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Introduction

This review of mental health services for children and young people with Autistic Spectrum Disorder (ASD) was commissioned by Calderdale CCG.

Scope of the Review

The original brief was to review services delivered to children and young people on the autism spectrum or who have been highlighted as requiring an assessment for an Autistic Spectrum Disorder (ASD), as well as support for parents/carers to support the child’s mental health and emotional wellbeing after assessment across Calderdale.

At project initiation the commissioners of the review requested that 80% of the focus of the review and subsequent report was to be on the wait times to assessment and determining how this could be better. This was in light of the particular challenges Calderdale faced with its ASD Assessment waiting times and to minimise overlap with other improvement initiatives being conducted at a local level looking at quality and service provision. The review team were tasked to look at the project plan and see what elements could be changed to focus on initiatives around waiting lists and the impact of these initiatives.

The core activities expected from the original brief were followed, albeit with more of a focus on wait times and the ASD Assessment pathway:

- Current and projected needs and trends in the population for children with ASD within Calderdale
- Past, current, or developing remodelling of services around children with ASD since the last Service Specification
- Gap analysis and limitations of CAMHS ASD provision.
- Evidence base and good practice
- Horizon scanning of national and local direction of travel and legislation

During the review stage the commissioners expanded the review to incorporate the following elements:

- Highlight the current process in terms of Quality Assurance (compliance with NICE guidance and other quality indicators)
- Examine data, current capacity across services and pathway (highlighting barriers and opportunities) to services to fully understand the extent of the potential need
- Assess processes with service users via Face to face interviews with parents
- Apply national prevalence data and public health profile data to local population
- Draw on evidence for what works for specific demographics to contribute to future pathway modelling Including the review possibility of investment into care coordination rather than triage
Methodology Used

The review includes a mix of methods for the collection and analysis of information including:

- A review of existing local pathway documentation and supporting data
- Lean Current State and Future State Value Stream Mapping
- Best practice review of other ASD pathway models
- Quantitative and qualitative data analysis
- Internal and external stakeholder consultations and interviews, including parent consultation
- Review of relevant literature, guidance and policy documentation

Executive Summary

The review identified the following elements that are working well:

- The CAMHS ASD teams are very well established, skilled and knowledgeable and are passionate about the service and the delivery of a high-quality assessment process.
- The ASD school service is highly regarded by parents and professionals and works hard to see children in a timely manner post-diagnosis.

A number of gaps and areas for development were identified through the review as follows:

- Capacity within in the CAMHS ASD service to see children and families in a timely manner.
- Clarity regarding the commissioning data and performance requirements.
- Skills of generic CAMHS staff to work consistently and confidently with children, young people with ASD and their families
- A post diagnostic intervention offer across all areas of provision

Key Recommendations

An ASD Assessment Pathway has been developed for Calderdale based on the findings of the literature review, interviews, consultations, problem solving, analysis and value stream mapping exercises. The following recommendations are consistent with NICE guidelines and Lean principles and methodology to deliver a pathway that if implemented in full could significantly reduce waiting times, provide consistency and clarity to service users, free up professionals to spend more time working with children and young people and deliver quality assessment outcomes for children, young people and their families in a timely manner.

Core to the recommendations contained within this report is the development of an ASD Pathway linking assessment and intervention services to deliver a comprehensive integrated multiagency solution operating across all levels of a Thrive/ tier less framework in support of the children or young people and their families across Calderdale:
• **Co creation and ongoing participation:** As with all related services, it is highly recommended that children, young people and their families are involved and consulted and in guiding the direction of all service and pathway developments.

• **Commissioning:** It is essential that the delivery of both the ASD Assessments and the ongoing programme of support are explicitly commissioned using clear integrated commissioning processes.

• **Data Driven Decision Making:** Data and management information must be routinely, accurately and consistently collected across all provider organisations (health and local authority) to enable the development, implementation, ongoing maintenance and fully accountable and transparent commissioning.

• **Fully Funded and fully resourced ASD Assessment Process:** In conjunction with undertaking the opportunities to reduce waste within the system it is essential that the team responsible for delivering the pathway is sufficiently funded and resourced to meet current and future demand.

• **Single Core Assessment Pathway within an integrated team:** Agree a single assessment pathway that will simplify communication processes, balance waiting times and deliver a more equitable service regardless of age. Bring together the early years and school age services as one pathway under one caseload coordinator to enable improved economies of scale as resource is pooled. It is not necessary for this pathway to be operated by a single provider, although it must be operated in a seamless and boundary-less way that has the wider team integrated and able to work in an open and collaborative manner.

• **Development of an accountable process:** The pathway development includes a quantifiable process to continue to identify and measure activity and resource allocation to ensure a cost-effective service.

• **Integrated ASD Assessment and Intervention Pathway:** The initiation of the package of support from the ASD Service should be incorporate into the assessment process to ensure a seamless transition along the pathway from assessment to support.

• **Signposting and External Support:** Signposting and additional packages of support should form part of the pathway and be made in a consistent and timely manner based on the needs of the child or person and their family.

• **Single Subject Matter Experts and Succession Planning:** Currently single points of expertise are causing multiple bottlenecks and leaving the process vulnerable to absence and attrition. It is essential that the core assessment roles within the pathway are shared across a number of individuals.

• **Workforce Development:** Undertake a comprehensive training needs analysis and subsequent training programme that is targeted at ensuring there is sufficient knowledge and expertise across the whole system to support children with ASD and their families with awareness, identification, assessment, support and therapeutic interventions within a Thrive/tier less system framework. All workforce development to be underpinned by a whole system staff competency framework in relation to working with children, young people with ASD and their families.

• **Proactive Caseload Management:** Allocate a single point of responsible (non-clinical) for proactively managing the pathway and matching resources to demand to support timely diagnosis and flow through the pathway.
• **Diary Management:** Centralise triage and administration functions to create a team of process and pathway experts with the ability to coordinate referrals across functional and trust boundaries. This team would handle all external communications and booking activities, chasing information etc. which will free up additional clinical time currently tied up in these activities.

• **Simplified Assessment Process:** Agree a simplified assessment process based on NICE guidance that removes duplication and unnecessary professional involvement.

• **ASD Assessment Proforma:** Create an electronic proforma to cover all stages of the new process that can be shared with all stakeholders. The aim is to create an assessment document that remains electronic, can be updated immediately, requires no additional inputting, avoids unnecessary duplication and ensures a consistent approach to assessments across Calderdale.

• **Logically Scheduled Professional Involvement:** SALT, Physical, Psychological and Paediatrics assessments conducted in a logical order based on how to best build an understanding of the child or young person, professional availability and cost, and ensuring the right professional is available at the right time for the child and young person and their family.

• **Physical Health Examination:** Introduce a nurse led physical examination after the SALT ASD Assessment to perform a general physical examination and systematic assessment for conditions that may coexist with autism or may be misdiagnosed as Autism

• **Diagnosis:** Combine the Paediatric ASD Assessment with the communication of assessment findings to the parent to remove unnecessary additional delay

**Current Short-Term Risks**

In addition to the mid to long term recommendations contained within the report and the ongoing issues with waiting times, the following short-term risks to the existing pathway have been identified as a result of the service review:

• **Succession Planning:** There are 3 key members of the ASD pathways all leaving at the same time risking a substantial loss of knowledge and expertise and further impact on waiting times

**Initial Screening:** The owner of the initial screening process is leaving. Whilst the project team have been advised this step is no longer part of the current pathway it has been suggested that around 71 children and young people may still be waiting for an initial screening. It is essential that these people do not get missed in any handover of responsibilities.
Waiting Lists Blitz

Concerns were raised by a number of professionals around any proposed approach to blitzing the waiting lists using either a temporary process or temporary staff. It was felt by some that previous attempts to reduce waiting times by utilising external agencies had not been effective and concerns were raised that the output of these assessments may not have been of an equivalent quality to the core process.

It is the assertion of the review that a permanent solution is required and any temporary measures taken to reduce waiting times will be ineffective in the long term unless accompanied by a fully resourced and more efficient pathway. However, if the proposed improvements and future state pathway are to be introduced then a systematic approach will be required to remove the waiting list backlog. This may be approached in a number of different ways, but must occur as part of the overall implementation of any agreed future state pathway:

**Waiting List Blitz:** CAPA adopts an approach whereby any referrals received 8 weeks prior to the go live date or less are booked onto their 1st (Choice) appointment as per the new CAPA process and any referrals received prior to that date are seen within the 8-week lead-up period as a Choice Appointment and offered the opportunity to take up Partnership Appointments from the go live date. For the proposed Future State Pathway this would equate to the SALTs Assessment process being conducted for all Children and Young People currently on a waiting list within a pre-agreed period prior to ‘go-live’ with Psychology and Paediatrics Appointments following on shortly after.

**Stop Referrals:** Cambridgeshire and Peterborough stopped referrals to their neurodevelopmental services during the interim period when introducing their new process and were able to reduce their waiting time of previously over three years to under eighteen weeks.

The benefits of blitzing the current waiting list with the new process is that although it may add a temporary strain on other services as resources are allocated to the ASD Assessment Pathway, it would support the recommended wider pool of professionals supporting this process to become familiar with the electronic pro-forma, the assessments and assessment process.
Context

Local Context

The ASD health service across Calderdale comprise of two services, separated by age range:

1. Pre School age children hosted at the Early Years Rainbow service, provided by the Calderdale and Huddersfield Hospital Trust
2. School age service hosted within Tier 3 CAMHS, provided by South West Yorkshire NHS Partnership Trust.

Prior to the review commencing and during the process there has been a range of work undertaken to support the development of the CAMHS ASD service. This work is aligned to the Calderdale Local Transformation Plan (LTP) and overseen by the Calderdale Multi Agency Steering Group. The work consists of (not an exhaustive list):

- Appointment of an Assistant Psychologist (temporary)
- Development of an information pack for families on the waiting list
- Parent consultation undertaken by Calderdale Commissioning Group. The consultation has not been included in the Appendix 1 and referred to in the Parent Consultation chapter
National and Local Prevalence Data

Calderdale Children and Young People Population (0-24 years)

The following graphs illustrate the projected CYP population in Calderdale through 2028. The 2016 figure is an estimate taken from the ONS Population Estimates\(^1\) (mid-2016), while the projections for period 2018-2028 are based on ONS Population Projections\(^2\) (2014) adjusted to account for discrepancies observed between forecast and estimated population in Calderdale in 2016. Separate graphs are provided for projected male and female populations along with a combined graph showing the projected total population.

The projections indicate the following change in the Calderdale CYP population between 2018 and 2028:

- The male CYP population is expected to **increase** by 2.7%
- The female CYP population is expected to **increase** by 2.3%
- The total CYP population is expected to **increase** by 2.5%

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\(^1\) ONS (2016) Population Estimates for UK, England and Wales, Scotland and Northern Ireland

\(^2\) ONS (2014) Subnational Population Projections for Local Authorities in England
CYP ASD Prevalence Data

To estimate the population of CYP with ASD in Calderdale, consideration of the national prevalence data for ASD is shown in the table below.

Data is broken down by gender and age group, with data pertaining to the 5-10 and 11-16 age groups sourced from Mental Health of Children and Young People in Great Britain (ONS 2004)\(^3\) and data from the 16-24 age group from Adult Psychiatric Morbidity in England (ONS 2007)\(^4\).

<table>
<thead>
<tr>
<th></th>
<th>5-10 year olds</th>
<th>11-16 year olds</th>
<th>16-24 year olds</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Autistic Spectrum Disorders</td>
<td>1.9%</td>
<td>0.1%</td>
<td>1.0%</td>
</tr>
</tbody>
</table>

\(^3\) Mental health of children and young people in Great Britain (ONS 2004)

\(^4\) Adult psychiatric morbidity in England: results of a household survey (ONS 2007)
CYP ASD Population Projections

The prevalence data from Table 1 applied to the mid-year population projections for Calderdale in order to project the CYP ASD population in Calderdale for the period 2018-2028, shown in the table below. Note that due to the overlap between the 11-16 and 16-24 age groups, the 16-year-old population has been split in half and distributed between the aforementioned age groups.

<table>
<thead>
<tr>
<th>Year</th>
<th>5-10 year olds</th>
<th>11-16 year olds</th>
<th>16-24 year olds</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>2018</td>
<td>156</td>
<td>8</td>
<td>69</td>
<td>34</td>
</tr>
<tr>
<td>2019</td>
<td>156</td>
<td>8</td>
<td>71</td>
<td>35</td>
</tr>
<tr>
<td>2020</td>
<td>157</td>
<td>8</td>
<td>72</td>
<td>36</td>
</tr>
<tr>
<td>2021</td>
<td>155</td>
<td>8</td>
<td>73</td>
<td>36</td>
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<td>2022</td>
<td>155</td>
<td>8</td>
<td>74</td>
<td>37</td>
</tr>
<tr>
<td>2023</td>
<td>153</td>
<td>8</td>
<td>76</td>
<td>37</td>
</tr>
<tr>
<td>2024</td>
<td>153</td>
<td>8</td>
<td>77</td>
<td>37</td>
</tr>
<tr>
<td>2025</td>
<td>153</td>
<td>8</td>
<td>77</td>
<td>37</td>
</tr>
<tr>
<td>2026</td>
<td>153</td>
<td>8</td>
<td>77</td>
<td>37</td>
</tr>
<tr>
<td>2027</td>
<td>154</td>
<td>8</td>
<td>76</td>
<td>36</td>
</tr>
<tr>
<td>2028</td>
<td>154</td>
<td>8</td>
<td>76</td>
<td>36</td>
</tr>
</tbody>
</table>

Table 2 – CYP Autistic Spectrum Disorder Population Projections for Calderdale (by year, age range and gender)

Observations

Due to the projected increase in population in Calderdale during the period 2018-2028, it is observed that the CYP ASD population is projected to increase from 410 to 421, an increase of 2.7%, almost all of which occurs in the latter half of the period.

Breaking this down by gender and age group, it is observed the following due to the change in population profile during the period:

- The ASD population (5-10) is projected to decrease by 1.2%.
- The ASD population (11-16) is projected to increase by 8.0%.
- The ASD population (16-24) is projected to increase by 3.7%.
Proportion of Children with autism known to Schools

A comparison of the proportion of children with autism known to schools in Calderdale and its CIPFA statistical neighbours, using data from PHE Fingertips\(^5\) was undertaken.

The chart (right) and the accompanying table describe the proportion of children with autism known to schools against the resident population, for both Calderdale and its statistical neighbours.

It is observed that the proportion of children with autism known to schools in Calderdale (red) at 7.6 per 1000 is lower than all but one (Kirklees) of its statistical neighbours; and is significantly lower than England as a whole at 12.5 per 1000.

