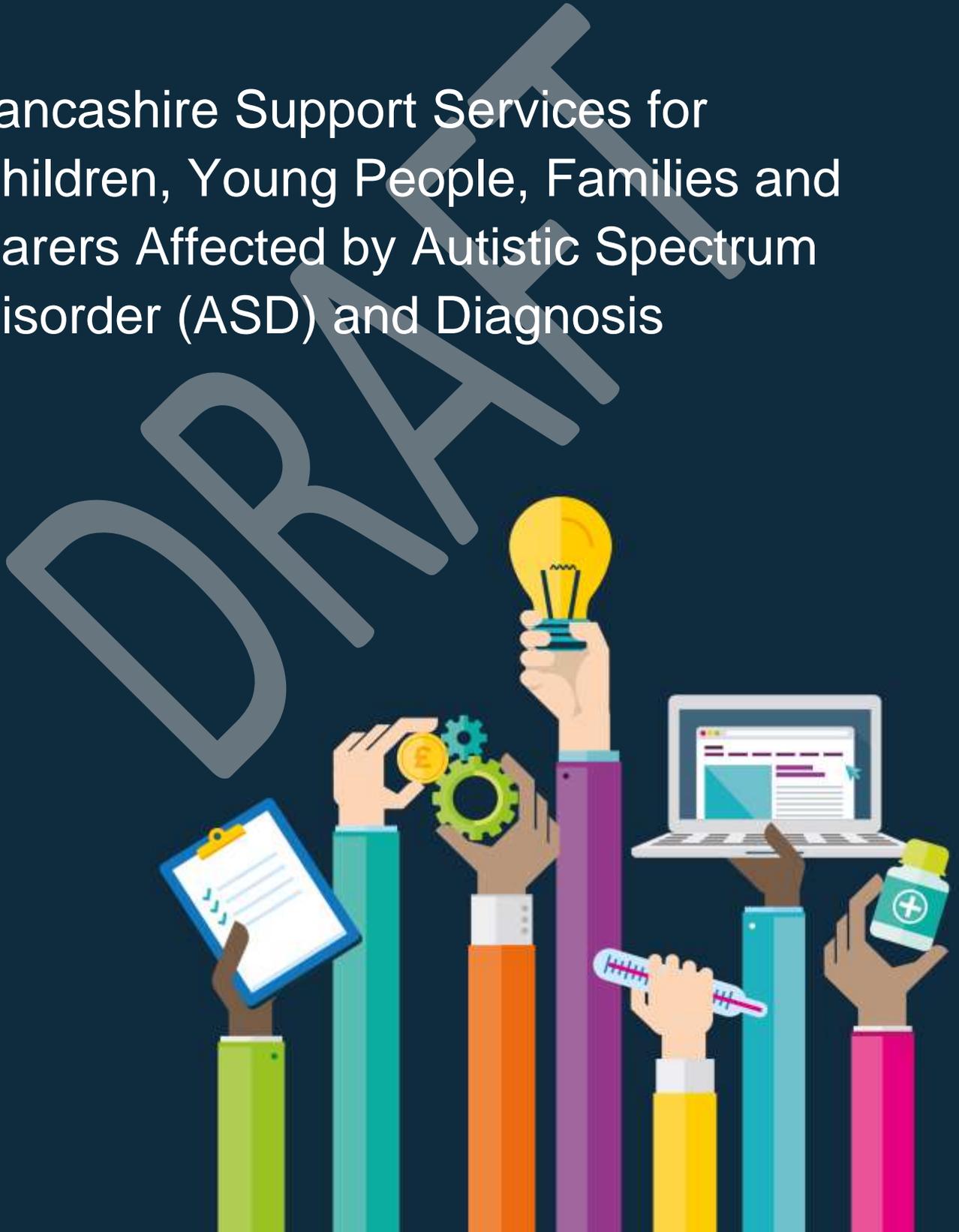




Project Initiation Document:

Lancashire Support Services for
Children, Young People, Families and
Carers Affected by Autistic Spectrum
Disorder (ASD) and Diagnosis



1. Background

The Children and Young People's Emotional Wellbeing and Mental Health (CYP EWMH) Transformation Plan for Lancashire (2015-2020) was published in January 2016. The document set out the first iteration of a five-year plan for Lancashire, to support local implementation of the national ambition and principles set out in Future in Mind – promoting, protecting and improving our children and young people's mental health and wellbeing.

