl adults. | explore the extent to which the Scottish Intercollegiate Guidelines Network 98 guidelines on the assessment and diagnosis of autism spectrum disorder were adhered to in child autism spectrum disorder diagnostic services in Scotland and whether there was a significant relationship between routine practice which more closely reflected these recommendations (increased adherence) and increased waiting times | Used various directories to compile list of possible services; carried out a telephone survey ascertain which services conducted diagnostic assessment of individuals with ASD. This resulted in a list of **64 child services, of which 53 routinely assessed for ASD. Of the 53 services, 23 were CAMHS, 15 were CDCs or equivalent and 15 were specialist ASD or communication teams.**<br>The inclusion criteria for the case notes were that the individual concerned had received a diagnosis of ASD from the participating service and was one of the 10 most recent cases where the individual had received a diagnosis of ASD. A total of 80 case notes were obtained from **eight services**. | 80 case notes. | the assessment and diagnostic practices were consistent with the relevant Scottish Intercollegiate Guidelines Network guideline recommendations. Increased adherence to the 19 included recommendations was not significantly related to increased total waiting times, indicating that the Scottish Intercollegiate Guidelines Network 98 recommendations have generally been integrated into practice, without a resultant increase in patient waits. |
| McKenzie, et al., 2015 | Scotland | Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults | 16 diagnosing services across Scotland (eight adult and eight child ASD diagnostic services) | a cross-sectional, retrospective case note study of eight adult and eight child ASD diagnostic services. | To identify the main factors predicting delays in diagnosis for Autism Spectrum Disorder (ASD) at three stages in the diagnostic process: wait for first appointment; assessment duration, and total wait for diagnosis. | Data were gathered from 150 case notes (**80 child** and 70 adult cases) from 16 diagnosing services across Scotland. | 150 case notes (80 child and 70 adult cases) | Within children's services, increasing the **amount of relevant information available pre-assessment** is likely to reduce total duration of the assessment process by reducing number of contacts required.<br>The results of the present study would suggest 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**.<br>It is also important that relevant information, which is collected by **services which are not necessarily specialists in relation to the diagnosis of ASD**, for example **generic general psychiatric services**, is communicated in a timely way to specialist services. This will help to ensure that diagnosis is not delayed because the individual is seen by numerous professionals before being referred to diagnostic services. |

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| RCPCH (Royal College of Paediatrics and Child Health), 2017 | UK | invited reviews the first four years (2012-2016) | paediatrics in general (not Autism focused) | Review | to provide a `state of play` of the service together with recommendations for future service design, workforce planning and support to our members and paediatrics in general. | The RCPCH provides a unique review service by bringing together clinical and policy expertise to work with local teams to identify and resolve issues of concern. The service launched over four years ago and has undertaken over 60 acute, community, neonatal, emergency and individual reviews.<br>The scope of a review can range from examining an individual case or doctor`s practice, to a theme, pathway, service or network of services.<br>Review teams comprise, as a minimum, two paediatricians and a staff administrator; they have agreed terms of reference and reviews are conducted with tact, diplomacy and discretion. Two additional reviewers provide a quality assurance review of the draft report; the client has a chance to comment on the draft and is encouraged to share the final report as widely as possible. | Over 75 RCPCH members have been involved with reviews alongside lay representatives and nominees from other clinical disciplines. | Emerging themes from the reviews to date include tackling clinical resistance to change, the integration of primary and secondary pathways and problems with covering Tier 2 medical rotas. It is important that clinicians are fully involved in the development of new ways of working, they must be clear about the benefits for children, and they must have confidence in clinical leadership.<br>Most reviews have recommended greater engagement with children and young people, involving them and their families in the design and operational policies of paediatric services. The establishment and assurance of adequate networks to support arrangements for escalating the care of very sick children must be prioritised.<br><br>Most are about **paediatrics in general**. Key info re autism:<br>Page 16 : 4.4 Community Paediatrics 'The changes to the assessment of children with special educational needs were rolled out in September 2014 under the Children and Families Act, resulting in increasing numbers of referrals from parents and schools seeking an autism assessment to identify resources for educational support. Each clinical commissioning group (CCG) is required to identify a Designated Health Officer for special educational needs, usually a senior community paediatrician, to support the contribution to the Education, Health and Care Plans.<br>Child and adolescent mental health services are increasingly pressured and with tight contracts many services are handling referrals for emotional and behavioural concerns through a 'single point of access' and against clear referral thresholds. This can lead to accepting only children and young people with the most severe symptoms or clear mental health need, referring any with suspected attention deficit hyperactivity disorder (ADHD) or autism (ASD) back to an already stretched paediatric team for initial assessment.'<br>and following highlighted findings |
| Ford, et al., 2019 | England | The agreement between the referrer, practitioner and research diagnosis of autistic spectrum conditions among children attending CAMHS over 2yrs | agreement about diagnoses between the **referrer**, **CAMHS practitioner** and a **research diagnosis**, as well as the stability of the practitioner's diagnosis over time | quantitative, secondary analysis | explore the levels of agreement about the diagnoses of Autistic Spectrum Conditions between the referrer, CAMHS practitioner and a research diagnosis, as well as the stability of the practitioner's diagnosis over time | secondary analysis of data from 302 children attending two Children's Team (Tier 3/secondary care), which provided **multidisciplinary treatments** to children up to the age of 16 and the Early Interventions Team (Tier 2/primary care) | 302 children aged 5–11 years recruited from 861 consecutive referrals accepted on the CAMHS waiting lists during the recruitment period (2006 and 2008) | Child health mapping suggests that one in every ten children utilising CAMHS has an ASC.<br>Their findings suggest that where practitioners are confident that a child definitely does or does not have an ASC, there was considerable agreement between practitioner and research diagnoses and clinical diagnoses were stable over time. However, for some children, initial diagnostic uncertainty led to confusing and prolonged fluctuations in practitioner assessments that may have undermined both engagement and intervention. **The use of standardised assessments and observations** might be particularly helpful for these children and could be evaluated further.<br><br>In this study, once assessed by CAMHS, most children with ASC receive a diagnosis within the first six months, which approximates to The National Autism Plan for Children recommendation that time from referral to diagnosis should not exceed 17 weeks. It also runs counter to reports of long delays and multiple assessments reported by others . We do not, however, have details on when these families first sought advice or which services they may have been in contact with prior to the index presentation to CAMHS. |

