Supplementary Document 3. Programme theories with CMO configurations

Programme theory 1 – 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 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). 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. 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). 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). 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		

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). 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). 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). 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). 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 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.		
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. 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). 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). 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. 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.

	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). 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. 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.

Programme theory 4 – Diagnostic feedback 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). 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). 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). 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 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.		

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). 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). 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 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.		

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. 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). 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). 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.

	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). 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 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). 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.

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). 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). 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.