The Plan aims to improve the resilience, emotional wellbeing and mental health of children and young people, making it easier for them and their families to access help and support when they need it and improving the standard of mental health services across Lancashire.

During the latter part of 2016/early 2017 we have worked closely with local stakeholders including service providers, clinicians and most importantly children, young people and families to review the plan. As part of this review we have looked at new national requirements and imperatives to ensure our refreshed plan reflects these, streamlined our objectives and deliverables, engaged with children, young people, families and wider stakeholders to prioritise our objectives for the coming 4 years, produced and published the outputs from this process within this, our re-freshed plan and secured sign-off for our re-freshed plan across the health and social care system.

For the Care of the Most Vulnerable work stream, this Project Initiation Document (PID) sets out in detail the aims, objectives, scope, proposed approach and timeline to achieve:

Objective 21: Implement minimum service offer to improve access and assessment for children and young people with ADHD/ASD, and the

Deliverable: By 31 March 2021 we will have implemented a minimum service offer "pathway for vulnerable groups" which seeks to improve access and assessment, services and outcomes as follows:

- a) Children with attention deficit hyperactivity disorder (ADHD)
- b) Children with Autism Spectrum Disorder (ASD)**
- c) Children looked after
- d) Children with Learning disabilities
- e) Children vulnerable to exploitation
- f) Children in contact with the youth justice system
- g) Children with adverse childhood experiences

Autism was once thought to be an uncommon developmental disorder, but recent studies have reported increased prevalence and now the condition is thought to occur in at least 1% of children. NICE recognises that individuals and groups prefer a variety of terms, including autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. The ASD NICE quality standard recognises the important role that families and carers play in supporting their child and aims to improve the experience of not only the children and young people but also those who care for them.

Autism Diagnosis in Children and Young People: Recognition, referral and diagnosis of children and young people on the autistic spectrum (**NICE Clinical Guideline 128, January 2014**).

Recognising Possible Autism in Children and Young People (NICE Pathway August 2013).

Referral of Children and Young People with possible Autism (NICE Pathway August 2013).

The National Service Framework for Children, Young People's and Maternity Services (Department of Health, 2004) articulated the need for specialist services for children with Autism Spectrum Disorders to be provided in a seamless fashion as close to the child's locality as possible (Standard 9). It stressed the importance of multidisciplinary and inter-agency working in order to meet the child's needs effectively and without undue delay, and emphasised that universal services have a clear role to play in child mental health, though some children and young people also need ready access to appropriately skilled specialist mental health professionals.

Children and Families Act 2014

The Special Educational Needs and Disability Code of Practice: 0-25 years was published in June 2014 jointly by the Department of Health and the Department for Education and provides statutory guidance on duties policies and procedures relating to Part 3 of the Children and Families Act 2014. Organisations who are bound by this statutory guidance includes local authorities (education, social care and relevant housing and employment and other services), clinical commissioning groups, NHS Trusts and NHS Foundation Trusts.

The Special Educational Needs and Disability Code of Practice (2014) main changes from the SEN Code of Practice (2001) are:

- The code of practice (2014) covers the 0-25years age range.
- There is a clearer focus on the views of children and young people and on their role in decision making.
- It includes guidance on the joint planning and commissioning of services to ensure close cooperation between education, health services and social care.
- For children and young people with more complex needs a coordinated assessment process and the new Education, Health and Care Plan(EHC Plan) replace statements and Learning Difficulty Assessments(LDAs).
- There is new guidance on the support pupils and students should receive in education and training settings.
- There is a greater focus on support that enables those with SEND to succeed in their education and make a successful transition to adulthood.