There is no apparent correlation between total population and known cases of autism, nor any indication that the lower proportion of children with autism known to schools is correlated with the relatively low affluence of these areas.

![Figure 1 - Children with Autism Known to Schools: Calderdale and Statistical Neighbours](image)

<table>
<thead>
<tr>
<th>Area</th>
<th>Value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>12.5</td>
<td>12.4</td>
<td>12.6</td>
</tr>
<tr>
<td>Rotherham</td>
<td>21.3</td>
<td>20.0</td>
<td>22.7</td>
</tr>
<tr>
<td>Medway</td>
<td>20.1</td>
<td>18.9</td>
<td>21.4</td>
</tr>
<tr>
<td>St. Helens</td>
<td>18.4</td>
<td>16.8</td>
<td>20.0</td>
</tr>
<tr>
<td>Doncaster</td>
<td>14.9</td>
<td>13.8</td>
<td>16.0</td>
</tr>
<tr>
<td>Derby</td>
<td>14.2</td>
<td>13.1</td>
<td>15.3</td>
</tr>
<tr>
<td>Darlington</td>
<td>14.1</td>
<td>12.4</td>
<td>16.0</td>
</tr>
<tr>
<td>Wakefield</td>
<td>13.9</td>
<td>13.0</td>
<td>14.9</td>
</tr>
<tr>
<td>Barnsley</td>
<td>12.8</td>
<td>11.7</td>
<td>14.1</td>
</tr>
<tr>
<td>Stockton-on-Tees</td>
<td>10.8</td>
<td>9.7</td>
<td>11.9</td>
</tr>
<tr>
<td>Telford and Wrek</td>
<td>10.3</td>
<td>9.2</td>
<td>11.5</td>
</tr>
<tr>
<td>Bury</td>
<td>10.3</td>
<td>9.2</td>
<td>11.4</td>
</tr>
<tr>
<td>Warrington</td>
<td>9.3</td>
<td>8.3</td>
<td>10.4</td>
</tr>
<tr>
<td>Bolton</td>
<td>9.1</td>
<td>8.3</td>
<td>9.9</td>
</tr>
<tr>
<td>Wigan</td>
<td>7.8</td>
<td>7.1</td>
<td>8.7</td>
</tr>
<tr>
<td>Calderdale</td>
<td>7.6</td>
<td>6.7</td>
<td>8.5</td>
</tr>
<tr>
<td>Kirklees</td>
<td>5.0</td>
<td>4.5</td>
<td>5.6</td>
</tr>
</tbody>
</table>


\(^5\) Public Health England: Learning Disability Profiles (Feb 2018)
Of interest, however, is the following table, which describes the proportion of children with learning disabilities in general, also from PHE Fingertips:

<table>
<thead>
<tr>
<th>Area</th>
<th>Value</th>
<th>Lower CI</th>
<th>Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>35.0</td>
<td>34.8</td>
<td>36.1</td>
</tr>
<tr>
<td>Telford and Wrekin</td>
<td>60.1</td>
<td>57.5</td>
<td>62.9</td>
</tr>
<tr>
<td>Wigan</td>
<td>55.7</td>
<td>53.6</td>
<td>57.8</td>
</tr>
<tr>
<td>Derby</td>
<td>55.3</td>
<td>53.2</td>
<td>57.6</td>
</tr>
<tr>
<td>Calderdale</td>
<td>63.1</td>
<td>50.9</td>
<td>56.4</td>
</tr>
<tr>
<td>Barnsley</td>
<td>50.6</td>
<td>46.3</td>
<td>53.0</td>
</tr>
<tr>
<td>Bolton</td>
<td>50.1</td>
<td>46.2</td>
<td>51.9</td>
</tr>
<tr>
<td>Doncaster</td>
<td>49.6</td>
<td>47.7</td>
<td>51.6</td>
</tr>
<tr>
<td>Stockton-on-Tees</td>
<td>48.3</td>
<td>46.0</td>
<td>50.7</td>
</tr>
<tr>
<td>St. Helens</td>
<td>42.8</td>
<td>40.5</td>
<td>45.3</td>
</tr>
<tr>
<td>Bury</td>
<td>40.4</td>
<td>38.3</td>
<td>42.7</td>
</tr>
<tr>
<td>Kirklees</td>
<td>37.0</td>
<td>35.6</td>
<td>38.4</td>
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<tr>
<td>Darlington</td>
<td>35.7</td>
<td>33.0</td>
<td>38.7</td>
</tr>
<tr>
<td>Warrington</td>
<td>34.5</td>
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<td>36.6</td>
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<td>Wakefield</td>
<td>32.4</td>
<td>30.9</td>
<td>33.9</td>
</tr>
<tr>
<td>Rotherham</td>
<td>28.8</td>
<td>27.3</td>
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</tr>
<tr>
<td>Medway</td>
<td>27.1</td>
<td>25.6</td>
<td>28.6</td>
</tr>
</tbody>
</table>


Table 4 - Children with Learning Disabilities Known to Schools: Calderdale and Statistical Neighbours

Here, it is observed that Calderdale schools recognise a significantly higher proportion of children with learning disabilities (53.1 per 1000) than all but three of its statistical neighbours (Telford and Wrekin, Wigan, Derby) – and of England as a whole. This is notable as numerous studies have shown a correlation between learning disabilities and autism. In adults, the prevalence of autism in adults with severe learning difficulties living in private households has been estimated at 35.4%; while in adults with mild or severe learning disabilities living in communal care it is 31.0%.

If it is assumed a similar correlation between learning disabilities and autism exists in school-age children, then recognition of autism by Calderdale schools appears significantly lower than expected at only 14.3% – or 1 in 7 – of the number of children recognised with learning disabilities in general. This is far lower than most of its statistical neighbours; indeed, in many neighbouring LAs, there appears to be an inverse relationship at work, with those LAs that recognise the most children with learning disabilities being the ones that recognise the fewest children with autism and vice-versa. It may be, therefore, that in those LAs, including Calderdale, autism recognition is being masked by learning disabilities in general, rather than being recognised in its own right.

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6 IBID
CQC analysis

In addition, a review of CQC reports was undertaken to ascertain the characteristics of effective service provision and further delve into ‘what good look like’. However, the publication of a review of CQC’s CAMHS thematic review⁸ has been timely for this review and offers a more comprehensive analysis than the CQC CAMHS report trawl originally undertaken. The key themes arising from this review are:

- The system for children and young people’s mental health services is complex and fragmented, and different parts of the system do not always work together in a joined-up way.
- Early opportunities to provide support are being missed because people working in school and primary care settings may lack the necessary skills in mental health. Combined with workforce pressures, this is placing specialist services under increasing pressures and children are waiting longer for admission, often having to travel out of area to be admitted.
- Some children and young people are falling through the gaps in the system. Vulnerable children and those with a learning disability face particular challenges in getting timely access to good care.
- Most NHS specialist services are rated as good or outstanding and across all services there are examples of good and outstanding practice, but there is also variation in the quality of care.
- Safety remains the CQC’s biggest overall concern about specialist services, followed by staffing matters and a lack of person-centred care approaches in some services.
- Phase 2 of the CQC’s review including fieldwork in ten local areas, will explore the reasons for variation and what could be done to make it easier to improve access and quality.

These themes have already been highlighted from a range of sources within this review to the particular needs of children and young people with ASD in Calderdale. The similarities of themes of this national review into a range of CAMH services to those of Calderdale’s CAMHS ASD service will come as no surprise to the reader. The CQC findings underpin the importance of the findings from the Calderdale review with the recommendations offering a range of achievable solutions to achieve positive outcomes for children and families.

Other service provision and reports

In order to inform future service development, the review undertook horizon scanning to explore other service developments, concentrating initially on neighbouring services and then other areas of the country. It is useful to indicate that the majority of other service areas are similar stage of maturity in terms of their development of ASD Services.

The areas where either information was obtained or received and /or dialogue with the services occurred were:

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• Cumbria\(^9\) (and telephone interview with stakeholder partner)
• Cambridgeshire and Peterborough\(^{10}\) (and telephone interview with Clinical Lead)
• Kirklees (telephone interview)
• Wakefield\(^{11}\)
• Worcestershire \(^{12}\)

Information from these services was obtained from a range of sources. Initially by direct conversation where able as the preferred choice, then by third party information (partners involved in the transformation process), reports and service information from the internet.

One particular area, Cambridgeshire and Peterborough has managed to reduce their neurodevelopmental services waiting time of previously over three years to under eighteen weeks. This was undertaken over an eighteen-month period with a whole system change approach to address assessment and waiting times. The initial step taken was to stop referrals to the waiting list in the interim period. With the aid of additional funding, a new, integrated multi-disciplinary team was developed from two existing teams, one from mental health based and the other a paediatric, physical health-based team. At the same time a multi-agency process change occurred in terms of adopting a whole system approach to early help, based on needs, rather than diagnostic basis. A single pathway was developed with core offers of parenting support and group support in the waiting period.

The key outcomes reported have been:

• Fewer children waiting for diagnosis and interventions
• Short waiting time
• Increased satisfaction
• No recent complaints – better staff morale
• Better user participation and co-production
• Better outcomes

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\(^{10}\) http://www.cpft.nhs.uk/training/cambridgeshire-neurodevelopmental-service.htm

\(^{11}\) https://www.wakefieldccg.nhs.uk/fileadmin/site_setup/contentUploads/Public_Information/Wakefield_Statement_of_Action_v13_-_Final_Draft.pdf

Other key themes arising from all of the information gained were the importance of:

- Establishing positive multi-agency partnerships across organisational boundaries
- Maximising commissioning opportunities to harmonise provider organisation’s structures and processes.
- Develop services to highlight needs based rather than diagnosis led processes.
- Diagnosis/ Assessment seen as a process rather than an end in itself.
Parent Consultation

A parent consultation was undertaken as part of this review which was devised specifically to build on a previous consultation undertaken by the CCG. A report from this is contained in Appendix 1.

The scope of the parent consultation was to interview parents to obtain comparative descriptive and subjective information from parents who, as part of a diagnosis have received comprehensive package of care as well and also from parents who have received a diagnosis only. The aim of the parent consultation was to outline the benefits and challenges in providing support packages from a parent’s perspective and understand outcomes for achieved from both experiences.

Two sessions were initially arranged, but due to adverse weather conditions these were cancelled and the re-arranged session took place at Unique Ways Halifax on the 6th March 2018 in the evening.

A group of parents and one young person attended the event. The individuals in the group were passionate to tell their stories of their experience of CAMH Services during the ASD assessment process. There were a range of issues to be drawn from the feedback.

In addition, there were issues raised which branched across the previous consultation such as:

- Awareness training for universal staff in relation to ASD.
- Availability of a post diagnostic service.

The aim was not to duplicate those issues in this section of the report, as they are already detailed in the previous consultation and contained within the CCG report recommendations. However, some elements have been added to the themes raised in the CCG consultation and National Autistic Society (NAS) recommendations from a more detailed and/ or assessment specific experience perspective.

Themes relating to CAMHS:

The parents’ themes highlighted below related to issues arising from their experiences of the CAMHS ASD assessment process.

The themes relating to CAMHS were as follows:

- **Availability of a post diagnostic, intervention service**: A significant issue raised within the group was that there is no post-diagnostic intervention service. As per the previous consultation it was felt once a diagnosis is given, families feel like they drop off the edge. The group outlined that it did not matter who delivered a post diagnostic service but was clear one was needed.

- **Working in a multi-agency way**: It was felt a true commitment to multi-agency working was needed, with sign-up to the development of an ASD Service Hub to enable services for children with ASD to work more effectively together.

- **Offering a person-centred approach**: parents discussed that although CAMHS staff felt they understood this concept, in practice it was rarely undertaken on a consistent basis with families needing to ask for simple, specific ways of supporting their child over and over again.
This issue could be further exacerbated by the range of professionals seen through the CAMHS process, but staff being mindful of the importance of offering a person-centred approach could mitigate this issue.

- **A shared understanding about ASD and mental health:** A range of sometimes conflicting explanations were offered within CAMHS regarding how mental health issues arise in children and young people with ASD. From the examples offered, it could be viewed that staff felt the need to offer a clinical formulation or hypothesis which did not incorporate or even disregarded ASD related ways of viewing the world. This often resulted in parents and young people feeling confused, blamed and responsible for the issues they were asking for support with.
  - The specific skills required to identify and assess girls with ASD was an area identified for further development.

- **Knowing what good looks like:** This issue related not only to having a shared understanding about ASD and mental health, but also to ensuring that CAMHS staff feel confident and competent how to meet the needs in a consistent way utilising a range of clinical skills, CBT, Family Therapy etc. Parents highlighted that when offered, family therapy work was well received as they felt staff from a family therapy background were able to listen to their experiences more effectively.

- **Offering a Think Family Approach:** The group felt the needs of the family as a whole were not considered in the assessment process; siblings, parental relationships were not taken into consideration as part of a clinical formulation. Working effectively with young people and parents was believed to be a key issue for staff development. The box below offers some quotes received from individuals about their experience of CAMHS.

  - ‘Child has self-diagnosed’
  - ‘It is to be expected’
  - ‘Anxiety is part of ASD’
  - ‘We don’t treat ASD’

An issue that parents spoke about during the consultation was of parents being offered a justification for a poor CAMH service. This was felt to be due to a range of issues such as staff turnaround and posts being vacant in the service for a considerable time, but also staff confidence and competence in working with children with ASD was felt to be an issue (as highlighted above). The group wanted to respond to this in the consultation in a supportive way and outlined that they felt CAMHS was a really difficult place to work under the current circumstances. It was felt that offering targeted recruitment to specific posts for ASD and nurturing and leadership support to frontline staff were felt to be solutions in what must be a difficult role.

The group were keen to ensure that lessons are learned from the consultation and that services change and develop as a consequence.
Analysis of Existing Services

Analysis Process

For the purposes of the review the two diagnostic services working across Calderdale (The Early Years Complex Communication Assessment Team and the School Age ASD Assessment Team) were interviewed and Value Stream Mapping exercises were conducted separately with both.

Value Stream Mapping is a collaborative Lean technique that was used in this review to document and analyse the flow of information as it makes its way through the system from referral to a child or young person receiving an assessment outcome and subsequent support. Value Stream Mapping was used because it is particularly useful in identifying waste processes and reducing cycle times. Versions of the Value Stream Maps created during the review meetings are reproduced in Appendix 2 in full and provided separately in Portable Document Format (PDF).

In addition, as part of the scope, the services were benchmarked against NICE guidance from a qualitative perspective. The outcomes of the NICE benchmark (Appendix 3) have been amalgamated into the Value Stream Mapping and dialogue in this chapter to reduce duplication in the report.