**Supplementary Document 2.2 - Key papers from secondary searches**

| **Author (year)** | **Country** | **Title** | **Settings/service types** (e.g. ASD, ASD & CAMHS) **& service models** | **Study type** | **Aims** | **Method** | **Sample size** | **Summary of findings relevant to programme theory** |
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| Ahlers, K., et al., 2019 | US | A pilot project using pediatricians as initial diagnosticians in multidisciplinary autism evaluations for young children please can we stick to UK spelling? | The University Developmental Assessment Clinics (UDAC) used a multidisciplinary team for autism spectrum disorder (ASD) evaluations, including psychologists (3), general pediatricians (4), developmental pediatrician (1), speech and language pathologists (SLPs; 2), occupational therapists (OTs; 2), and an audiologist. The UDAC is a clinical program operated by the Division of General Pediatrics at the University of Utah. | quantitative | to examine the feasibility of an alternative diagnostic model and evaluate the differences in wait time (to diagnosis) and fees charged for families whose children were evaluated for ASD in each of the 2 models. | Data were gathered through record extraction (n = 244) and parent questionnaire (n = 57). Authors compared time to diagnosis, charges, and parent satisfaction between traditional and alternative models. Agreement between paediatrician and psychologist diagnoses was examined for a subset (n = 18). | record extraction (n = 244); parent questionnaire (n = 57); Agreement between paediatrician and psychologist diagnoses was examined for a subset (n = 18). | Efficient use of available clinicians with additional training in Level 2 autism screening resulted in improvements in time to diagnosis and reduced charges for families. Coordination of multidisciplinary teams makes this possible, with strategic sequencing of patients through workflow. Flexibility was key to not only allowing paediatricians to refer uncertain cases to psychology for diagnosis but also allowing for diagnosis by a paediatrician when symptomatic presentation clearly met diagnostic criteria. However, there were concerns that the abbreviated pathways could lead to issues of inequality, with families receiving different outputs depending on their route. |
| Department for Education and Department of Health and Social Care, 2015 | England | Special educational needs and disability code of practice: 0 to 25 years. | Services for children and young people who have special educational needs or are disabled | staturory guidance - Code of Practice | Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities | The Code of Practice is the product of extensive consultation, and draws on the experience of pathfinder local authorities which have been piloting new approaches with local communities. | NA | This Code of Practice provides statutory guidance on duties, policies and procedures relating to Part 3 of the Children and Families Act 2014 and associated regulations and applies to England. It relates to children and young people with special educational needs (SEN) and disabled children and young people.<br>The aim is to identify special educational needs and disabilities at the earliest point with support routinely put in place. Relevant to programme theory 6b, the role of the SENco (SEN Co-ordinator). |