The National Autism Plan for Children (NIASA, 2003) sets out the need for a co-ordinated approach for the identification, assessment and diagnosis of children with Autism Spectrum Disorders. Current practice varies considerably across the country and the National Autism Plan for Children sets out best practice in diagnostic assessment, making it clear that this should be multiagency and include observations of the child across different settings in addition to taking the early developmental history from parents/carers.

The Autism Spectrum Disorder (ASD): Improving Community Services Recommendations Report from the ASD Special Interest Group (Cheshire and Merseyside Strategic Clinical Networks) December 2015 makes 7 key recommendations to improve access to service for children with a suspected ASD and their families.

The Project will incorporate the THRIVE model Gold Standard to ensure the future of high quality service provision.

Current provision Pan Lancashire varies between local CAMHS and Community Paediatric services.

Autism diagnosis is led by different services across Pan Lancashire. In some areas this is Community Paediatrics and in some areas this is CAMHS services. In line with NICE guidance a panel of professionals should make the diagnosis, however the multi-disciplinary team model different in each area, as does the assessment tools used. Therefore we need to ensure there is equitable provision provided across Pan Lancashire so all families and carers are supported from the initial recognition that their child may have either or both ASD.

2. Definition

2.1 Aims

To implement a minimum service offer to improve access and assessment for children and young people with ASD. The service will also include a cost effective Pan Lancashire wide ASD provision to support children, young people, families and carers affected by ASD pre and post diagnosis. This support would also involve assisting families and carers who have children and young people presenting with challenging behaviour. The third sector/voluntary organisations can play an important role in offering the required support across Lancashire.

2.2 Objectives

- To map current provision across the region.
- To assess the current baseline position.
- To map against the THRIVE Gold Standard model.
- To recommend appropriate outcomes such as:
 - a clear referral pathway; improved access to services;
 - a reduction in waiting list times for diagnosis;
 - the provision of diagnosis panels in line with NICE Guidance;
 - the development of a consistent approach to diagnostic tools;
 - the development of a consistent approach to services offering autism diagnosis;
 - any additional funding required
- To engage with children, families and carers to gain knowledge of what they feel would be the best way to support them through the pre and post diagnosis pathway, including complex behaviour.
- To make recommendations which enable financial investment to bring services to a similar level in respect of pathways and service delivery.
- To develop a Communication Framework which consults and involves children, young people, families and carers in their choices, decision-making, process and expectations on the ASD pathway.
- To identify and signpost CYP, families and carers to digital on-line and self-help interventions.
- To identify and signpost CYP, families and carers to appropriate support organisations and programmes.

2.2

2.3 Scope and Exclusions

The project includes:

- CAMHS provision from LCFT for some CCGs; Community Paediatrics provision from ELHT for Pennine Lancs and Blackpool Council through Blackpool Communication, Learning and Autism Services for Blackpool.
- Pan Lancashire Community Paediatric services.
- Third sector support from Action ASD, ASD parent support groups and any other identified as part of the project research.

The project does not include:

- Determination of the commissioning approach. It is envisaged that the provision of the service will be within the inclusion of all CCGs and the CYPEWMH Transformation Board.
- Development of mobilisation plans for implementation. This will be undertaken by service providers once the commissioning approach has been agreed.

2.4 Dependencies and Interfaces

The project has the following interdependencies:

- There will be interdependencies with children's disability services and other third sector/voluntary organisations.
- Developing a financial model for the ASD service within the context of ongoing work to agree arrangements for alignment of budgets across the CYPEWMH Transformation Programme.

Work on this objective within the project will need to both inform and be informed by the work of the Accountability and Transparency work stream, Commissioning and Finance Group. It is proposed that all aspects of project work related to the development and agreement of a financial model for ASD will be taken through the Commissioning and Finance group for agreement prior to formal agreement by the Board and individual CCGs.