The key steps used within the Calderdale review meetings with the Assessment Teams were:

- Map the current process (Current State Value Stream Map)
- Identify any idea, questions and improvement opportunities relating to the current process
- Prioritise these ideas, questions and improvement opportunities in terms of ease of implementation and impact if they were addressed

The Value Stream Maps that were created at these meetings were subsequently shared with external stakeholders so they had an opportunity to add their own ideas, questions and improvement opportunities and validated by the service providers.

Key Review Meetings:

- 27th November 2017 – Meeting with School Age Team (CAMHS & FPoC) for initial value stream mapping and Kaizen analysis
- 29th November 2017 – Meeting with Early Years Team in Calderdale for initial value stream mapping and Kaizen analysis
- 9th January 2018 – Meeting with key stakeholders in both ASD Assessment Processes to review process maps and add to Kaizen
- 31st January 2018 – Meeting with Early Years Team in Calderdale
- 20th February 2018 – Phone call with staff member from FPoC team

In addition to the value stream mapping; existing process maps, historically reported high-level data, one-to-one discussions and data returns specific to this project were used to inform the core content of the analysis of the current state.
Data Limitations

Early Years
No usable granular data was received regarding the Early Years Complex Communication Process

School Age
The review team were provided with granular data relating to the First Point of Contact process and the Initial Screening (Extended Triage). No granular data regarding the standard ASD Assessment and the alternative (Review) ASD Assessments was received.

The Early Years’ Service
The pre-school service is delivered from the Early Years Rainbow Service at the Calderdale Royal Hospital. It operates as a multi-professional and agency team and consists of:

- Speech and Language Therapist (SALT)
- Service Administrator
- Early Years’ Service Coordinator
- Educational Psychologist
- Associate Specialist Paediatrician

Pathway Overview
The diagram below is re-produced in larger scale in Appendix and is broken down to steps throughout the narrative in this chapter.

Referrals are made from professionals via letter or email for a Complex Communication Assessment from the Early Years Team based in the Child Development Unit (CDU) within Calderdale Hospital. Referrals are given an initial appointment with the resident Paediatrician (for screening purposes) who then refers onto the Complex Communication Assessment waiting list. After a significant wait the child and parent(s) or guardian(s) are offered an assessment appointment. Assessment observations are conducted within the Child Development Unit, followed by face to face meeting with other professionals who have worked with the child being assessed. All professionals involved in the assessment write up their reports which are then compiled and any diagnosis is fed back to the
If there has been an Autism diagnosis then the initial feedback to parents is followed up by a phone call a week later to address any questions or concerns. All diagnosed cases are passed to the ASD School Support Team.

**Strengths and Limitations of the process**

**Strengths**

The service appears to offer a significant amount of containment for parents/carers within the assessment process. The families appear to be ‘held’ by the service, by telephone calls built into the process to clarify that parents understand the assessment procedure prior to the initial appointment and a reminder to ensure attendance (although not tested out with families). Within the initial screening appointment with a Paediatrician, a plan of care is developed and referrals are made to appropriately highlighted support services. This offers something significant to families in terms of meaningful engagement and intervention for their child. This also appears to offer a less dependent position for the parents in terms of reliance on a diagnosis as the only outcome available. Key roles in the early years’ service connect school and the ASD school services. The SALT and Early Years Support Coordinator both work in the pre-school team and ASD team and LA education service respectively. This adds exponential benefits in terms of connectivity and continuity for children and families.

The multi professional play-based assessment is based on DSM5 criteria, detailed and offers a meaningful narrative of the child’s behaviour to base understanding and subsequent intervention on.

The pre-school assessment team is very well established, skilled and knowledgeable and is passionate about the service and the delivery of a high-quality assessment process.

Concerns expressed over lack of succession planning. There is currently a cohesive, experienced team with one member leaving next year. The team were not aware of succession plan for the role in the long term.

**Limitations and NICE Benchmark**

The service is only available during term time which limits coverage of the delivery. Within the process families are currently waiting for around a year for the outcome of a complex communication assessment. Given the age of children this is a key issue in terms of providing a timely service to optimise positive outcomes for children.

From discussion with the staff team there appeared to be a lack clarity about the specific commissioning processes and performance activity. This does not enable an understanding of the current resourcing and quality of performance of the service. Staff also raised the difficulty of a lack of dedicated administrative time allocated to the service. Given the importance of effective coordination of the process, this would seem a significant gap.

One of the strengths of a well-established staff team is also a potential risk in terms of succession planning to meet the changing construction of the team. Concerns were expressed over sustainability in the long term if staff skill mix changes or approach to the work. The importance of this was clarified as key staff are due to retire in the next year.
There was discussion about how work was undertaken in their own time and the commitment to accept undertaking work in own time to ensure current standards and workload is maintained. Staff were not aware of a specific succession plan for either specific roles or the service overall. A key role in the team would be retiring in the next year so the need for a clear plan is important. This may also have a potential impact on the diagnostic process. In additions the impact on new (potentially, less experienced) staff in the team may affect the assessment process. As outlined in the literature review, inexperienced staff may feel more confident using a recognised diagnostic tool. Current staff are trained using Autism Diagnostic Observation Scale (ADOS). There will be a requirement to review the training needs of a reconstituted team once key staff have retired or leave.

Occupational Therapy is not a contributor to the ASD assessment process. It was discussed that there is no availability/ commissioning for sensory assessments within the area.

From the interviews and literature submitted intervention with children and families occurs via the development of a Family Support Plan for pre-school children. The NICE Benchmark audit - see Appendix Four - highlighted that the waiting time is the single most significant factor required to improve within the assessment process.

Referral

The Calderdale and Huddersfield NHS Foundation Trust (CHFT) advise that they receive referrals from a number of different professionals working with children, although the majority of referrals are received indirectly from the Portage and Early Years Support Teacher Team (PEYST). PEYST will typically refer to the child’s GP or the SALT Team who will then refer onto the Paediatrician within the CDU.

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All referrals into the CDU team for a Complex Communication Assessment are booked an appointment with the resident Paediatrician. On average the team estimate that a child will wait approximately 120 days between referral and their initial appointment with the paediatrician which will last between 45 minutes and an hour.
After the Paediatrician appointment there is an approximately 359 days wait before the child’s referral starts to be included within the monthly planning meeting. There will be a short review of names (approximately 4 minutes per child and 6 children per meeting) and then a request for information is sent out to professionals involved with the child and the child’s parent(s) or guardian(s) will be contacted and advised of the assessment date. On the day before the assessment the parents are contacted and reminded that the Assessment is the next day.

On the day of the assessment there is a short team briefing before the Complex Communication Assessment is conducted. Two child and parent observation sessions are conducted at the same time for 90 minutes by five professionals. The assessment team comprises of a core team of a speech and language therapist, an educational psychologist and the paediatrician, along with a specialist teacher and the child development assistant.

After the observation the professionals meet to discuss their observations, and other professionals who have worked with the child are invited in to share their knowledge and to contribute to the assessment teams wider understanding of the child. Once these meetings have been completed the assessment team have 10 days to write-up their observations and findings.
After the professional meeting there are five separate reports written by the individual professionals involved in the assessment. These are then sent to the service administrator who compiles them in time for the face-to-face feedback to the parents. The compiled report is reviewed by the lead who along with another professional have a meeting with the parent(s) or guardian(s). If the child receives a diagnosis they are referred directly into the ASD Team and if they do not then the child is signposted to PEYST. Because it is acknowledged that receiving a diagnosis for your child can be overwhelming and questions can arise after the initial feedback meeting, the CDU team phone the parents between 2 – 7 days later to answer any questions that may have arisen subsequently.
Demand and Takt Time

Time in the System

Excluding the time taken to get a referral into the CDS and measuring the process from the moment the referral arrives into CDS to the point at which the parents are given the outcome of the Complex Communication Assessment, the child is in the system for approximately 529 days.

Process Cycle Efficiency (PCE)

During that time there are approximately 21.8 resource hours applied to each referral to provide an assessment outcome to the parents. However, from the child, parent(s) or guardian(s) perspective, they are directly involved for approximately 3.2 hours (Appointment with Paediatrician (52 min); phone call to book Observations (5 min); Observations (90 min) and Assessment Feedback (45 min)).

If we assume that all resource time is employed in value add activities then the Process Cycle Efficiency (PCE) for the assessments process is 0.17% (21.8 hours of resource applied during 529 days (12,696 hours) of time in the service. That means that something was actually happening to the child’s referral for just 0.17% of the time that the child was waiting for a diagnosis.

Value-Added, Non-Value-Added and Necessary Waste Activities

If we take a more focussed Lean perspective on the process and separate these stages into ‘value added’ and ‘non-value added or necessary waste’ steps, where value add is defined as either adding form or feature to the assessment or must be performed to meet the customer need (in this tight definition an assessment outcome), then the stages can be separated thus:

<table>
<thead>
<tr>
<th>Value Added Activities</th>
<th>Non-Value-Added Activities or Necessary Waste</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointment with paediatrician (52 min)</td>
<td>Appointment with paediatrician booked</td>
</tr>
</tbody>
</table>
Complex Communication Assessment (90 min)  
Professionals Meeting (60 min)  
Feedback to Parents (45 min)  

| Monthly Planning (Review of names)  
| 3 weekly planning (Request for Info)  
| Contact Parents  
| Team Briefing  
| Report Writing*  
| Compile Reports  
| Lead Reviews report  

*whilst a report is required later in the process, it is not necessary to reach an assessment outcome

This more focused analysis of the process suggests that the Process Cycle Efficiency (PCE) for the assessments process is 0.03%, based on 4.1 hours value added time within the 529 days in the system. The remainder is either ‘pure waste’ or ‘necessary waste’. Efforts should be made to reduce or remove as much of pure waste activities as possible whilst increasing the effectiveness of the value-added activities. Necessary waste relates to those activities which do nothing to move the child or young person closer to receiving a diagnosis/ non-diagnosis but must be undertaken none-the-less.

**Ideas, Questions and Opportunities**

As part of the value stream mapping exercise, participants were asked to analyse the process and identify key ideas, questions and improvement opportunities based on what they had mapped and their personal experiences of the pathway. There were 23 core ideas, questions or recommendations made, of which the following 16 were used to inform the proposed future state pathway.

A complete and detailed record of the ideas, questions and opportunities identified during the value stream mapping exercises, along context and response rationale is included within the appendices.

**Key Improvement Opportunities**

**Assessment**

- Increasing time allocated to staff to support the Complex Communication Process
- Ensure that there is cover for staff holidays
- Provide an all year-round service
- There are more professionals involved than are required by NICE best practice guidelines.
- Use returned Proformas rather than Face to face meetings with other professionals
- The Early Year team appear to provide an assessment involving many different professionals and provide a bespoke and nuanced for every assessment. This is time-
consuming and expensive, and in the absence of any significant new money and with a 1 year wait, it is appropriate to ask if families would prefer a less nuanced assessment quicker or would they rather wait for the current offering?

**Report Writing and Output**

- Provide feedback and diagnosis on the day rather than make the parents or guardians wait an additional 10 days for reports to be completed
- Have time allocated within core hours to write reports
- Reduce the time taken for feedback sessions from 45 minutes to 30 minutes
- Reviews to run parallel to feedback sessions

**Whole**

- Increase Resources/ Staff Capacity to better meet demand (more time needed)
- The service should be commissioned & acknowledged within CHFT & Calderdale Council
- Official agreements in place i.e. contracts in relation to time allocated to support the Complex Communication Assessment process
- Succession planning needed. The process needs a skilled workforce and there are a number of single points of expertise currently within the process that pose an additional risk to the process.
- Better relationship and knowledge sharing (about the process & CDS) between CHFT and the LA
- Agree a consistent approach between both ASD assessment providers (CDS & CAMHS)
The School Age Service

The school age service is delivered from the Laura Mitchell Wellbeing Centre in Halifax.

Pathway Overview

The team discussed a lack of clarity about the pathway structure during the review. There had not been any Paediatrician input in the team for some time. From discussion with the staff this originally occurred due to sickness but had not been reinstated.

The school age service is operated as a fluid service working across existing teams to coordinate referrals and the assessment process. The core team consists of:

- Clinical Psychologist
- Psychology Assistant

Referrals come into the First Point of Contact (FPoC) team in Northpoint (CAMHS Tier 2) via online, postal or telephone referral. These referrals are triaged by FPoC before being passed to the Tier 3 CAMHS ASD Pathway at South West Yorkshire Partnership NHS Foundation Trust. They are then streamed onto either a ‘standard’ or ‘review’ waiting lists at point of entering the service based on the amount of prior ASD related professional involvement. Then there is a significant wait until the assessment process is undertaken. School age ASD Assessments are conducted separately by a Speech and Language Therapist and a Clinical Psychologist who then meet to discuss their findings and attempt to reach a diagnosis. The family are contacted with the result of the Assessment and if it has been determined that the child or young person is on the Autism spectrum then they will be onward referred to the ASD Team who will provide practical support to the family and school.

Strengths and Limitations of the Pathway

Strengths

The ASD service works across existing CAMHS services with a single point of access enabling the referral to CAMHS. Staff in the ASD service are committed to development of the service and have been working with the CAMHS ASD strategy group to improve service provision. The staff in the team are skilled and experienced and have a clear understanding of the limitations of the current process. The recent appointment of an Assistant Psychologist has supported developments such as an information pack for families on the waiting list.

From the initial staff interview there appears to be capacity and commitment from Psychiatry to offer input in the current service. This would offer exponential benefits as the Psychiatrist is part of core CAMHS and would therefore offer continuity for working with interventions with young people with ASD.

Limitations and NICE Benchmark

Young people currently wait three years for a diagnosis. Clearly this is not acceptable.

The team does not contain the comprehensive range of clinical skills in terms of medical input to meet the needs of the service requirements. Currently the medical input into the team is not available either...
from a Paediatric or Psychiatry perspective. As with the pre-school service, Occupational Therapy input is not provided into the assessment process.

**Referral**

It was acknowledged at meetings with Service Providers (27th November 2017) and key stakeholders (9th January 2018) that there were multiple routes into the service and it would be impractical to capture all of them.

The VSM captures some of the most typical routes into the ASD Assessment Pathway, although many more exist. What is clear from the mapping is that although we are unable to quantify it, the time it takes from initially questioning whether a child or young person may be on the Autism Spectrum to that CYP arriving with a referral at the First Point of Contact may in itself be significant, and the children and young people and their families route to diagnosis often starts a long time before they eventually arrive at FPoC.