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| Hayes, et al., 2018 | UK | Clinical practice guidelines for diagnosis of autism spectrum disorder in adults and children in the UK: a narrative review | ASD services | narrative review | to consider how the content of clinical practice guidelines shapes diagnoses of Autism Spectrum Disorder in the UK; and investigate where, within those guidelines, social factors and influences are considered. | searched multiple databases (NICE Evidence Base; TRIP; Social Policy and Practice; US National Guidelines Clearinghouse; HMIC; The Cochrane Library; Embase; Global health; Ovid; PsychARTICLES; PsychINFO) and relevant web sources (government, professional and regional NHS websites) for clinical practice guidelines.<br>extracted details of key diagnostic elements such as assessment process and diagnostic tools.<br>A qualitative narrative analysis was conducted to identify social factors and influences. | Twenty-one documents were found and analysed. | Guidelines varied in recommendations for use of diagnostic tools and assessment procedures. Although multidisciplinary assessment was identified as the 'ideal' assessment, some guidelines suggested in practice one experienced healthcare professional was sufficient. Social factors in operational, interactional and contextual areas added complexity to guidelines but there were few concrete recommendations as to how these factors should be operationalized for best diagnostic outcomes.<br><br>Relevant to PT6a in terms of context of assessements; while supporting MDT assessements, it is unclear how disagreement is resolved; there is a lot of variation between guidelines which can sew confusion; the role of clinical judgement. |
| Hennel, S., et al., 2016 | Australia | Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice. | Australian Paediatric Research Network - members paediatricians who saw children with ASD - diverse clinics | Survey- quant & qual questions | 1) compare parents' experience and preferences with paediatrician report of (i) diagnosis delivery and (ii) information given at diagnosis and<br>2) identify types and usefulness of resources accessed by families post-diagnosis. | The design used for the study are parent and paediatrician surveys. Participants are parents of children aged 1.5–18 years, diagnosed with autism between 01 January 2010 and 30 September 2012 and their paediatricians who are members of the Australian Paediatric Research Network. Study-designed quantitative and qualitative questions about diagnosis delivery and information given at diagnosis (written and spoken vs. neither) and parent perceived importance and harms of information accessed post-diagnosis. | Paediatricians (53/198 (27%)) identified 1127 eligible families, of whom 404 (36%) participated. | Parents want more information than can be conveyed in a single diagnostic consultation. Developing a tailored 'autism action plan' with written materials could improve parents' understanding of and satisfaction with children's autism diagnoses.<br>Relevant to PT4a in terms of practical suggestions: clinicians should (i) encourage a support person to be present; (ii) provide information about school support, tailored therapy plans and choosing effective therapies either at diagnosis or afterwards; (iii) refer families to allied health professionals; and (iv)encourage families to explore evidence-based websites In addition to face-to-face clinical consultations, parents find written in- formation useful, particularly for understanding the diagnosis and explaining it to friends and family. |
| Jordan, E., Farr, W. & Male, I., 2017 | UK | Pirate adventure assessment software: a new tool to aid clinical assessment of children with possible autism. | UK based Child Development Centres | pilot - software in clinical assessment of children with possible autism | presents a computer based tool, developed by the research team, which early clinical experience suggests could provide additional information to the initial assessment. | The Pirate Adventure Autism Assessment software includes a number of psychometric tests adapted into a pirate adventure storyline.<br><br>The app has been piloted by paediatric consultants working in three local Child Development Centres, two at initial appointment, in one at a diagnostic clinic. | NA | Early experience, presented here, suggests the tool is a useful adjunct to parental history and school questionnaire obtained at initial clinic, in determining the need for the child to proceed to a full, time consuming, expensive, diagnostic assessment. |
| Juárez, et al., 2018 | US | Early identification of ASD through telemedicine: potential value for underserved populations. | Study 1: a diagnostic clinic at a university-affiliated medical centre due to early concerns about ASD.<br><br>Study 2: a regional health center serving a rural 23 county region, geographically distant from the urban diagnostic centers of our state. | Accuracy; Feasibility & acceptability | evaluate a telemedicine assessment procedure | 1) compared telediagnostic accuracy to blinded gold-standard evaluations (n = 20).<br>2) evaluated telediagnostic feasibility and acceptability in a rural catchment.<br>Children (n = 45) and caregivers completed the telemedicine procedure and provided feedback. | Study 1: Participants were 20 children (16 boys, 4 girls) between 20 and 34 months of age (mean = 26.65, SD = 4.49) and their caregivers.<br>Study 2: Participants were 45 children (mean age = 26.80 months, SD = 3.12, range 19–32; 35 boys, 10 girls) and their caregivers | Findings support preliminary feasibility, accuracy, and clinical utility of telemedicine-based assessment of ASD for young children. ASD cases identified via telemedicine were confirmed by in-person evaluation. However, 20% of children diagnosed with ASD in-person were not diagnosed via telemedicine.<br>Families indicated high levels of satisfaction. Remote diagnostic clinicians diagnosed 62% of children with ASD, but did not feel capable of ruling-in or out ASD in 13% of cases.<br>This pilot work demonstrated that a large percentage of children with ASD may be accurately diagnosed via remote observation of standardized assessment procedures, and many families and providers ascribe clinical value to the procedure. |

