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 b. Describe the pathway development process and service changes implemented 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. 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). One clinician from each team (n = 7) was interviewed about main aspects of the diagnostic services such as personnel involved and process followed. 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. Methods reported include: local improvement action planning; evidence based pathways; systematic clinical data gathering and a training plan. Model: see Fig 1 for all the steps including: a) Comm Paed + SLT *OR* CAMHS, b) specialist ASD Ax via triage, 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. *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. Objectives: - To explore the reasons clinicians give to explain long wait times for diagnosis for ASD. - 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. - 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. **Model: see Table 1** - 8 child ASD service, all **multi-disciplinary, specialist or general**, mix of profs ***See Table 4-5 & Fig 2 is good - check we've incorporate all in PTs***

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: (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 (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 (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: people with autism: 186 workshops & 237 questionnaires; parents and carers: 457 workshops & 719 questionnaires; multi-agency: 463 workshops & 595 questionnaires. Overall 1106 workshops & 1106 questionnaires	single point referral for access (p7) 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.' 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. page 32: appendix 1 - '3. Theme One: Diagnosis' - findings from survey p32, W/L so long, went private page 64: Appendix 2-the experiences of service providers and statutory agencies. '2. Theme One: Service Provision and Assessment' page 69: Appendix 2-the experiences of service providers and statutory agencies. '3. Theme Two: Joint Working and Referral' Talks about **GIRFEC: getting it right for every child** - specific to Scotland. **Wider remit** than ASD. **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. 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). 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. 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. **Models: various types profs & services, not the focus/not specified** **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.' ***N.B. note multi-agency & multi-disc - does it stipulate more specifically than this?***

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. **Table 8** has explanations/**Ms** related to **accessibility** (in terms of ease of making referral & screening process), **diagnostic proces**s & **post-diagnostic support** **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. **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 1) A NHS multi-disciplinary neurodevelopmental team from one health board in South Wales (including psychiatrists, clinical psychologists, occupational and speech therapists, n=8); 2) in education sector: 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. **Three workshops** were conducted in September 2015 with (see sample size): 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); (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 (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**. 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. 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.** **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.

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. 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. **Model of ASD**: Thinking Patterns in Autism (TPA) Profiling Model - with visual profiling. **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. 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' yes, p15-16 on training - public & profs 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 page 23: 'Diagnosis and Post-Diagnostic Support' page 85-86: 'Engagement Events – Afternoon Sessions' - 'Diagnosis, post-diagnostic support and services' **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. 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. Theme 1: time & resources - lack of is major difficulty for clinicians 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. Theme 3: **diagnostic tools vs clinical judgement** Theme 4: use of supporting information for diagnosis - some professionals undertook their own observations, others delegated. Not problematic in itself. Theme 5: **multi-professional/multi-agency or individual diagnosis?** 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. **Model**: not stated, assume various

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 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. **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' 'Research evidence on **multidisciplinary compared to single assessment** is limited.' But recommends (**model**): 'The use of **different professional groups** in the assessment process is recommended as it may identify different aspects of ASD and aid accurate diagnosis. 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. **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. **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. 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. 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.' 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' page 14: definition of Diagnostic assessment 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. page 18 'What the quality statement means for service providers, health and social care practitioners, and commissioners' & ...'for service users and carers' page 33 'Quality statement 7: Assessing possible triggers for behaviour that challenges'

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. **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 **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. 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. **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.

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. 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. Specialist multidisciplinary teams to assess people with ASD should be set up for adults as well as for children. 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 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. 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. a retrospective case note analysis of 150 individuals diagnosed with ASD by these services. 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). 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). 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. Page 3: 'How long is the wait for diagnosis?' Page 5: 'What affects the length of the wait? - Statistical analysis of the 150 cases illustrated: ⍰ In child cases, having more information about the child prior to diagnosis was associated with shorter assessment durations. ⍰ 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. ⍰ 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. Child and adult service focus group discussions suggested frequent reasons for delays included: ⍰ less efficient working and communication ⍰ high non-attendance rates ⍰ inappropriate referrals ⍰ ineffective care pathways. page 5-6: 'Are standardised diagnostic assessments used?' page 6: 'To what extent do services adhere to the Quality Diagnostic Standard?' page 6-7: 'What can be done to reduce delays?' 'These key solutions were identified by services as follows: ⍰ 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:

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. *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)* *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,* *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** ?* *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. 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. 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. 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. 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. 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

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). 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)) 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. 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 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.** 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. 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**. 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.

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. 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. 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. 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. Most are about **paediatrics in general**. Key info re autism: 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. 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.' 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. 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. 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**
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. 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).

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. extracted details of key diagnostic elements such as assessment process and diagnostic tools. 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. 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 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. 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. 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. 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). 2) evaluated telediagnostic feasibility and acceptability in a rural catchment. 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. 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. 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. 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.

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: 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. 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 1) Diagnostic pathway experienced in the non-integrated approach; 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. 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. 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: -review of existing training frameworks (MacKay and Dunlop, 2004) -evidence and best practice guidelines -engagement with the autism community regarding experiences of contact with services -Learning Needs Analysis amongst NHS staff - Review of existing education and training in autism spectrum disorders - consultation with professional bodies, thrid sector orgs and educational institutions -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. .
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.