The core routes into CAMHS for a school age ASD Assessment were mapped as predominantly through the school (typically either initiated by the parents or the school SENCO) or via the child or young person’s GP. The child may be directed straight to FPoC by the SENCO or GP, but may also go to SALTs, Educational Psychologist (SENCO only) or Paediatrician. In the referrals pathway mapped, there was the potential for up to 6 consecutive referrals and hidden waits before the CYP arrived at FPoC (Family to SENCO; SENCO to Ed Psych; Ed Psych back to SENCO; SENCO to SALTs; SALTs to Paediatrician and Paediatrician to FPoC).

Referrals from Professionals into FPoC come in via 3 routes:

- Online Referral form ([www.CAMHS.org](http://www.CAMHS.org))
- Postal Referrals
- Telephone Referrals (not advertised as an option)

In addition to the referrals that are identified as ASD and triaged as such, there are also referrals for ASD Assessment that come internally from other CAMHS which go directly to the Waiting List Sift conducted by the ASD Pathway coordinator.
The First Point of Contact (FPoC) team are operated by Northpoint. Once a referral is received into FPoC it is logged and triaged. Accepted referrals for ASD Assessment are then reviewed by the FPoC Coordinator and Assistant Psychologist before being passed across to the ASD Pathway Coordinator at South West Yorkshire Partnership NHS Foundation Trust.

FPoC received 1432 referrals over a 12-month period (January – December 2017), of which approximately 13% (192) were ASD related.

81% of all referrals into FPoC are received from a combination of GP referrals and school referrals (School and SENCO combined), with the majority of all referrals into FPoC (59%) coming from GPs alone.

Only 4% of GP referrals are ASD related and 16% of school referrals are ASD related, whilst 86% of SALTs referrals are ASD related and 28% of paediatrician referrals to Tier 3 CAMHS are ASD related.

Over the 12-month measurement period, 68% of all referrals were accepted by FPoC and on average take 9 days from referral being received to receiving a referral outcome (either declined or accepted). Accepted referrals are then added to the appropriate services waiting list.

Looking at the 192 ASD referrals only; 88% of all referrals for ASD come from a combination of Schools and SENCO (35% combined); GPs (26%); Paediatrics (15%) and Speech and Language Therapists (13%).

The Paediatrics led Early Years ASD Assessment team advised that when a pre-school child referred into their service is going to reach school age before they are able to provide a Complex Communication Assessment they will onward refer to the School Age ASD Assessment Process, which will account for some of the 15% of School Age referrals that are recorded as Paediatrician referrals.
Although it is difficult to determine an accurate ‘accept rate’ figure for the number of ASD referrals received due to not all ASD referrals being marked as ASD prior to screening it is believed to be around 75%. All ASD Assessment referrals that were rejected were due to other presenting issues being present, there being an existing diagnosis, or there being no active mental health presentation. Rejected ASD referrals received in the 12 months were referred onto Local authority ASD service (~12); Self-help/digital resources (~10); Other CAMHS intervention (~8) and Other service (e.g. voluntary sector counselling) (~6).

On average ASD referrals took 21 days to triage from receipt to passing to Tier 3 CAMHS ASD Pathway at South West Yorkshire Partnership NHS Foundation Trust. However, the time taken to process an ASD referral is dependent on where that referral has been received from. If a referral is received from the SALTs team then the child or young person will already have been assessed using Gilliam Autism Rating Scale (GARS) or Gilliam Asperger’s Disorder Scale (GADS). In these instances, FPoC simply phone the parents or guardian to confirm that the child or young person is on system and offer signposting (typically to Unique Ways & SENDIASS). Other referrals typically don’t arrive with prior assessments and so require the FPoC to conduct information gathering contact with family, school and other agencies by phone. Coordinating diaries to conduct these meetings (especially with other professionals) can add significant delays to the triage process. In addition to the triage, FPoC will also signpost these parents to Unique Ways, the National Autism Society & SENDIASS.

**Staffing**

<table>
<thead>
<tr>
<th>Role</th>
<th>Grade</th>
<th>Headcount</th>
<th>FTE</th>
<th>Hours allocated to ASD (planned)</th>
<th>Hours allocated to ASD (actual)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FPoC Co-ordinator</td>
<td>band 6 / 7</td>
<td>1</td>
<td>0.8</td>
<td>n/a</td>
<td>50 mins*</td>
</tr>
<tr>
<td>Therapeutic Practitioners</td>
<td>band 6</td>
<td>6</td>
<td>1.5</td>
<td>n/a</td>
<td>20 mins*</td>
</tr>
<tr>
<td>FPoC Support Workers</td>
<td>band 3 / 4</td>
<td>3</td>
<td>1.5</td>
<td>n/a</td>
<td>30 mins*</td>
</tr>
</tbody>
</table>

*approximate time taken per ASD referral
Throughput

The processing timings provided by FPoC during the data submission differed slightly from those originally allocated to key steps during the value stream mapping exercise on the 27th November, the data submission suggests that for each ASD referral there is on average a total of 100 minutes of value added processing time and each referral is in the system for 21 days. If it is assumed that all processing time (100 minutes) is value added activity and a simple Lean calculation of Process Cycle Efficiency (PCE) is applied, as being total value-added time in the process divided by the total time in the process, then the PCE for triaging ASD referrals is 0.3%. This means that for the 21 days the average ASD referral is in FPoC it is actively being processed 0.3% of the time. The remaining 99.7% of the time is wait caused by waiting for information from other agencies and professionals and internal bottlenecks and competing workloads.
Historically, after FPoC had passed the referral to SWYFT there was an initial ASD Screening process that occurred prior to a child or young person joining the Multi-Agency or Review Assessment waiting list. This could include an initial meeting with parents, a structured conversation with the child’s teacher using GADS or GARS assessment tools, and a further meeting with parents also using GADS and GARS. In some circumstances this may also have included a school observation.

As part of the process mapping and review process there was conflicting information on this process and to what extent it exists within the pathway:

- The process mapping group identified that although there were plans to drop this process, for some children and elements had been incorporated into the FPoC Screening process. The process was still operational and some children and young people were still receiving this enhanced Initial ASD Screening prior to joining the Assessment waiting list, but the majority did not.

- At a later date, it was reported that there was currently a 15 month wait to reach screening, with the Assistant Clinical Psychologist providing the majority of screening and the Consultant Clinical Psychologist providing some screening.

- At a later date again, it was stated that this process had been changed 3 months earlier and no children received an Initial ASD Assessment, although some elements had been incorporated into the core FPoC core triage (phone calls with parents and schools etc.) and additionally there were a large backlog of children and young people (71) on a separate waiting list who may still receive the old process.
The rationale for dropping the extended triage appears to predominantly be that as well as adding additional wait to the process, by the time the assessment occurred the information gathered would be out of date, the child’s teacher group will have changed and these assessments would need to be repeated. Whilst this additional triage stage has been identified for removal from the pathway it is less clear to what extent that has yet happened.

It was reported that there were approximately 160 new referrals last year to the various points of the ASD Pathway – for initial screening; for an alternative pathway assessment; for a review; and for a multi-agency assessment for those already fully screened.

FPoC report that between January 2017 and December 2017 they onward referred 144 children and young people to the ASD Pathway. SWYFT report that during the same period 102 children and young people received the Initial 1st Screening. Over the recording period 69% of all ASD referrals passed from FPoC received an initial screening assessment from SWYFT. The data is also consistent with the assertion made by FPoC that it is the referrals typically from SALT that require little additional screening.

It was reported that the primary referral route wait time increased from 10 months for a referral received in January 2017 to 15 months for a referral received in December 2017 and was set to increase further. In addition, the alternative wait time had increased from 3 months to 14 months during the same period.

Assessment

Once a copy of the electronic proforma is received from FPoC and any Initial ASD Screening has occurred the child or young person’s referral is prioritised by the ASD Pathway coordinator within Tier 3 CAMHS ASD Pathway at South West Yorkshire Partnership NHS Foundation Trust. Children and young people are typically moved onto the prioritised pathway (known as the ‘Review’ or ‘Alternative Pathway’) if they are
being referred internally from CAMHS, have been moved from the Early Years to the School Age pathway, have been in the system for an extended length of time or are just about to turn 18.

Waiting lists are actively monitored by the ASD Pathway coordinator but are significant.

SWYFT reported in January that there were a total of 241 children and young people somewhere on the waiting/ screening/ review/ alternative/ MAA waiting lists.

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*The current school-age waiting time in Calderdale for a child referred today to the ASD Pathway for assessment is likely to be 52 months (15 months to reach screening; 1 month to screen; 36 months on Multi-Agency list).*

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*SWYFT (3rd Jan 2018)*

Approximately 10 weeks before the scheduled ASD Assessment an Assessment Request will be sent to the SALT team with a scheduled date and time for the ASD Multi-Agency Team Meeting. During the next 10 weeks both the Clinical Psychologist (ASD Pathway Coordinator) and a member of the Speech and Language Team will conduct ASD Assessments with the Child and Young Person. It has been advised that both sessions took approximately 5 hours each to conduct.

Previously a Paediatrician would have also conducted an assessment of the child or young person, but reportedly due to a decision made by Calderdale and Huddersfield Foundation Trust to charge South West Yorkshire Partnership NHS Foundation Trust (SWYFT) for Paediatric support, SWYFT CAMHS have stopped requesting this support meaning that current assessments are conducted by two rather than the NICE recommended minimum of three professionals (including one doctor).

### Staffing

<table>
<thead>
<tr>
<th>Role</th>
<th>Grade</th>
<th>Headcount</th>
<th>FTE</th>
<th>Hours allocated to ASD 1st screening (planned)</th>
<th>Hours allocated to ASD 1st screening (actual)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistant Psychologist</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>8</td>
<td>Not known but more on average</td>
</tr>
<tr>
<td>Consultant Clinical Psychologist</td>
<td>8c</td>
<td>1</td>
<td>0.5</td>
<td>6</td>
<td>Not known but more on average</td>
</tr>
</tbody>
</table>

Currently there are 14 hours per week allocated to the ASD pathway.
Throughput

The processing times provided by SWYFT during the value stream mapping exercise and subsequently suggest that a child or young person currently joining the ASD Assessment pathway could be expected to wait up to 36 months for an Assessment, although it was also stated that the service would never leave a child or young person waiting that long.

Based on the information provided during the value stream mapping, there was approximately 13 hours of value added processing time involved in the assessment process per child or young person:

- 1 hour per child or young person for prioritising the referral upon receipt and sending out the Assessment request 10 weeks prior to Multi-Agency Meeting.
- 5 hours for each of the 2 assessments
- 1 hour for the ASD meeting (2 professionals)

SWYFT that ‘The current human resource is able to assess and process an average of 8 children and YP each month, which means that there is an addition of between 5 and 6 children each month to the overall lists – on average.’

If the above processing time (13 hours) is all value-added activity and the true wait is 36 months for an assessment then the Process Cycle Efficiency (PCE) for the assessments process is 0.05%. This means that for the 1095 days the child or young person waits for an ASD assessment their referral is actively being processed 0.05% of the time. The remaining 99.95% of the time is wait and waste caused by bottlenecks and backlogged workload.

Demand and Takt Time

Demand

Based on their being no predicted significant change in local demographics we can forecast future ASD Assessment demand based on 2017 referral numbers as continuing at approximately 144.
Capacity

There are currently 14 hours per week allocated by 2 staff members combined to support the ASD assessment process. However, based on 10+ years length of service, each current full-time staff member works 43.94 weeks per year. This 14 hours per week for 43.94 weeks per year equates to 615 hours available.

Based on the currently reported 8 hours of processing per referral (assessment only and excluding 5 hours for the SALT assessment) the 144 ASD Assessment workload per annum equates to 1,152 hours of work. To meet current demand without changing the process would require a near doubling of the hours allocated to the process (from the current 14 hours per week to 26.2 hours per week).

Takt Time

Takt time is the amount of available work time divided by the demand during that period. This measure enables us to see the speed a process needs to operate at to keep up with demand.

To process all 144 referrals being received per year SWYFT would need to conduct 3.3 ASD assessments per week every week during the 43.94 weeks there is resource available. Based on their being 14 hours available per week this would require each assessment to take in total no more than 4.2 hours each. Currently each assessment is reported as taking 8 hours each (excluding the SALT Assessment).

To meet current demand there either needs to be a significant reduction in the time taken to reach a diagnosis (from 8 hours to 4.2 hours per referral) or there has to be a significant increase in the hours allocated to the process (from 14 hours per week to 26.2 hours per week).

Outputs

Once an assessment has taken place, the output from that assessment is shared with the parents or guardians and also with the Schools ASD Team if the young person receives an ASD diagnosis. Currently the output from the School Age team is a simple yes/no diagnosis with little nuanced detail around where the child or young person is on the autism spectrum or the particular way in which the child or young person’s ASD presents.

Once a diagnosis has been received the school can contact the Schools ASD Service and request a support package. It was believed by those present that there was no particular additional wait for ASD specific support once a child had received their diagnosis.

Value-Added, Non-Value-Added and Necessary Waste Activities

Using a more focussed Lean perspective on the process and separating these stages into ‘value added’ and ‘non-value added or necessary waste’ steps, where value add is defined as either adding form or feature to the assessment or must be performed to meet the customer need (in this tight definition an assessment outcome), then the stages can be separated thus:

<table>
<thead>
<tr>
<th>Value Added Activities</th>
<th>Non-Value-Added Activities or Necessary Waste</th>
</tr>
</thead>
<tbody>
<tr>
<td>FPoC Referral Screening</td>
<td>FPoC Referral Logged</td>
</tr>
</tbody>
</table>
Irraoulas, Questions and Opportunities

As part of the value stream mapping exercise, participants were asked to analyse the process and identify key ideas, questions and improvement opportunities based on what they had mapped and their personal experiences of the pathway. There were 36 core ideas, questions or recommendations made, of which the following 34 were used to inform the proposed future state pathway.

A complete and detailed record of the ideas, questions and opportunities identified during the value stream mapping exercises, along context and response rationale is included within the appendices.

**FPoC Triage**

- Increase capacity within the FPoC team
- If a joint referral is received for both SALTS and FPoC these get rejected until SALTS have assessed for ASD. The SALTS assessment the Child or Young Person receives is significantly more thorough and robust than the FPoC triage process so there are good reasons why FPoC may wait for this assessment. However, this means that the eventual wait to assessment will be greater for those children referred to SALTS and FPoC than those referred directly to FPoC only.
- SALTS assessments use GADS/GARS assessment tools, however no other referral source conducts sufficient assessment prior to referral. If non-SALTS referral then parents and school are contacted by FPoC and asked questions relating to the ‘Triad of Impairments’
- An electronic proforma based around ‘Triad of Impairments’ has been created by the FPoC team. This proforma is completed by FPoC and sent to CAMHS via the weekly Review Meeting but because they work off different systems this is printed out by CAMHS and updated manually.
- If all case notes systems could communicate better the proforma could remain an electronic document which would improve record keeping and traceability and could reasonably be expected to help speed up the process through the removal of unnecessary rework.
- There should be Service Level Agreements established between services.
- Currently reported ‘Wait to Assessment’ times start at point triaged referral is passed from FPoC to CAMHS and not the point the CYP is referred into FPoC - This is driven by lack of communication between 2 provider organisations case notes systems but creates an additional hidden wait that is experienced by the CYP and their family.