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| Male, Farr & Reddy, 2020 | UK | Should clinical services for children with possible ADHD, autism or related conditions be delivered in an integrated neurodevelopmental pathway? | two CDTs:<br>1- based in a large mixed urban–rural county, where there are three provider trusts, four CDTs and four CAMHS teams. While a newly commissioned, joint CAMHS/CDT complex cases clinic pilot is about to start, to assess children with diagnostic complexity, current commissioning and practice requires children with possible autism up to age 11 to be seen within CDTs, while children with possible ADHD and older children with possible autism are the remit of CAMHS.<br>2- a fully integrated CDT/CAMHS service, colocated in a single building, in a city organised as a unitary authority, facilitating close working between health, education, social care and child and family support services. | Viewpoint paper | We present the journeys of a typical primary school-aged child referred with a history suggestive of either autism and/or ADHD and the pathways they would follow in each service. This illustrates how the integrated and non-integrated approaches can affect the professional time involved, the resulting NHS costs and the patient journey. | Scenario<br>1) Diagnostic pathway experienced in the non-integrated approach;<br>2) Diagnostic pathway experienced in the integrated approach | NA | It's often a very inefficient and, for the parents, frustrating journey to a diagnostic conclusion for their child presenting with a mixture of difficulties in social communication, concentration and hyperactivity. Commissioning of separate autism and ADHD pathways, one with the CDT and the other with CAMHS, resulted in the child having to go through both pathways despite considerable overlap of assessment. The integrated approach, by running a single assessment process, cutting out this overlap, required less professional time (13 vs 20.75 hours), at a lower cost (£817 vs £1357), and reduced the time taken to reach a completed diagnostic formulation. Furthermore, the additional time and cost taken reduced the capacity of the first service to meet wider demand for assessment.<br><br>Why integrated pathways are still a novelty at secondary care level in neurodevelopmental services: CAMHS and CDTs often sit in different health trusts, who have been commissioned to deliver specific pathways; the separation of autism and ADHD in previous diagnostic coding systems; the current financial pressures on all NHS trusts.<br><br>moves toward running integrated CDT/ CAMHS services for children with potential neurodevelopmental and/or mental health conditions have the potential to improve efficiency of service delivery. |
| NHS Education for Scotland, 2014 | Scotland | The NHS Education for Scotland Autism Training Framework - Optimising Outcomes - A framework for all staff working with people with Autism Spectrum Disorders, their families and carers | various health and social care settings | Training Framework | The framework is not prescriptive, but its clarity and breadth of scope should facilitate individual employees, service providers and organisations to understand the knowledge and skills required and how this applies to their practice. | the framework developed was informed by:<br>-review of existing training frameworks (MacKay and Dunlop, 2004)<br>-evidence and best practice guidelines<br>-engagement with the autism community regarding experiences of contact with services<br>-Learning Needs Analysis amongst NHS staff<br>- Review of existing education and training in autism spectrum disorders<br>- consultation with professional bodies, thrid sector orgs and educational institutions<br>-consultation iwth the subgroups of the Scottish Strategy for Autism | NA | The NES Autism Training Framework has identified four Levels of Knowledge and Skills required, dpeending on the nature, extent and likely impact of contact during day-to-day work in the particular service, rather than defining levels specific to profession or position in a service. The Four levels: 1. Autism Informed Practice Level- for all professionals working with Autism in health and social care settings; 2. Autism Skilled Practice level- for all staff with direct and/or frequent contact with individuals with Autism or those who have a role with high impact on these individuals; 3. Autism enhanced Practice Level- for professionals with more regular or intense contact with individuals with Autism where their role focuses specifically on the condition and providing interventions, or service managers; 4. Expertise in autism Practice Level – for professionals who have a specialist role in the care, management and support of people with Autism.<br><br>. |
| RASDN, 2011 | Northern Ireland | Six Steps of Autism Care - for Children and Young People in Northern Ireland | various community settings, including GP, Autism services, social care & voluntary organisations | leaflet to parents/carers | to provide parents/carers with information about the new regional 'Six Steps of Autism Care' Pathway for children and young people in Northern Ireland. | NA | NA | This leaflet tells parents about the agreed journey child/ young person, and parents, will take through the integrated assessment, diagnosis and intervention process. It gives information about each step in the process about who will see the child/young person; which tests will take place; tell parents whether their child/young person has ASD, or not, and the follow up support that will be made available to the child/young person and family, with the following 6 steps (Page 4 flow diagram): 1. First appointment; 2. Integrated Multi-disciplinary Team Assessment; 3. Integrated Multi-disciplinary Team Formulation; 4. Family Feedback and Care Planning; 5. Integrated Family Intervention and Support Services Delivered Over Pre-Planned Sessions; and 6. Child and Family Care Plan Review at Regular Intervals. |

**Supplementary Document 3.** Programme theories with CMO configurations

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| **Programme theory 1 – Listening and recognition**<br><br>If frontline health and education professionals (e.g. GPs, teachers) are confident in recognising the signs and symptoms of autism, are cognisant of referral pathways and take parents/carers' concerns seriously then CYP will be referred to the appropriate service, in a timely manner, reducing parental frustration. | | |
| 1a. Parents/carers concerns are listened to and discussed | If frontline health and education professionals (e.g. GPs, teachers) take parents' concerns seriously (M), discuss and explain developmental behavioural concerns sensitively (M) and agree any actions to follow (M), then they will refer in a more timely manner (O) and parents will feel reassured with stress levels reduced (O).<br><br>Also, if professionals at nurseries and schools (teacher or others) make a difference in "pushing" for a diagnosis or a specific form of support (M), then this will lead to timelier referral (O) and improve parental satisfaction (O) with the referral pathway.<br><br>However, mis-diagnosis can be detrimental (C), so while parents should request referral for possible autism diagnosis (M) this has to be balanced against respecting professional expertise and enabling the development of a co-operative relationship (O). | NICE, 2011; Abbott, et al., 2013; The Scottish Government, 2014; Rogers, et al., 2016; O'Reilly, et al., 2017; Unigwe, et al., 2017; Crane, et al., 2018; Dowden, 2018; Rutherford, et al., 2018; Hurt, et al., 2019. |
| 1b. Frontline health and education professionals are cognisant of autism and referral pathways | If frontline health and education professionals (e.g., GPs, teachers) are trained in recognising the signs & symptoms of autism and referral routes (M), then their ability, confidence and skills in identifying children or young people (CYP) who need an autism diagnostic assessment will improve (O) and they will refer to the 'right' service in a timely manner (O).<br><br>If proportionately fewer CYP go through the full process (M) then accessibility of services will increase (O), and the risk of unnecessarily raising parental concern over autism when it is not present will reduce (O).<br><br>However, it is important to sensitively manage (M) a balance between supporting parents to accurately identify autism as early as possible, and not causing unnecessary concern amongst those who do not meet criteria for autism but may show some isolated Autistic-like features (O). | NICE, 2011; Reed and Osborne, 2012; Abbott, et al., 2013; The Scottish Government, 2014; Crane, et al., 2016; O'Reilly, et al., 2017; RCPCH, 2017; Potter, 2017; Dowden, 2018; Hurt, et al., 2019; Ford, et al., 2019. |
| **Programme theory 2 - Referral and triaging** | | |