- Review of key performance indicators (KPIs), outcome measures and reporting arrangements for inclusion in the Service Specification is interdependent with ongoing work to develop an overarching outcomes framework and performance dashboard for CYPEWMH services. It will be important to ensure that any KPIs and outcome measures developed as part of the project are incorporated into the overarching outcomes framework and dashboard.
- The project could also require changes to current Tier 3 CAMHS services to support the instances where the ASD service (Community Paediatrics) and the local CAMHS team co-work cases where CYP have a diagnosed ASD alongside co-morbidities which would benefit from CAMHS involvement.

- The project also has a key interdependency with the workforce work stream of the Transformation Programme. There will be a need to understand the workforce requirements of a revised ASD pathway; to audit the current workforce including skills audit and to source appropriate funding to support implementation.
- The CAMHS 0-19 Objective to incorporate the THRIVE redesign.

2.5 Constraints

The key constraints are:

- Uncertainty about what the CAMHS service will look like after 2017/18.
- Available capacity to progress the actions needed to complete the project as set out in the CYP Programme Dashboard. Resource has been identified for the project but this is subject to competing demands in CCGs, providers and other partner agencies.
- Ensuring there is sufficient funding to provide equitable support services Pan Lancashire.
- All CCG's are committed to support the funding from the CYP Transformation funding allocation.
- Available third sector/voluntary organisation provision.

3. Approach

- An ASD audit benchmarking tool will be redistributed for completion by CCG which would map the current ASD diagnosis pathway.
- A small Task and Finish Group to be established made up of key individuals with the responsibility and authority to complete the tasks necessary to deliver the project objectives. Group membership and roles will be:
 - Commissioners
 - Third Sector/Voluntary organisations
 - CYP Service Users
 - Service Redesign
 - Finance
 - CAMHS

3.1 Overview

The following table summarises the timeframe for implementation as set out in the detailed draft project plan:

Action	Timeline
ASD proposal to the Care of the Most Vulnerable Group	23 March 2017
PID written	3rd May 2017
ASD proposal to the Transformation Board	19 th May 2017
PID produced and presented to the Board	19 th May 2017
EIA produced	May 2017
PID presented to the Care of the Most Vulnerable Group	15 June 2017

Implementation of Task and Finish Group	June – September 2017
Service Specification pathway	30 September 2017
Agreed service provider/s	31 December 2017
Programme Board to agree implementation of new provision	January 2018
New pathway commences	April 2018

3.2 Assumptions

It is assumed that:

- All eight CCGs will support this planned approach to producing a consistent ASD pathway on a Pan Lancashire footprint.
- It will be possible to develop a Service Specification model that can be agreed by all eight CCGs.
- The provision will provide the much needed support to families at a very anxious and distressing time.

3.3 Plan

3.3.1 Deliverables and Benefits

Deliverable	Benefit
Shorter waiting times for assessment and diagnosis	<ul style="list-style-type: none"> • Compliance with NICE guidelines for family and carer support • Consistent and equitable level of service to be available for all CYP, families and carers across Lancashire • Reduce levels of anxiety, stress and family breakdown • Better outcomes for CYP, families, carers, education
Service Specification and clear pathway for a Pan Lancashire ASD support service for all children, families and carers affected by ASD	<ul style="list-style-type: none"> • Compliance with NICE guidelines for family and carer support • Consistent and equitable level of service to be available for all CYP, families and carers across Lancashire • Reduce levels of anxiety, stress and family breakdown • Better outcomes for CYP, families, carers, education
A pathway that is sustainable and consistent across all CCGs and the Transformation Board	<ul style="list-style-type: none"> • Better use of CYP Transformation funding • Understood by all stakeholders • Transparency and parity

3.4 Stakeholder engagement and communications

Key stakeholders include:

- CAMHS provider organisations
- Families and carers affected by ASD
- Finance
- Third sector/voluntary organisations
- Commissioners

The project group will ensure that plans for communication and engagement are incorporated into the detailed project plan.