**Initial ASD Screening**
There are a range of screening activities that currently occur between FPoC ASD Review Meeting and the Waiting List sift. This includes:

- Meetings with parents
- Gilliam scale (GARS)
- School Observations

There is already work underway looking at avoiding this unnecessary rework, but it is unclear at moment what percentages could avoid elements of this so it is difficult to determine if the impact of this change will warrant the effort to implement.

Why do we do this process at the beginning and repeat it at the end as data is out of date? Could this be moved to become part of final assessment. Unclear what benefit this stage gives the process.

The delay between FPoC ASD Review Meeting and Waiting List Sift is currently 8 weeks. What would this delay look like if the extended triage is dropped because sufficient information exists to move the child or young person directly onto the waiting list?

Assessment

- It would aid the Assessment Process if the child or young person’s development history was available in a standardised semi-structured and computerised format.
- This may link into the challenges faced by FPoC with their electronic proforma
- There is currently no Paediatrician on the MDT. The group felt that although there needed to be a 'doctor' on the MDT they advised that NICE guidance suggest that this doesn't have to be a Paediatrician.
- Use Autism Diagnostic Observation Schedule (ADOS) as part of the standard assessment process. The current process is that if there is no agreement at MAT meeting then the ADOS will be used.
- How are complex cases managed and assessed: LD, Attachment, ADHD – Comorbidity shouldn’t always exclude ASD.
- More professional resources need to reduce waiting times. Taking into account improvement opportunities, it was felt by the group that under- resourcing was the single biggest hurdle to improving wait to assessment times and addressing this would have the single biggest impact upon wait times
- The additional resources to support the assessment process could be somewhat addressed by all members of the MDT being integrated into one team (Trust) - SALT, Psychiatry, Psychology and Educational Psychology etc. integrating all involved into one Trust would reduce complexity, remove rework, enable better tracking of referrals and reporting of true wait times and provide economies of scale
- Reintegrate Educational Psychology back within the Multidisciplinary Team and Assessment Process. Could the Clinical Psychology Assessment be replaced by an Educational Psychology Assessment?
- The agreed process for Calderdale school years Autism Assessments is for 3 professionals to conduct separate assessments and to feed this into a Multi-Agency Team meeting. In reality only 2 assessments per child or young person are currently being conducted. This is
reportedly because Paediatrics are from a separate Trust which have begun charging for support and so are no longer supporting the process

The team suggested the Core assessments required were:

- Clinical Psychology Assessment
- Medical Assessment (Paediatric or Psychiatrist)
- SALTS Assessment

- The grade of professionals conducting assessments is based on the grades of professionals within the team rather than because that is the banding required. It was felt that a team of lower grade professionals could support this process and would cost less. E.g. Clinical Psychology assessment current being completed by an 8C but could be done by Band 6
- It was stated during the meeting that although the assessments take place these assessments are not recorded in writing or otherwise as there is insufficient time. This could pose a significant compliance risk as professionals will be unable to provide any evidence of why a decision is made if it is challenged
- The stakeholder group felt that assessments needed at least 3 professionals to give wider perspective. This was raised in relation to the revelation that currently only 2 people contribute to the MDT Assessment and neither is a Paediatrician

Outputs

- The team felt that providing training for practitioners or supervision for people working with ASD would be high impact.
- Currently the team provide a yes/no answer as the key output of the assessment. This is different to the more nuanced output from the Early Years Process. The team felt that providing a greater differentiation of diagnosis, more clinical detail/pointers or advice to services following MDT assessment would be highly impactful. However, this would be more time consuming and resource heavy than current processes and could not be implemented without further damaging already significant wait times or requiring additional resources.
- Families would like more information from Assessment on what next and less information on what we did. Early Years tend to provide long reports with lots of ‘what we did’, school age tend to provide yes/no diagnosis with little detail.

Post Assessment

- CAMHS could offer post diagnosis treatment:
  - Medical
  - Psychological
  - Behavioural
- Working more closely with other agencies who work with ASD (Training/ research & Development)
- School still required to apply for support

Whole

- It is clear that even with making improvements to the existing process there are not enough staff to support the current demand and assessment process. However:
• Where are more staff needed?
• Where are higher trained/skilled staff needed?
• What can lower skilled staff do?
• Increased capacity across the board.
• All aspects of the process – from triage, screening, MDT assessment to be done by one unitary team – currently undertaken by Northpoint, SWYFT & CHFT
• Clinical Psychologist only working 1.5 days per week
• Why is there a split between Early Years and School Age?
Literature Review

Introduction

This literature review has concentrated on enabling a practical understanding to the current difficulties faced by children, young people and families across Calderdale and also work towards offering the underpinning evidence base to inform a range of practical solutions to the service level and process needs within the system. The review team is aware that Calderdale has made a commitment to introducing a THRIVE Framework\(^\text{14}\)/ tier-less service and has incorporated literature relating to THRIVE within this chapter.

Achieving an early diagnosis of neurodevelopmental disorders, such as autism spectrum disorder (ASD), is an on-going issue for both public health and clinical practice\(^\text{15}\). There is a delay from a caregiver’s initial concerns around a child’s behaviour - which research suggests is reported around 18-24 months - to then receiving an autism diagnosis\(^\text{16}\). In some instances, this may be due to delays in seeking professional support, or delays once support has been sought to undertake the assessment process. This delay is not limited to UK health services, but is also experienced by a number of other healthcare systems, such as the U.S.A.\(^\text{17}\).

Despite NICE (2011)\(^\text{18}\) guidelines proposing diagnostic assessments should be underway within 3 months of referral to an autism team, the documented wait-times from first referral to diagnosis is as long as 3.5 years and has not demonstrated a notable decrease in the last 20 years\(^\text{19,20}\), with the


median age of diagnosis in the UK being around school age. A report exploring access and waiting times for young people, by the Education Policy Institute, analysed the results of 57 providers of specialist child and adolescent mental health services (gathered through a freedom of information request). It was found that although the majority of professionals estimated that services were providing timely access to an Autism Spectrum Disorder assessment, around 40% of services were failing to meet the recent NICE guidelines (2011, 2012) to commence an assessment within 12 weeks of referral.

Across UK NHS Trusts, neurodevelopmental disorders have been found to have the longest average waiting times for both assessment and treatment. Delays for diagnostic services is problematic for several reasons, not least because it hinders the commencement of early intervention and autism-specific support services, which research has shown to be optimised at younger ages (NICE, 2011) and less effective as age increases. There exists a growing body of research which suggests that early intervention programmes can improve overall functioning, social communication, language, cognition and adaptive behaviour in children with autism spectrum disorder (ASD).

There is an increase in much needed initiatives aimed at reaching families and diagnosing ASD earlier in a child’s development, however this is likely to place even more of a strain on services who are already having difficulties with lengthy waiting lists, increased referrals, resource constraints, and the expectation of adherence to clinical guidelines and national targets. A common approach to the management of waiting lists within the UK has been primarily through additional funding put into health care services. However, for those who access and deliver services, progressing with a pathway – such as that for the diagnosis of autism – comprises of multiple specific stages, each of which may contribute to waiting times at varying points along a diagnostic process. Subsequently, each specific stage may require specific, bespoke solutions, which cannot necessarily be solved solely through additional budgets which often focus on increasing staffing capacity. Therefore, it is suggested that a


more detailed analysis of the pathway could be a more effective way of managing resources and waiting times 28,29.

Should all of the emphasis be on waiting times?

Whilst policy directives identify waiting times as a main focus for improvement by healthcare providers, there is little tangible guidance in the form of initiatives and strategies to cope with high volumes of referrals and lengthier still waiting times. The wide variation in service provision and outcome data between providers indicates a disparity between the sharing of information and best practice, as well as how service data is captured, evaluated and utilised22. Ultimately this presents a difficulty in ascertaining a) strategies that providers have employed to improve their service, as well as b) the effectiveness of those service strategies and their impact on waiting times and service outcomes. Nevertheless, this emphasis is rightly driven by parental and service-user concerns and the evidence is clear in terms of the consequences for families with little access to provision and a lack of understanding about their child’s behaviour. However, it has been argued that support for a child and their family should be driven by need, and not diagnosis. Considering the structure, pathways and provisions of an existing service – as well as ideals for a service going forward - likely determines the extent to which an emphasis on waiting time reduction strategies are employed.

Understanding the impact of waiting times for service users and resolutions

It is important for services to have an awareness of the experience of engaging with the diagnostic pathway from the perspective of service users; their experiences illuminate not only areas of good practice, but also aspects of the process which could be developed. Parents report that the process of getting an Autism Spectrum Disorder (ASD) diagnosis is arduous, lengthy, and fraught with

difficulties\textsuperscript{30} and is a source of anxiety\textsuperscript{31}. A recent analysis\textsuperscript{32} of pathway survey data examined the experiences of parents of a child with ASD, compared with parents whose child had a different developmental disability (e.g. intellectual disability; developmental delay). Despite substantially earlier parental concerns about their child’s development, the ASD group (n = 1,420) received their current diagnosis on average, around 7 months later (mean age at diagnosis = 62.8 months) than children in the group diagnosed with a different developmental delay (n = 2,098, mean age at diagnosis = 55.4 months).

Parents have been noted to express dissatisfaction with the diagnostic process. In a survey of 1,047 parents, 52% were not satisfied with the process and this was linked to waiting times\textsuperscript{16}. Long wait times have been cited as a barrier to accessing and engaging with mental health services and can contribute to a deterioration of mental health and ability to function in daily life, as well as reducing motivation to seek help\textsuperscript{33}. One study found that some young people have not accessed services they felt they needed because of being placed on a waiting list\textsuperscript{34}.

What can be done whilst children and families waiting for a service?

Whilst receiving a diagnosis has been linked to enhancing the understanding of a child’s behaviour from the perspective of their parents/caregivers\textsuperscript{35}, research indicates that a later diagnosis often leaves families with little guidance on ‘making sense’ of their child’s condition, and leaves families with limited resources to manage this life-changing event. Equally, families waiting for an ASD assessment


\textsuperscript{33} Cox, K., Smith, A., Peled, M., & McCreary Centre Society. (2013). Becoming whole: Youth voices informing substance use system planning. Vancouver, BC.

\textsuperscript{34} Cox, J. (2017). Access to child and youth mental health services in BC: Barriers, recommendations, and strategies for improvement.

often experience difficulties explaining, or making sense of, the referred young person’s behaviour. Therefore, just as understandable information is necessary for families whose child has received a diagnosis, research suggests that extending this to families who are waiting for an assessment may also benefit, by allowing access to more information and early discussions with clinicians, which some have considered is an intervention in itself.

Whilst waiting for interventions, parents have found interim services useful in bridging the gap, such as books, internet sites and parenting workshops. Interim services could offer several valuable contributions: engaging parents who may otherwise discontinue their efforts to secure support; provide the information needed to participate in service planning decisions (this links to current practice on Shared Decision Making); prepare parents for treatment, and, in some cases, reduce the need for a service. Further findings have noted that as a result of engaging in a programme whilst on a waiting list, parents gained an enhanced feeling of control and confidence. It was also emphasised that support programmes should promote ‘male voices’, for fathers who may otherwise ‘hold their feelings in’. Additionally, the combination of long wait times with limited resources to draw upon, can see parents looking online for help, where they are faced with an overwhelming amount of information. Some of which may highlight more severe cases, hinder an understanding of empirically supported claims, and increase anxiety and fear over the unknown.

Reducing the length of time between a parent’s initial concerns about their child’s development, to then receiving a diagnosis would be an optimal scenario in going some way to enhancing parental satisfaction with the diagnostic process and service engagement. However, it is important to acknowledge that, in some cases, clinicians are simply not able to provide a child with an accurate diagnostic label at an early stage and therefore reassessment after a specified time frame is necessary. It is important to make parents aware of this, and to provide an explanation of the decisions made, to ensure they feel heard and that their concerns are being taken seriously. A case study example of consulting service users is presented in Box 1 below.

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Using the research to inform practice

- Research suggests parents find it helpful if professionals inform them about the length of the diagnostic process beforehand.\[^{42}\]
- Where caregivers are signposted to support whilst on the waiting list, it is important to state that they do not yet know whether their child meets the criteria for a neurodevelopmental diagnosis, but that they are receiving this information as some parents report that receiving accurate information aids in alleviating anxieties surrounding the diagnostic process.\[^{42}\]
- It is important to let parents know why it may be the case that a child cannot be diagnosed straight away and any reasons for additional referrals or increased wait times.
- Parents’ own views are that information/resources/support whilst they are waiting for an assessment and diagnosis is extremely valuable. This resonates with the idea of providing support based on need rather than diagnosis.
- Offering workshops such (see Box 1) can serve to reassure families that they are still ‘in the loop’ and being held in mind by a service. It also provides a space where families and service users can meet others who share this experience; benefits have been cited as stress-buffering.

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**Box 1. What are other services doing to reach out to families who may feel isolated and unheard? A Case Study Leeds Community Healthcare Trust**

The CAMHS team for Leeds Community Healthcare NHS Trust held an event accommodating parents and young people who were still waiting to be seen by the service. During the event families spoke openly about the impact waiting to be seen has had, such as eliciting feelings of isolation and distress. Suggestions were made around how a CAMHS service can better inform families of what help is available and this included self-help. The workshop appeared to enable families to feel heard and reassured.

In response to the event Leeds Community Healthcare have begun to review the leaflets and correspondence they send out to families, creating information sheets about where families can go for help; and looking into setting up email communication with families.
and providing emotional, social and practical support that cannot be fully satisfied by family friends or health professionals.\textsuperscript{43}

### Linking THRIVE to research and practice

Calderdale has set out a commitment to implementing THRIVE (2015) within their Local Transformation Plan. This section of the literature review is reserved to understanding the practical application of this conceptual approach.

THRIVE Elaborated (2015) outlines several examples of providing advice for young people and their families (see box 2), which resonates with evidence presented above, as to what families want when they are waiting to be seen, or where they have confusions or concerns. Services can consider where these techniques can be implemented within their service and pathways.