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| If autism diagnostic services provide clear guidelines for referrers on what information is needed and how to refer, then time will be saved at the triaging stage and fewer CYP who do not have autism will go through the full process. | | |
| 2a. Referral process | Referrals often lack relevant information; this adds to waiting lists and clinician time, as they gather appropriate additional information, delaying the diagnostic process (C).<br><br>If referral is via a single point of access (for all neuro-developmental conditions and incorporating mental health expertise) (M) and referrers are provided with a systematic method of gathering relevant information from home and other settings preassessment (M) (e.g. proforma or digital assessment dashboard) and guidelines on how to do so (M), then referrers will know what information to gather, how to refer and what to expect following referral (O).<br><br>When referrals are declined, the referrer should be provided with an explanation (M), advice for improving the referral (M) and/or other appropriate services to refer to. Collectively, these measures will contribute to reducing the waiting list and low diagnostic yield (low numbers of positive diagnoses) (O). | NICE, 2011; Carpenter, 2012; The Scottish Government, 2014; MacKenzie, et al., 2015; Healthcare Improvement Scotland, 2016; Rutherford, et al., 2016; Rutherford, et al., 2018; Autistica, 2019; Tollerfield and Pearce, 2020. |
| 2b. Triage | Services that triage referrals depend on having the necessary information (C). Cross-organisational triaging (e.g. monthly meetings with a representative from CAMHS, CCH and SLT), while time intensive, has several benefits including improved joint working (M response); a forum to discuss complex cases (M); improved compliance with the care pathway (O); only referrals with adequate information are accepted and therefore clinicians will use their time well (O); and this avoids referrals bouncing between agencies (O).<br><br>Other approaches to triaging include an initial interview with an experienced clinician (M) who feels confident to identify CYP who clearly do, or do not, have autism; a community paediatrician carrying out a General Developmental Assessment/'Stage 1' Assessment, before referring to the MDT for further assessment, if needed (M).<br><br>Although triaging and referral management requires very clear guidance and training for staff (M) it results in proportionately fewer CYP going through the full process who do not have autism (O) which reduces the risk of unnecessarily raising parental concern over autism when it is not present (O). | NICE, 2011; The Scottish Government, 2014; MacKenzie, et al., 2015; Healthcare Improvement Scotland, 2016; Rutherford, et al., 2016; Rutherford, et al., 2018; Hurt, et al., 2019; Tollerfield and Pearce, 2020. |

| **Programme theory 3 - Diagnostic assessment**<br><br>There is wide variation in the model for autism diagnostic services and national staff shortages but these can be addressed with a structured and consistent approach, making best use of available staff and clinical expertise. | | |
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| 3a. Model & skills mix | Current services have different condition-specific remits and models (e.g. Autism only, all neuro-developmental conditions, and/or integrated with CAMHS), catchment areas and commissioning agreements which raises challenges around capacity, care pathways and funding (C). Streamlining (M) the autism diagnostic pathway requires a structured and consistent approach (M) so that the number of assessments per individual are minimised, alongside developing efficient working and communication (e.g. shared proformas for report writing; on-line reports) (M), thereby saving resources (O) and reducing waiting lists.<br><br>There is very little evidence to guide optimal service configuration (C) and the skills mix of diagnostic teams often relates to funding streams and the development of services over time (M). Core multi-disciplinary diagnostic teams are advisable (M) but there are national shortages of suitably trained professions including paediatricians and child psychiatrists who are the costliest members of the team (C).<br><br>However, the role of professions that are available locally (e.g. SALT) can be extended by training them to carry out aspects of the assessment not requiring medical expertise (e.g. observational assessment) (M) which will reduce costs (O). Similarly, incorporating questions previously undertaken by psychiatrists into the parent interview (M) will free up time for psychiatrists to focus on complex diagnoses (O).<br><br>Planning resources to meet need requires services to review their service configuration and skill mix (M) to accommodate demand within the available resources (O). Also recommended is ensuring that a core group of staff have dedicated autism time (M) and have shared skills for core aspects of autism assessment (M) to avoid overdependence on one clinician.<br><br>However, disadvantages of MDT diagnostic assessment are that it takes longer and different professions may disagree (C). To reduce this added stress on families, professionals sometimes make their diagnosis independently (O). | NICE, 2014; Karim, et al., 2014; Gray, et al., 2015; Halpin, 2016; Healthcare Improvement Scotland, 2016; MacKenzie, et al., 2016; Rogers, et al., 2016; Galliver, et al., 2017; Rutherford, et al., 2018. Ahlers, et al., 2019; Autistica, 2019; Tollerfield and Pearce, 2020. |