#### Box 2. THRIVE Section: Getting Advice

- key elements of ‘getting advice’ might include providing families with research or experience-based information related to the difficulties presented to the professional
- information is relayed in such a way as to enhance the self-efficacy of the family and increase the chance of taking appropriate action;
- using the interview to draw out the options available to the family and inviting the family to consider the pros and cons of each of the options;
- making suggestions for limited changes in aspects of the child’s and family’s routines;
- helping to identify existing resources both within their social network or support agencies, voluntary groups etc.,
- an invitation for re-contacting the service is embedded in the offer of any advice if things do not improve or they deteriorate.


### Factors affecting waiting times

The following section will outline factors affecting waiting times within mental healthcare services. After consulting existing literature, it became clear there are several recurring factors amongst

services which may contribute to lengthy waiting times and service inefficiency. In a report by Autism Achieve Alliance (2014) it was found that, of 94 services across Scotland (64 of which were child services), frequent reasons for delays in the pathway were cited as:

- less efficient working and communication
- high non-attendance rates
- inappropriate referrals
- ineffective care pathways.

Research highlights that professionals perceive service improvements to be warranted in several different areas, such as improving knowledge and training (for professionals who refer individuals to services); the need for clear, open and accessible pathways into services; reduce the time taken to access first appointments. This reiterates recommendations put forward in the NICE guidelines (2011, 2012) as well as the views of parents and adults who have experiences the ASD diagnostic process.

**(In)efficiency in the pathway**

An ASD diagnostic pathway has 3 parts, which cumulatively provide the total wait for the diagnosis (from referral to receiving diagnosis):

1. Wait for the first appointment (from referral)
2. Duration of the assessment
3. Wait to receive the diagnosis

Alternatively, Rogers et al (2015) investigated views of professionals (n=116) involved in ASD diagnosis and assessment, regarding three key stages of the diagnostic pathway: service accessibility, the diagnostic process and post-diagnostic support, in order to understand aspects which are working well in practice and areas for improvement, particularly in relation to the NICE (2011/12) guidelines.

It was found that although the majority of professionals estimated that services were providing timely access to an ASD assessment, around 40% of services were failing to meet recent NICE guidelines (2011, 2012) to commence assessment within 12 weeks of referral. A comment relating to long wait times was: “People get referred in but the time gap to diagnosis is too long – there are significant delays in accessing the required assessments and then for the case to be discussed. It is a lack of capacity within the services to meet demand”.

It was noted that efforts need to be made to enhance the accessibility to a service, to reduce wait times for initial access to a service, but also to reduce the wait times for the initiation and completion of the diagnostic process.

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Pre-referral stage

There is a need to educate referrers to better identify ASD to improve the quality and relevance of referrals and to increase knowledge about the referral process\textsuperscript{26}, as this stage in the diagnostic process can cause significant delays. The Education Policy Institute gathered information from 57 Child and Adolescent Mental Health Service (CAMHS) providers and examined the main reasons as to why a referral was not accepted (e.g. rejected; not considered appropriate)\textsuperscript{32}. The most common category was a ‘mistake by the referrer’ and the following reasons were cited:

**Inappropriate referral**

1.1. not enough information provided by referrer;
1.2. child/young person not been seen by referrer prior to making referral;
1.3. referral not according to agreed pathways; and
1.4. duplicate referral.

Does not meet CAMHS criteria:

1.5. not met criteria for significant mental health problem;
1.6. not met specialist Child and Adolescent Mental Health Services threshold;
1.7. commissioning gap
1.8. child does not have the disability/disorder specific to the service
1.9. referrals that are querying ASD but do not provide clear evidence;
1.10. referrals that are not specifically for mental health concerns; and
1.11. referrals that request CAMHS input for what appears to be unresolved social care issues.

The mistakes evident within the referral process indicate \textbf{a)} the administrative difficulties present in the referral process and \textbf{b)} the need for greater awareness and training amongst those who make referrals (e.g. GPs, teachers). This is likely to become more poignant with the recently published Green Paper indicating that schools and colleges are to take more of a role in identifying and escalating the mental health needs of children and young people\textsuperscript{46}. Additionally, it has been found that CAMHS staff may benefit from training in understanding of school and education systems to improve clinical skills in detecting education-related mental health problems, and to develop strategies to increase joint working with schools and colleges\textsuperscript{47}. Indicating that joint collaboration and inter-disciplinary learning is vital.


Using this research in practice

- Understanding the reasons for inappropriate referrals to a service, as well as establishing an action plan to resolve issues\(^\text{26}\), can go some way into identifying key moments in the pathway where delays occur.
- Consider where the waits are coming from e.g. are families able to access and find the service easily? Data could be collected which investigates how long it takes families to access the service. This could highlight areas where a service can improve its public visibility, and subsequently families may be able to access the service earlier in the child’s life. This does not by default address the issue of the diagnostic process waiting times, however cumulatively it may mean that children overall may receive a diagnosis, and therefore support earlier.

Appointment non-attendance

Research with autism service professionals highlighted that high non-attendance rates for services have contributed to delays and therefore waiting times\(^\text{48}\). In some evaluations of mental health services, waiting times themselves have been highlighted as contributing to further waiting times\(^\text{49}\). For instance, waiting lists have been linked to higher no-show rates for appointments, and therefore a service with reduced efficiency. In an experimental study varying waiting times\(^\text{50}\), a significant relationship between waiting times of 1 to 2 weeks and a higher rate of non-attendance. People referred for psychiatric care in primary care clinics or community mental health centres are more likely to miss their appointment the longer they wait. The direct applicability of this to a specialised neurodevelopmental service needs to be considered carefully as there is limited research, however increased wait-time has been found to be a reason for cancellations to an outpatient paediatric autism clinic\(^\text{51}\) and reported by some professionals in autism services\(^\text{48}\).

One study\(^\text{52}\) found emotional barriers were a reason scheduled appointments were not kept; the negative emotions about going to see the doctor were greater than the perceived benefit of keeping the appointment. Another barrier was the perception of respect, or lack of, by the service. From a service user perspective is was proposed that professionals: did not respect patients, discounted patients’ time, opinions, and feelings. This dissatisfaction has been highlighted in previous research with parents whose children were diagnosed with autism, where a sense that their needs have not


been understood⁵³ is a cause of frustration, with parents reporting a greater satisfaction with the diagnostic process if professionals are perceived to be taking their initial concerns seriously and highlighting the need for prompt responses to their concerns and a more sensitive approach from professionals⁵⁴.

A further reason for missing appointments is due to service-users not knowing what happens in a service if there is a failed appointment⁵², with the presumption that it will give the clinicians more free-time, or space to see the next person. It is postulated that interventions, such as open access scheduling systems (outlined in the following sections) that decrease the delay between scheduling and appointment, should effectively address no-shows caused by service-user anxiety as they will be seen the same day. On the other hand, filled waiting rooms (and therefore longer wait times on the day) have been linked to service-users feeling disrespected, which in turn is a hypothesised reason as to why people are more likely to cancel and not let a service know.

**Using this research in practice**

- Offer information about the impact of missing scheduled appointments and what this means for the service generally and for service user future experience in particular.
- Where open/same-day access is implemented, professionals should explain clearly to patients that they can be seen today but may have to wait for a longer period of time.

**Approaches and initiatives to reduce waiting lists**

The following section provides an overview of some existing approaches and initiatives which have been devised and/or applied within healthcare settings with a view to reduce waiting times. The summaries detailed below have been selected due to their relevance to healthcare settings.

**Advanced Access Model**

One direct approach to managing waiting lists is to utilise an advanced or open access scheduling system, in which patients are offered an appointment the day that they call or within 24 hours⁵⁹,⁵⁵. It

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is a system which promotes patient-driven scheduling in lieu of prearranged appointments. Its premise is that most waiting is due to problems in matching a clinician’s capacity to offer appointments with patient demand for appointments on a day-to-day basis, rather than a total lack of capacity per se.

It is acknowledged that implementing such a model within healthcare systems could have its difficulties; notably around the organisational/workforce culture and the deeply held beliefs of staff around what they feel can be achieved with the resources they are currently working with. Barriers here are cited as a fear of change and lack of confidence that the existing service resources can sufficiently meet the demand of service users. It is noted however that if demand exceeds capacity permanently (and not just on the occasional day) no model is likely to work, whether advanced access or otherwise. The primary design objective of an advanced access system is to do today’s work today and sort appointments by clinician capacity, not clinical urgency. It is for this reason that he advanced access model must be driven by data and services should have a solid understanding of their service user population, level of demand, available appointments etc.

The model involves monitoring supply and demand and developing a “continuous flow” system designed to match demand, reducing existing backlogs, developing contingency plans for unusual circumstances, and increasing the availability of bottleneck resources. This model has been tested in primary care clinics, where it has been shown to improve wait times and no-show rates, but effects on patient satisfaction were mixed. The Ontario Centre of Excellence for Child and Youth Mental Health notes that some changes in implementation would need to be made in order to use advanced access scheduling in a mental health clinic.

**Adopting the Advanced Access approach: A Quality Improvement Model**

One case study adopted the ‘advanced access’ approach to deliver a ‘quality improvement model’ to improve waiting times and no-show rates for an adult outpatient service which provided psychiatric evaluations in the United States. It was found to significantly reduce wait times without increasing staff resources and improvements in access to care led to a more efficient system, with less staff time wasted in no-shows and higher staff morale associated with teamwork and higher quality care. The service employed ‘specific change strategies’ which enabled the implementation of a same-day approach.

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service, the capture and use of data to understand and improve the service and general ‘good practice’ which enhanced the efficiency of the service (see. Box 3).

The actual number of days from referral to initial psychiatric appointment was compared for all service users seen in the 18 months before implementing the access project and the 18 months after access implementation. There was a statistically significant ($p<0.001$) reduction in the delay from referral to appointment, from 11 days reduced to 2 days. Before access implementation 12% of service users saw a psychiatrist on the same day as contacting the service, compared to 80% post-implementation. In addition, the no-show rate for an initial appointment decreased from 52% 6 months before access implementation, to 18% after full implementation (the study did not provide exact figures).

Box 3. Specific Change Strategies

1. Develop an effective Access Team

The service organised Access Team to liaise with the consultants, learn the access model and develop and implement changes to the system. Several team members including clinical director, case manager, therapists. Team met weekly to plan and evaluate implementation changes over a 1-year period.

2. Identify/track data weekly

Measures employed to provide continuous weekly feedback. For example, demand and supply (calls made to service vs. number of available appointments); no-show rates; delays to available appointments.

3. Evaluate the current system and outline goals

Team members walked through pathway from a service user’s perspective to identify barriers to the system. Comparison of demand and supply data. Analysis of service data e.g. it was found that 90% of service users are eventually prescribed psychiatric medication, indicating that all clients could benefit from a psychiatric evaluation.

4. Reduce the existing backlog

Before same day appointments were offered, existing waiting list was cleared. The medical director ran a one-day clinic for service users awaiting first appointment; remaining service users were seen by clinicians who offered additional hours (temporarily).

5. Provide all new clients evaluations within 48 hours

Psychologists/therapists set aside weekly intake times to meet the typical daily demand identified through initial data analysis. On days where intake was higher, the program managers also undertook this workload.

6. Meet service user immediate needs immediately

Undertaking an intake appointment and psychiatric evaluation on the first session allowed service users to tell their story once and their greatest needs were addressed in the first visit.

7. Address new problems as they arise

The weekly team meetings allowed the opportunity to strategise problems as they arose.

Points to note:
• Whilst this approach has been used in primary care, and in the above case study for mental health care of psychiatric disorders, assessments for autism for instance, tend to be undertaken in conjunction with other agencies (e.g. schools, observations, family reports etc.). it is therefore necessary to consider what could be done in a ‘same-day’ appointment if an assessment requires a multi-agency approach. Therefore, it is difficult to conclude whether or not this approach can be applied directly to neurodevelopmental services.

• The demographic in the above example may be different to the service users who access a neurodevelopmental service in the UK. For example, they are mostly care-givers of, or children/young people themselves, who may not be available for a same-day appointment.

Access-Initiative

One study devised a new model to decrease the wait time for an appointment for a Gastroenterology evaluation, as well as increasing new patient access. Although gastroenterology is a sub-speciality, the service embedded an “access paediatrician” (AP) (a general paediatrician with no formal additional specialist training) into the service to review clinical presentations and evaluations of common patient complaints. The AP developed a management plan that reflected their primary care experience, a synthesis of evidence-based methods used by the other division members, and an updated review of the literature. The AP became familiar with appropriate use of procedures and specialized testing through observation, literature review, education conferences, and ongoing discussions with service colleagues. The access paediatrician evaluated patients alongside the subspecialists who were available for timely consultation. The service also hired a ‘nurse navigator’ to triage patients’ referrals, contact patients ahead of time, and navigate patients to the appropriate clinician (access paediatrician or specialist). Out of 4,901 patients who engaged with the service over a 7-month period, of 889 patients evaluated by the AP, 95.1% of them were new patients (n=845) and the specialists dealt mainly with follow-ups.

After the implementation of the access paediatrician, the service increased their total patient volume by 20.9% and increased new-patient volume by 57.4% and follow-up volume by 2.1%. For new patients the wait-time until first appointment decreased from a mean of 24.5 days to a mean of 0.94 days. This was statistically significant (p<.001), indicating that the effect was due to the implementation of the access paediatrician. It was concluded that the success of the access paediatrician was only made possible through advanced scheduling, subspecialty support, and a nurse navigator. Furthermore, the willingness of the referrers to accept the access paediatrician role is important.

Points to note with this approach:

• It is worth noting that in this study the paediatrician was dealing with primarily physiological complaints – in which they were trained. Considering the unease at which professionals have reported feeling in relation to mental health issues particular - without additional formal

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Moreover, an increased number of appointments has been cited as a reason for lengthier waiting times, therefore it is important to ensure that seeing a paediatrician does not delay access to a specialist where the concerns are complex.

- Schedulers received ongoing feedback to ensure ongoing appropriate screening and triaging of patients.
- Parents/families with questions about the AP’s role received additional explanations during the visit and were receptive to the model due to the short wait time until an appointment.
- Few patients who saw the AP required referral to the gastroenterology subspecialist. The AP referred 72 patients (8.5%). The actual number of individuals who are referred to neurodevelopmental services who then do not go onto a formal assessment and diagnosis is not known. Therefore, it is difficult to conclude whether or not increased referrals to the specialists would then have resulted in a bottleneck for specialist appointments – and with it increased waiting times.