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| | Some CYP referred for autism diagnosis may require mental health expertise and when unavailable, have to return to the waiting list for CAMHS (C). If the same Trust manages both community paediatrics and mental health services (M), this potentially allows for a seamless transition, avoids duplicate waits and enables families to see all relevant professionals at the same time (O). | |
| 3b. Clinical judgement | Diagnosis should involve interview, observation and recognised tools (C). Less experienced clinicians appear to prefer using formal extended tools compared to their more experienced counterparts (C). However, standardised tests lack subtlety and children may not meet cut-offs (e.g. atypical presentations) to receive a positive diagnosis. Clinicians often use their clinical judgement (M) to 'upgrade' the diagnosis so that the child is entitled to support (O).<br><br>Many psychiatrists and paediatricians rely on the reports and observations of other professionals to inform their decisions while some, particularly educational psychologists, prefer to carry out their own observations within educational or home settings (C). This is valuable but time consuming; one solution (O) may be for professionals to only do observational assessment (M) if there are discrepancies between school and home reports.<br><br>It is not always possible to provide a child with an accurate diagnosis at an early stage (C). Diagnostic uncertainty can lead to confusing and prolonged assessments (M) that may undermine both engagement and intervention (O). Therefore, reassessment after a specified timeframe (M) is necessary and the use of standardised assessments and observations (M) might be particularly helpful to aid diagnosis (O). | Carpenter, 2012; Karim, et al., 2014; Crane, et al., 2016; Rogers, et al., 2016; Rutherford, et al., 2016; Healthcare Improvement Scotland, 2016; Ford, et al., 2019. |
| 3c. Digital technology | Children with autism sometimes feel an affinity for computing technology (C), as it is may be seen as a safe environment (M) to learn and practice skills that may be difficult in everyday life. The use of such technology in autism diagnosis is at an early stage (C) but shows potential, for example, using tablets/computers at school to collect observational data in a natural setting (M). If clinicians are able to access observations in advance (M), this would supplement other sources of data (O), save clinical time (O) and contribute to faster diagnosis (O). Telemedicine for autism screening &/or diagnosis is in the early stages of development (C) but shows some promise identifying individuals for further assessment (O) and early data suggest may be feasible and acceptable to parents and children (M). | Tryfona, et al., 2016; Jordan, et al., 2017; Juárez, et al., 2018. |

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| **Programme theory 4 – Diagnostic feedback**<br><br>If parents understand the diagnostic process and feel supported this can moderate parental expectations. Feedback should take an assets-based approach and the management plan should be individualised, taking account of co-existing conditions. Reports should be timely and in a format that everyone finds helpful. | | |
| 4a. Diagnostic feedback to parents and CYP | Parents can find the diagnostic process stressful, and may fear the stigma attached to diagnosis, but anticipate that a positive diagnosis will act as a gateway to individualised information, advice, support, services and/or treatment (C).<br><br>Receiving the diagnosis can affect parents' ability to absorb information but irrespective of the format (e.g. single professional or multi-disciplinary) (C) parents value: feedback that focuses on their child's strengths (asset based approach) (M) as this enables them to understand their child's needs (M), communicate these needs to others (O) and identify services to meet them (O); a structured and focused approach and the opportunity to ask questions (M); being put at their ease, listened to and given time to absorb information (M); and a positive and open parent-clinician relationship, established during the assessment process (M).<br><br>Parental satisfaction is further enhanced (O) when the diagnosis results in an individualised management plan that identifies co-existing conditions (M); support post-diagnosis is co-ordinated and tailored to need (M); and appropriate services are available (M).<br><br>Unintended consequences (O) include no autism or neurodevelopmental diagnosis which means parents may not be entitled to access condition specific services. Some CYP do not identify any benefits to diagnosis and fear being singled out as 'not normal' and subsequently stigmatised (O). | NICE 2011; NICE 2014, RASDN, 2011; Calzada, et al., 2012; Carpenter, 2012; Reed and Osborne 2012; Abbott, et al., 2013; Karim, et al., 2014; The Scottish Government, 2014; Halpin, 2016; Healthcare Improvement Scotland, 2016; Hennel, et al., 2016; Reed, et al., 2016; Rogers, et al., 2016; Crane, et al., 2018; The Scottish Government, 2018; Autistica, 2019; Hurt, et al., 2019; |
| 4b. Report format | A standardised template for report writing, using consistent terminology, visual tools, enabled professionals to collate reports in a timelier manner and in a format that all found helpful. | MacKenzie, et al., 2016; Tollerfield & Pearce, 2020. |
| **Programme theory 5 - Working in partnership with families**<br><br>Parents find the diagnostic pathway stressful so find it helpful to have a single point of contact; to be provided with explanations about the process; and to be included in decision-making. | | |

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| 5a. Parent/carer as co-experts in the diagnostic process | Contributing to the patient-professional tension is a debate around who is the expert (C). Parents expect to be listened to during the diagnostic process and their concerns taken seriously because they 'know' their child (C); if they feel belittled and/or do not understand the process or terminology (Ms), they will disengage from the process (M) and/or resist alternative diagnosis (O) which will have a detrimental impact on the parent-professional relationship (O). Professionals need to explain the diagnostic pathway and acknowledge that it is enhanced (O) when expertise is integrated with the perspectives of the individual and their family (M). Parents want to have a transparent and honest dialogue with professionals (M) and be involved in key decision-making (O). | Gregory, et al., 2013b; Rogers, 2016; Healthcare Improvement Scotland, 2016; Crane, et al., 2018. |
| 5b. Supporting parents/carers | Some parents perceive the system as poorly co-ordinated and feel it necessary to take charge of organising diagnostic and support processes. However, a consistent point of contact within the system would provide emotional support and enable parents to be kept up-to-date (O). When professionals explain the diagnostic process in advance and how long it will take (M), this improves parental satisfaction and can moderate expectations (O).<br><br>Non-attendance at appointments is frequent (C) and services need to have systems in place to reduce it, for example using reminders, opt-in systems and a support contact to facilitate attendance (M). By increasing attendance levels, this will reduce service costs and waiting times (O).<br><br>When contact with professionals during diagnosis has been perceived by parents as unsatisfactory, this may lead to subsequent treatments undertaken by the child being less effective than they otherwise might have been (C). Satisfaction can be improved by managing the process in a thoughtful and sensitive manner (M); clearly explaining the diagnosis (M); and demonstrating a high degree of knowledge and empathy (M). Also, if some professionals (e.g. nurses) provide advocacy for parents' views during assessment (M) and well-organised parent/carer groups are established (M), parents' concerns are more likely to be heard and parents will be empowered to speak up for themselves (O). | Calzada, et al., 2012; Abbott, et al., 2013; Gregory, et al., 2013b; NICE, 2014. |
| **Programme theory 6 - Inter-agency working**<br><br>If "experts" including people with autism, carers, professionals and specialist organisations work in partnership and the knowledge generated is effectively embedded into local services, this will build capacity, improve parent/CYP satisfaction and support planning of services both locally and nationally. | | |