## Linking THRIVE to service approaches and initiatives

THRIVE Elaborated (2015) proposes utilising a MINDFUL Framework (for an overview see Wolpert et al., 2014) alongside the THRIVE framework. This involves the consideration of multiple perspectives, interpretation focused on negative differences and use of directed discussions. Funnel plots should be used as a starting point to consider outliers, always keeping in mind an appreciation of uncertainty with learning collaborations of clinicians, commissioners and service users supporting data analyses.

This requires a seven-step process (see box 4 below for examples) to be applied separately to each of the five groups of need or choice included in the THRIVE model, with the relevant lead funder/commissioner for each leading on the review.

This way of thinking aligns the Advanced Access Model and Access Initiative examples provided in sections 4.2 and 4.3. For example, as can be seen in Box 2, where the case study employed ‘specific change strategies’ to improve their current service model and to improve waiting times and no-show rates for an adult outpatient service which provided psychiatric evaluations. The ‘specific change strategies’ share similarities with the MINDFUL approach, in that both have a focus on collecting and utilising service data to inform service direction and an emphasis on team discussion and learning.

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The Choice and Partnership Approach (CAPA)

The Choice and Partnership Approach (CAPA) is a patient management system based on the principles of ‘choice’ and ‘partnership’, which has an emphasis on the value of patient empowerment, designed for CAMHS. The first appointment (The Choice Appointment) usually entails the family choosing an intervention based on agreed goals and then engaging in partnership work, usually up to six

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appointments. If further treatment is needed, the family is offered an additional treatment, which is ‘specific’ to the presenting problem or diagnosis. The approach is informed by demand and capacity theory, which is a method of ensuring that there are clear procedures for staff time to be allocated to the part of the pathway to address the point in the care pathway that is causing delay. For a more in-depth overview visit www.capa.co.uk.

An evaluation of CAPA was undertaken using a single case study approach applied to a whole service (an inner city CAMHS service in London) which assessed its impact on service-user experience and satisfaction, as well as staff outcomes. The design of the evaluation involved three phases: a six-month pre-CAPA phase; a nine-month implementation phase; and a six-month post-CAPA phase.

**Waiting times.** Results indicated that – when comparing pre and post CAPA implementation groups – there was a trend of reduced waiting time between referral to first appointment, from an average of 82 days down to 71 days. This mean difference however was not statistically significant, thus limiting the conclusions that can be made in relation to whether it was the implementation of CAPA that contributed to the reduction in wait times. It was noted that the post-CAPA group had a smaller standard deviation (SD= 46.9 compared to SD= 108.1 pre CAPA), possibly indicating that there was less variation in waiting times post-CAPA implementation. Additionally, there was found to be an increase of 47% in the overall number of first appointments offered, from 49 cases in 2010 to 72 cases in 2011.

**Service user experience.** Results also indicated high levels of service-user satisfaction with the Choice appointments, which included feedback from parents, children and young people. Over 93% found the appointment helpful, 100% of parents and young people reported feeling listened to and so did 86% of children under 12 years of age. The study reported high satisfaction rates at a three-month follow up.

**Staff experience.** A staff focus group identified four key themes relating to the change of service practice:

1. Enhanced collaborative working with clients,
2. Increased transparency between staff and families,
3. Increased awareness by the staff team about the necessity of closing cases in order to address the problem of increasing waiting times for new referrals,
4. Anxiety about not having enough time to complete additional administrative tasks.

It was noted that the predicted negative outcomes of CAPA implementation made by staff prior to the pilot (such as the risk of poorer outcomes; difficulties in handing over families between clinicians from Choice to Partnership work) did not emerge as major themes.

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Implementing CAPA – Key Service Considerations

An evaluation of a CAPA implementation within a CAMHS service in England identified several themes which were integral in order to establish CAPA as an approach that worked for the service and its client group66:

1. **Adequate management** was necessary in order to adequately manage demand and capacity. Teams said it was important to regularly collect and evaluate data pertaining to the flow of families through the service. Staff felt this information should be discussed with the team on a regular basis, which would allow accurate capacity planning for the team and individual job plans.

2. It was necessary to have **adequate administrative capacity** to support implementing and sustaining the CAPA model. For example, robust administrative systems were needed to manage clinicians’ diaries. Clinicians cited poor administrative organisation as a main factor hindering the success of the CAPA model, leading to confusion over appointments, double booking, and not responding to families.

3. All teams interviewed (n=6) noted the need for **facilitative management**, meaning a need for the clinical lead to effectively engage with service managers. One interviewee commented that it was essential that the clinical lead was on board, citing that ‘clinical credibility’ was an important factor in encouraging clinicians to modify their ways of thinking and working.

4. **Management need to be aware of the confidence of the clinical team**. Managing the workforce and the Choice appointments is important; the outcome of the Choice appointment should be that the clinician and family are expected to have identified needs and decided on the appropriate course of action. It was found that less experienced clinicians were daunted by this expectation and that initial appointments were subsequently conducted in pairs (of clinicians) in order to offset this. Managers need to be aware of this when managing the workload of less experienced clinicians.

5. **Consider the service team**. CAPA was noted to work better in teams which were ‘unified’. Additionally, it was considered important to have a team which a diverse skillset (e.g. psychology, nursing, occupational therapy, social work, psychotherapy and psychiatry). This was noted as important because it allowed the team to **allocate appropriate team members to each service user**, dependent upon their need; this was cited as a reason the **waiting list reduced**, because the team knew each other’s’ competencies, and could allocate them accordingly. This streamlined the process of the initial appointment because a team member competent for the needs of the patient conducted the appointment, therefore reducing any inevitability of a patient having to then be referred to a more suitable professional and subsequently extending waiting times.

6. It was considered important that **team managers take an active role in planning the direction of the service**. It was important that they collect data in relation to capacity and demand, which in turn improved teams’ abilities to monitor service resources and patient demand, which some teams felt improved relationships with commissioning services. In addition, **job

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planning provided staff with more certainty around their workload, which alleviated some pressure and provided time to undertake necessary administrative tasks (e.g. making phone-calls).

Challenges of implementing CAPA

- **Occurrence of bottlenecks within the system.** In some instances, there was a build-up of internal waiting lists, for instance when a family moved from the initial, to a follow-up appointment. Robotham (2010) notes that this could occur for several reasons: inaccurate capacity and job planning; inadequate staffing; failure to plan the discharge of families; under-confidence in conducting initial assessments which meant that families would have more than one.

- **(Potential) de-valuing of specialist skills.** Some teams interviewed commented that resources were re-directed away from specialist time, into more generic core therapeutic works. This was poignant for psychotherapists (who are often utilised for more complex cases) who may, under the model, engage more with generic support, rather than providing their specialist support.

- **A lack of guidance in fitting complex cases into the CAPA model.** Following on from the above point, one interviewee noted the need for additional information/development of how to deal with more complex families.

THRIVE and CAPA

The Choice and Partnership approach (CAPA) is consistent with the THRIVE framework – which draws on the learnings of CAPA - and provides a potential model of implementation of the THRIVE principles. The THRIVE framework itself is not a blueprint for implementation but aligns with implementation models such as CAPA67 (see Box 5. for description).

67 THRIVE Elaborated is the second edition of the THRIVE framework developed in 2014. For a more comprehensive overview of the up to date framework see:

Box 5. Aligning THRIVE and CAPA

The following information is cited from THRIVE Elaborated (2015: 10-11). 

THRIVE aligns to CAPA in the following ways:

- The THRIVE groupings align with those used in CAPA of choice (getting advice) and partnership (core partnership is equivalent to getting help, Specific partnership with getting more help and getting risk support). CAPA, like THRIVE, defines the groupings in terms of needs/choices of individuals, description of needs, skill mix and resources needed to support those choices.
- CAPA focuses on helping people make explicit choices about what may most benefit them and links this with clear evidence-based packages of care. A focus on being clear what the task is and how it is to be delivered and the agreement on the task alliance with the client is embedded in CAPA.
- One of CAPA’s 11 key components is to change language to that which promotes strengths-based, collaborative work towards shared goals with young people and their families, thinking about skills needed, rather than access to a particular professional discipline. The THRIVE framework promotes this way of thinking by furthering the use of language to one that is helpful to young people and families and services.

CAPA addresses additional elements not addressed by THRIVE (this does not mean the THRIVE model endorses these elements):

- Workforce and capacity planning. In particular, CAPA segments work so that skills and capacity can be properly identified and deployed. In addition, CAPA identifies all the other types of work staff do in their job to allow capacity to be calculated.
- Consideration of staff training, for example in relation to language used with clients and with each other.

THRIVE emphasises aspects that are aligned but not synonymous with CAPA, including a more explicit and focused emphasis on:

- The difference between risk support and other forms of help. This includes being explicit about the role of children and young people mental health services, which is not about treatment, i.e. risk support is seen as the business of children and young people mental health services.
- The potential for treatment harm as well as the limitations of what can be achieved • endings, even when significant change has not been achieved and focus on more explicit discussion of this with service users
- Use of tools to support empowerment and shared decision making
- Interagency ownership of the framework including cross-sector outcome measurement.
Taking action: Examples from the literature for making a service more effective

1. **Action Learning:** Generating local action learning plans can allow services to consider the changes that can be made to improve the quality and efficiency of their service within existing resources and timescales\(^6\). Considering the perspectives of not only the service team, but also service-users (young people and their families) has proven useful in considering what is important to those involved in the service, and the development of meaningful amendments going forward. It also provides the time for teams to reflect on their practice, which was considered valuable by respondents who underwent this process\(^2\).

2. **A flexible approach towards assessment:** E.g. one child service’s clinical team only undertook contextual observations when there were discrepancies between the standardised scores between home and school contexts. It was felt that this utilised service time more effectively.

3. **Employing standardised instruments or local pro formas:** To gather contextual information. Most child services did this, and where school and home contexts reported the same difficulties, faith would be placed in the written reports. Again, where there are discrepancies, a member of the team would go to investigate.

4. **Standardised diagnostic tools:** These were viewed positively by staff, and where these were not directly utilised staff drew upon their training in the tools to conduct diagnostic assessments. In services where there were less experienced staff, they reported that having a standardised process would allow them to feel more confident with the diagnostic process – even where the knowledge within the service was seemingly already high. It was noted that ‘experienced’ adult teams felt that once a team becomes highly experienced in diagnosis, the accuracy of their clinical judgement then exceeds standardised tools\(^2\). However, research exists which critiques the accuracy of unstructured clinical assessments when compared to actuarial assessments\(^6\), with a consensus adopting a combination of the approaches\(^6\).

5. **The development of good multi-disciplinary communication** and team working have been cited as providing benefits for those involved in the service (this affects several steps in the pathway e.g. information gathering before assessment).

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6. Pathway efficiency could be improved through gathering more information on the service-user prior to the first appointment. Some services have therefore developed a proforma for gathering information from referrers at the point of referral.

7. Practitioners suggested creating more appointments through reviewing the skill mix and distribution of staff within the multi-disciplinary teams and the service.

8. McKenzie (2015) found that the duration of assessment was shorter when there are fewer appointments involved in the process – although it is noted that this may not be possible for complex cases.

Conclusion

The literature evidenced that the journey for young people and their families from initial appointment to a diagnosis is often long and complicated, and reliant upon the input of multiple agencies across a young person’s network. Where relationships between multi-agencies is confusing and inharmonious it can cause delays at various key stages of this journey, whether that is not obtaining enough information for a diagnosis or meaning ineffective implementation of post-diagnostic support; the need for clear and proactive multi-disciplinary working is clear.

There is no one steadfast approach to reducing wait times or creating the most effective pathway for children and young people with neurodevelopmental disorders. The above review is not meant to be exhaustive, but rather an overview of factors and approaches for consideration, which may impact on waiting times and the deliverance of an efficient service. It is about considering the evidence and best practice cumulatively and considering how each of the parts that makes up this journey can contribute to an efficient, competent and trusted service.

It is important to note that the case studies and literature span UK, European and American contexts, and so their transferability to a UK neurodevelopmental service will need to be considered in light of the context in which such a service is being delivered.

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Recommendations

In the absence of an identifiable existing best practice model, an ASD Assessment Pathway has been developed for Calderdale based on the findings of the literature review, interviews, consultations, analysis and value stream mapping exercises described above. The following recommendations are consistent with NICE guidelines and Lean principles and methodology to deliver a pathway that, if implemented in full, could significantly reduce waiting times, provide consistency and clarity to service users, free up professionals to spend more time working with children and young people and deliver quality assessment outcomes for children, young people and their families in a timely manner.

Key Recommendations

Core to the recommendations contained within this report is the development of an ASD Pathway linking assessment and intervention services to deliver a comprehensive integrated multiagency solution operating across all levels of a Thrive/tier less framework in support of the children or young people and their families across Calderdale:

- **Co creation and ongoing participation**: As with all related services, it is highly recommended that children, young people and their families are involved and consulted and in guiding the direction of all service and pathway developments.
- **Commissioning**: It is essential that the delivery of both the ASD Assessments and the ongoing programme of support are explicitly commissioned using clear integrated commissioning processes.
- **Data Driven Decision Making**: Data and management information must be routinely, accurately and consistently collected across all provider organisations (health and local authority) to enable the development, implementation, ongoing maintenance and fully accountable and transparent commissioning.
- **Fully Funded and fully resourced ASD Assessment Process**: In conjunction with undertaking the opportunities to reduce waste within the system it is essential that the team responsible for delivering the pathway is sufficiently funded and resourced to meet current and future demand.
- **Single Core Assessment Pathway within an integrated team**: Agree a single assessment pathway that will simplify communication processes, balance waiting times and deliver a more equitable service regardless of age. Bring together the early years and school age services as one pathway under one caseload coordinator to enable improved economies of scale as resource is pooled. It is not necessary for this pathway to be operated by a single provider, although it must be operated in a seamless and boundary-less way that has the wider team integrated and able to work in an open and collaborative manner.
- **Development of an accountable process**: The pathway development includes a quantifiable process to continue to identify and measure activity and resource allocation to ensure a cost-effective service.
- **Integrated ASD Assessment and Intervention Pathway:** The initiation of the package of support from the ASD Service should be incorporated into the assessment process to ensure a seamless transition along the pathway from assessment to support.

- **Signposting and External Support:** Signposting and additional packages of support should form part of the pathway and be made in a consistent and timely manner based on the needs of the child or person and their family.

- **Single Subject Matter Experts and Succession Planning:** Currently single points of expertise are causing multiple bottlenecks and leaving the process vulnerable to absence and attrition. It is essential that the core assessment roles within the pathway are shared across a number of individuals.

- **Workforce Development:** Undertake a comprehensive training needs analysis and subsequent training programme that is targeted at ensuring there is sufficient knowledge and expertise across the whole system to support children with ASD and their families with awareness, identification, assessment, support and therapeutic interventions within a Thrive/tier less system framework. All workforce development to be underpinned by a whole system staff competency framework in relation to working with children, young people with ASD and their families.