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| 6a. Macro-Meso level | A multi-disciplinary, inter-agency and holistic approach is essential (M) given the subjective nature of diagnosis and the significant differences in presentation of CYP with autism (C). However, there are multiple barriers to inter-agency working at all levels, particularly a hierarchical relationship between education and health (C), with education practitioners delivering daily interventions but having to rely on healthcare professionals to issue diagnoses to release additional funding or support.<br><br>Macro-level approaches to ameliorate these barriers include: setting up a national 'whole life' autism strategy that co-ordinates multi-agency planning (M); a national approach to support school pupils with autism (M); clear standards of training and expertise (M) for all service providers offering services for those with autism, and access to specialist training; positioning (strategically and/or physically) autism services alongside other CYP's services (M), as this enables the development of a shared understanding which promotes effective joint-working (O) and is particularly useful where CYP are at risk; a more integrated care pathway with additional ringfenced funding (M).<br><br>If teams are supported to structure and deliver services in a flexible, creative, 'can do' approach at all levels from the clinician working on a day-to-day basis, to cross agency working, up through middle and senior management (M), then the experience of parents, children, clinicians and referrers would be improved (O).<br><br>If partnership working across organisations develops and consolidates a combined skill set (M), has mechanisms in place to share information (M) and holds regular networking and multi-agency professional meetings (M), then this will support the development of a shared understanding of CYP, their support needs and those of their parents (e.g. negotiating with the wider system) (O). | NICE, 2011; Gregory, et al., 2013a; Karim, et al., 2014; NICE, 2014; The Scottish Government, 2014; Gray, et al., 2015; Healthcare Improvement Scotland, 2016; Rogers, et al., 2016; Galliver, et al., 2017; Hayes, et al., 2018; The Scottish Government, 2018; Williams, et al., 2018; Hurt, et al., 2019; Tollerfield and Pearce, 2020. |
| 6b. Micro level | Multi-agency working (M) is designed to minimise variations and enhance the engagement of all services (C). Improved co-ordination between health, education and local authorities (M), at the level of individual diagnostic assessment would help reduce the time taken from referral to diagnosis, improve parental perceptions of support following diagnosis (O) and, with clear documentation (M), improve information flow between involved parties (O). | NICE, 2011; Calzada, et al., 2012; Gregory, et al., 2013b; The Scottish Government, 2014; Tollerfield and Pearce, 2020. |

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| | Opportunities to enhance multi-agency working include a "one stop shop" coordinator for children with ASD (M) and split posts for staff which can act as bridges between different parts of the system or different organisations (M), aiding understanding and communication (O). One opportunity to build links with relevant (voluntary) organisations (O) is to rent space, such as a community clinic, to carry out ASD assessments (M) but it needs to be an environment suited to the needs of children with ASD. However, when CDTs are based in a dedicated CDC (M), they are more likely to have implemented good practice recommendations including recommended team working and family communication standards (O).<br><br>If ASD diagnostic services establish clear pathways, including detailed data on the use of time and tools at each stage of the process (M), this will improve effectiveness in assessing, diagnosing and supporting children with autism (O). | |
| **Programme theory 7 – Training, service development and evaluation**<br><br>Based on their needs, skills and knowledge for autism diagnostic assessments and working with families, health and community professionals should have access to tailored training, service development and service evaluation. | | |
| 7a. Training for professionals working with CYP in community settings | Training in many organisations is "ad hoc", varies widely and may have low priority given financial constraints (C); multi-agency training is limited (C). Clinicians working with CYP with developmental delay, speech, language and communication impairments and mental health difficulties will come into regular contact with children with autism, as will frontline staff in generic children's services (e.g. nurseries) (C). If multi-agency training for professionals is provided (M), with a targeted and coordinated approach across organisations (M), a wide breadth of coverage of basic training can be achieved (M) and awareness and training geared to the needs of managers as well as front-line staff (M). This will increase the local skill set of people who regularly work with children who may have autism (O).<br><br>Another approach is to develop a detailed framework, mapping staff skills and knowledge for autism diagnostic assessment at different levels (informed, skilled, enhanced and expert practice levels) (M). The levels of skill required by different staff depend on the nature, extent and likely impact of daily contact with individuals with autism (M), rather than defining levels specific to profession or position in a service. The framework can be used by individuals, organisations or training providers to identify current or future training needs at different levels (O). | NICE, 2011; Gregory, et al., 2013a; NHS Education for Scotland, 2014; The Scottish Government, 2014; Rutherford, et al., 2016; Rutherford, et al., 2018; The Scottish Government, 2018. |

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| 7b. Training for health professionals working in autism services | Training budgets have been reduced (C). If professionals working in autism services are provided with crucial supports, including backing for training, funding for a specialist library and practical resources (M) as well as access to supervision, links with other experienced professionals, and an open team culture of sharing ideas (M), then they will be able to work with CYP in the most skilled and effective way (O). As above, training programmes need to be tailored to the level of competencies required (i.e. enhanced and expert practice levels) (M). Training activities could include observing in a (tertiary) autism clinic (M) to develop skills and confidence (O); 'buddy up' with more experienced staff (M); regular Continuing Professional Development sessions for the team to review training needs (M); developing an explicit plan for succession planning and training needs (M); and a national forum to share experiences and knowledge, including people with autism and their families (M). As more staff become better trained in, for example, the use of standardised autism assessment tools (O), there will be a higher degree of consistency between local and specialist teams (O). | Gregory, et al., 2013a; Autism ACHIEVE Alliance, 2014; Rutherford, et al., 2016; Rutherford, et al., 2018. |
| 7c. Service development & evaluation | Structural and organisational barriers impact on the effectiveness of the autism pathway (C) and as services have become increasingly overburdened, clinicians have little time to engage with service evaluation and development (C). If services plan resources to meet need, based on audit data, for example reviewing service configuration and skill mix to accommodate demand (M) and make efficient use of administrative support to free up the diagnostic team (M), then time allocation and quality of autism services will be protected within resources and available capacity (O).<br><br>Services should maintain or develop efficient systems of collecting information about referrals, waiting times and outcomes, for example using a guidelines checklist at the front of each patient file (M); data can be collated (M) for senior managers and commissioners to evidence shortcomings in staffing and resources (O).<br><br>Suggestions to help promote service development and embed changes into practice (O) include having one person to lead/champion change (M); generating research within clinical teams (M); encouraging practitioners to co-create contextually sensitive solutions (M) in a cyclical process of service evaluation and development; and drawing on 'experts' within the field, including people with autism, carers and specialist organisations who could support local service development if identified and connected into the process (M). | The Scottish Government, 2014; Rutherford, et al., 2016; RCPCH, 2017. |

**Checklist: List of items to be included when reporting a realist synthesis**
**From Wong et al. BMC Medicine 2013, RAMESES publication standards: realist syntheses11:21**
**http://www.biomedcentral.com/1741-7015/11/21**
**Page 4 of 14**

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|---|---|---|
| **TITLE** | | |
| 1 | In the title, identify the document as a realist synthesis or review | ✓ p1 |
| **ABSTRACT** | | |
| 2 | While acknowledging publication requirements and house style, abstracts should ideally contain brief details of: the study's background, review question or objectives; search strategy; methods of selection, appraisal, analysis and synthesis of sources; main results; and implications for practice. | ✓ p2 |
| **INTRODUCTION** | | |
| 3 | Rationale for review. Explain why the review is needed and what it is likely to contribute to existing understanding of the topic area. | ✓ p3 |
| 4 | Objectives and focus of review. State the objective(s) of the review and/or the review question(s). Define and provide a rationale for the focus of the review. | ✓ p4 |
| **METHODS** | | |
| 5 | Changes in the review process. Any changes made to the review process that was initially planned should be briefly described and justified. | No changes p5 |
| 6 | Rationale for using realist synthesis. Explain why realist synthesis was considered the most appropriate method to use. | ✓p4 |
| 7 | Scoping the literature. Describe and justify the initial process of exploratory scoping of the literature. | ✓ p5 |
| 8 | Searching processes. While considering specific requirements of the journal or other publication outlet, state and provide a rationale for how the iterative searching was done. Provide details on all the sources accessed for information in the review. Where searching in electronic databases has taken place, the details should include, for example, name of database, search terms, dates of coverage and date last searched. If individuals familiar with the relevant literature and/or topic area were contacted, indicate how they were identified and selected. | ✓p5-6 |
| 9 | Selection and appraisal of documents. Explain how judgements were made about including and excluding data from documents, and justify these. | ✓p7 |
| 10 | Data extraction. Describe and explain which data or information were extracted from the included documents and justify this selection. | ✓ p7 |
| 11 | Analysis and synthesis processes. Describe the analysis and synthesis processes in detail. This section should include information on the constructs analyzed and describe the analytic process. | ✓p7-8 |
| **RESULTS** | | |
| 12 | Document flow diagram. Provide details on the number of documents assessed for eligibility and included in the review with reasons for exclusion at each stage as well as an indication of their source of origin (for example, from searching databases, reference lists and so on). You may consider using the example templates (which are likely to need modification to suit the data) that are provided. | ✓ p8 |

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| 13 | Document characteristics. Provide information on the characteristics of the documents included in the review. | ✓p8 |
| 14 | Main findings. Present the key findings with a specific focus on theory building and testing. | ✓p8-12 |
| **DISCUSSION** | | |
| 15 | Summary of findings. Summarize the main findings, taking into account the review's objective(s), research question(s), focus and intended audience(s). | ✓p12-14 |
| 16 | Strengths, limitations and future research directions. Discuss both the strengths of the review and its limitations. These should include (but need not be restricted to) (a) consideration of all the steps in the review process and (b) comment on the overall strength of evidence supporting the explanatory insights which emerged. The limitations identified may point to areas where further work is needed. | ✓ p14 |
| 17 | Comparison with existing literature. Where applicable, compare and contrast the review's findings with the existing literature (for example, other reviews) on the same topic. | ✓ p12-14 |
| 18 | Conclusion and recommendations. List the main implications of the findings and place these in the context of other relevant literature. If appropriate, offer recommendations for policy and practice. | ✓p14 |
| 19 | Funding. Provide details of funding source (if any) for the review, the role played by the funder (if any) and any conflicts of interests of the reviewers. | ✓ p15 |