- **Proactive Caseload Management:** Allocate a single point of responsible (non-clinical) for proactively managing the pathway and matching resources to demand to support timely diagnosis and flow through the pathway.

- **Diary Management:** Centralise triage and administration functions to create a team of process and pathway experts with the ability to coordinate referrals across functional and trust boundaries. This team would handle all external communications and booking activities, chasing information etc. which will free up additional clinical time currently tied up in these activities.

- **Simplified Assessment Process:** Agree a simplified assessment process based on NICE guidance that removes duplication and unnecessary professional involvement.

- **ASD Assessment Proforma:** Create an electronic proforma to cover all stages of the new process that can be shared with all stakeholders. The aim is to create an assessment document that remains electronic, can be updated immediately, requires no additional inputting, avoids unnecessary duplication and ensures a consistent approach to assessments across Calderdale.

- **Logically Scheduled Professional Involvement:** SALT, Physical, Psychological and Paediatrics assessments conducted in a logical order based on how to best build an understanding of the child or young person, professional availability and cost, and ensuring the right professional is available at the right time for the child and young person and their family.

- **Physical Health Examination:** Introduce a nurse led physical examination after the SALT ASD Assessment to perform a general physical examination and systematic assessment for conditions that may coexist with autism or may be misdiagnosed as Autism.

- **Diagnosis:** Combine the Paediatrician ASD Assessment with the communication of assessment findings to the parent to remove unnecessary additional delay.
Short-Term Risks

In addition to the mid to long term recommendations contained within the report and the ongoing issues with waiting times, the following short-term risks to the existing pathway have been identified as a result of the service review:

- **Succession Planning:** There are 3 key members of the ASD pathways all leaving at the same time risking a substantial loss of knowledge and expertise and further impact on waiting times
- **Initial Screening:** The owner of the initial screening process is leaving. Whilst the project team have been advised this step is no longer part of the current pathway it has been suggested that around 71 children and young people may still be waiting for an initial screening. It is essential that this people do not get missed in any handover of responsibilities.

Waiting Lists Blitz

Concerns were raised by a number of professionals around any proposed approach to blitzing the waiting lists using either a temporary process or temporary staff. It was felt by some that previous attempts to reduce waiting times by utilising external agencies had not been effective and concerns were raised that the output of these assessments may not have been of an equivalent quality to the core process.

It is the assertion of the review that a permanent solution is required and any temporary measures taken to reduce waiting times will be ineffective in the long term unless accompanied by a fully resourced and more efficient pathway. However, if the proposed improvements and future state pathway are to be introduced then a systematic approach will be required to remove the waiting list backlog. This may be approached in a number of different ways, but must occur as part of the overall implementation of any agreed future state pathway:

- **Waiting List Blitz:** CAPA adopts an approach whereby any referrals received 8 weeks prior to the go live date or less are booked onto their 1st (Choice) appointment as per the new CAPA process and any referrals received prior to that date are seen within the 8-week lead-up period as a Choice Appointment and offered the opportunity to take up Partnership Appointments from the go live date. For the proposed Future State Pathway this would equate to the SALTs Assessment process being conducted for all Children and Young People currently on a waiting list within a pre-agreed period prior to ‘go-live’ with Psychology and Paediatrics Appointments following on shortly after.

- **Stop Referrals:** Cambridgeshire and Peterborough stopped referrals to their neurodevelopmental services during the interim period when introducing their new process and were able to reduce their waiting time of previously over three years to under eighteen weeks.

The benefits of blitzing the current waiting list with the new process is that although it may add a temporary strain on other services as resources are allocated to the ASD Assessment Pathway, it would support the recommended wider pool of professionals supporting this process to become familiar with the electronic pro-forma, the assessments and assessment process.
Future Pathway

Overview

Taking into account the information garnered from the current state value stream mapping analysis, the parent consultations, the literature review and the horizon scanning of other service provision a future state model has been suggested below. The future state model incorporates the Lean process undertaken within the pathway analysis to offer a prospective model for consideration bespoke to the current and projected needs for Calderdale.

The proposed future state value stream map is for a fully staffed and integrated service with a single First Point of Contact for all ASD referrals. This approach would benefit all Emotional Wellbeing and mental health services across Calderdale if implemented more globally.

The future state service uses active and centralised diary management systems to enable the expanded FPoC to book appointments directly into professional’s diaries upon referral and to actively manage the flow of children and young people through the ASD diagnosis pathway.

The assessments flow through the service, typically starting with SALTs, who begin the assessment and initiate an electronic proforma. This electronic proforma will be added to during subsequent assessments and will contain all the information required to inform a diagnosis.

After the SALTs assessment the child or young person will receive an appointment with a Band 7 nurse who conducts a general physical examination and systematic assessment for conditions that may coexist with autism.

After the physical examination the child or young person will receive an assessment from either an Educational Psychologist or a Clinical Psychologist.

After this the child or young person will receive an appointment with a paediatrician who will give a diagnosis to the family during that appointment. The paediatrician will refer the child onto the ASD Service and confirm the diagnosis in writing.

The ASD Service will contact the family within 7 -10 days of the diagnosis to discuss a package of interventions and support in relation to the diagnosis.

Teams of professionals will support this process with a particular focus being put on reducing the number of single points of expertise in the process. This will enable the process to operate throughout the year (where possible) and avoid single points of expertise causing bottlenecks or breaks in service due to holidays, sickness or other absence.
### Future State Process Steps (Characteristics and Rationale)

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<th>Referrals via Professional</th>
<th>Rationale</th>
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<td><strong>Characteristics</strong></td>
<td><strong>Rationale</strong></td>
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<tr>
<td>As current process</td>
<td>Influencing and educating such a wide range of referrers on the ASD Assessment Pathway would require significant effort. For most referrers the ASD Assessment Pathway is just one of many pathways that they may refer into on a daily basis. Most refers require a little knowledge about a lot of conditions.</td>
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<th>FPoC &amp; Admin Team</th>
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<td><strong>Characteristics</strong></td>
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<tr>
<td>An expanded and rescoped FPoC with the ability to support referrals for all Children and Young People’s Emotional Wellbeing and Mental Health services across Calderdale. Combining existing mental health expertise with administration functions and process ownership to create centralised coordination and oversight.</td>
<td>Incorporating administration functions within the FPoC team would create a centralised team of process and pathway experts with the ability to coordinate referrals across functional and trust boundaries. This team would handle all external communications and booking activities, chasing information etc. This would free up additional clinical time currently tied up in these activities (e.g. clinical psychology assessments take 5 hours because of booking time with teachers can be so problematic).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FPoC Referral Logged</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
<td><strong>Rationale</strong></td>
</tr>
<tr>
<td>All referrals (Early Years and School Age) would be received and logged by the FPoC Team. This timestamp would transfer across case notes systems and would represent the true time a referral entered the service/ joined the waiting list for an ASD Diagnosis.</td>
<td>Treating both early years and school age as a single pathway enables a parity of service regardless of age. Capturing all referrals ensures that there is a complete picture and understanding of volumes and waits. Currently there are hidden waits or waits that are not recorded. FPoC reported that current referrals are being triaged in FPoC for approximately 21 days, however this is not</td>
</tr>
</tbody>
</table>
incorporated into the CAMHS ASD Assessment reported wait times. In addition, CAMHS consider the Initial Screening wait time and the ASD Assessment waiting time as separate whilst to the child, young person or family they are all part of the same wait to diagnosis.

<table>
<thead>
<tr>
<th>FPoC &amp; Diary Management Coordinator Team (Role)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
</tr>
<tr>
<td>This team is responsible to allocating work, monitoring demand and ensuring that sufficient resources are allocated and available to support timely diagnosis and flow through the pathway. The leader of this team would own the value stream and be responsible for ensuring its success and driving improvements in the process aligned with the future state vision. As part of the active management of the pathway this team may initiate alternative routes through the pathway to remove blockages e.g. if there is no capacity in SALTs but free capacity in Clinical Psychology this team may choose for some ASD Assessment to begin with Clinical Psychology instead of SALT etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Active Diary Management</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
</tr>
<tr>
<td>An open book diary management system owned by FPoC but operated across services. The expanded FPoC would book referrals directly into professional’s diaries and liaise with key stakeholders (parents, teachers etc.) to book assessments etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FPoC Referral Triage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
</tr>
</tbody>
</table>
As with the existing process for school age, FPoC would triage to ensure any gaps in the referral are filled and accept or reject the referral based on its suitability.

FPoC phone the parents or guardian to confirm that the child or young person is on system and to book the child in for their first or next assessment stage:

- If the child has not had an ASD Assessment from SALT then the triage team would book the child directly into a speech and language therapists diary for an assessment.
- If the referral comes from SALTs and the assessment has already been completed and the proforma started then the triage team will book the child directly into a psychologist’s diary.

In addition, the FPoC will initiate or refer onto any additional support packages as required and will continue to offer signposting to parents (currently to Unique Ways, The National Autism Society and SENDIASS).

The current process states that the time take to process an ASD referral is dependent on where that referral has been received from. If a referral is received from the SALTs team then the child or young person will already have been assessed using GADS or GARS. Other referrals typically don’t arrive with prior assessments and so require the FPoC to conduct information gathering contact with Family, School & Other Agencies (phone). Both existing pathways state that SALT involvement is standard for children and young people either prior to assessment or later in the assessment process.

<table>
<thead>
<tr>
<th>ASD Assessment (SALT)</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics</td>
<td>Rationale</td>
</tr>
<tr>
<td>All ASD Assessments will typically begin with a SALT conducting a GADS or GARS and initiating the Electronic Proforma*</td>
<td>All school age or early years ASD Assessment includes a SALT assessment. Currently there are inconsistencies and duplication in how this occurs. For some CYP SALT will conduct a GADS or GARS assessment prior to referral and for some they will not.</td>
</tr>
<tr>
<td>This SALT Assessment is the 1st stage of the ASD Assessment and assessment information gathered here is input directly onto the electronic proforma.</td>
<td>In most instances SALT will provide input and support to the child and young person while they wait for an assessment and yet are still required to attend the Early Years Observation Sessions and use observations from that session to inform their assessment or conduct School Age Assessments (separate from the GADs/GARs).</td>
</tr>
<tr>
<td>Unless there are questions around their observations, findings or conclusions there will be no further assessment information required from the SALT team.</td>
<td>Reducing and removing rework or over-processing within the assessment process will</td>
</tr>
<tr>
<td>Depending on their findings, SALT may signpost or redirect the child or young person is determined to not be on the Autism Spectrum.</td>
<td></td>
</tr>
<tr>
<td>A team of speech and language therapists support this process to avoid single points of</td>
<td></td>
</tr>
</tbody>
</table>
expertise causing bottlenecks or breaks in service due to holidays, sickness or other absence

With FPoC active diary management all appointments and observation sessions (including travel time where applicable) will be arranged and coordinated by the FPoC Admin team, freeing up clinical resource to focus on core work.

*see FPoC & Diary Management Coordinator Team

<table>
<thead>
<tr>
<th>Physical Health Assessment</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Characteristics</strong></td>
<td>This approach is consistent with NICE guidelines.</td>
</tr>
<tr>
<td>A physical examination completed by a nurse to perform a general physical systematic health needs assessment (with supervision built into the job role) for conditions that may coexist with autism, looking specifically for:</td>
<td></td>
</tr>
<tr>
<td>• skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood’s light</td>
<td></td>
</tr>
<tr>
<td>• signs of injury, for example self-harm or child maltreatment/</td>
<td></td>
</tr>
<tr>
<td>• congenital anomalies and dysmorphic features including macrocephaly or microcephaly.</td>
<td></td>
</tr>
<tr>
<td>In addition, the nurse will consider the following based on individual circumstances; the physical examination; clinical judgment and the child or young person’s profile:</td>
<td></td>
</tr>
<tr>
<td>• genetic tests, as recommended by your regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of a learning (intellectual) disability</td>
<td></td>
</tr>
<tr>
<td>• electroencephalography if there is suspicion of epilepsy.</td>
<td></td>
</tr>
<tr>
<td>Findings from this will be added to the proforma.</td>
<td></td>
</tr>
<tr>
<td>A team of nurses support this process to avoid single points of expertise causing bottlenecks or</td>
<td></td>
</tr>
</tbody>
</table>

free up significant resource to provide input and support to children and young people.
<table>
<thead>
<tr>
<th><strong>Breaks in Service</strong> due to holidays, sickness or other absence</th>
</tr>
</thead>
</table>

**ASD Assessment (Psychologist)**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Clinical Psychologist or Educational Psychologist will conduct school observations (main process) or CDU observations (Early Years). With FPoC active diary management all appointments and observation sessions (including travel time where applicable) will be arranged and coordinated by the FPoC Admin team, freeing up clinical resource to focus on core work. A team of psychologists should support this process to avoid single points of expertise causing bottlenecks or breaks in service due to holidays, sickness or other absence.</td>
<td>This approach is consistent with NICE guidelines that state: In each area a multidisciplinary group (the autism team) should be set up. The core membership should include a: - paediatrician and/or child and adolescent psychiatrist - speech and language therapist - clinical and/or educational psychologist</td>
</tr>
</tbody>
</table>

**Appointment & Diagnosis Feedback with Paediatrician**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>A team of Paediatricians support this process to avoid single points of expertise causing bottlenecks or breaks in service due to holidays, sickness or other absence. With FPoC active diary management all appointments and observation sessions will be arranged and coordinated by the FPoC Admin team, freeing up clinical resource to focus on core work.</td>
<td><strong>Recommended by NICE Guidelines:</strong> Communication of assessment findings to the parent or carer and, if appropriate, the child or young person. Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-5 criteria. After the autism diagnostic assessment, discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers (and if appropriate, the child or young person). Explain the basis of conclusions even if the diagnosis of autism has not been reached. Use recognised good practice when sharing a diagnosis with parents, carers, children and young people.</td>
</tr>
</tbody>
</table>

**ASD Team Phone Parents to discuss Next Steps**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Rationale</th>
</tr>
</thead>
</table>
ASD Service call parents or guardians within a week to 10 days of receiving a diagnosis to answer questions from the assessment and discuss and agree a support package and next steps.

For children and young people with a diagnosis of autism, offer a follow-up appointment with an appropriate member of the autism team within 6 weeks of the end of the autism diagnostic assessment for further discussion (for example, about the conclusions of the assessment and the implications for the child or young person).

## ASD Proforma

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Rationale</th>
</tr>
</thead>
</table>
| The Electronic Proforma is created to enable each assessment to contribute to the eventual assessment in a manner that that avoids unnecessary duplication of work, and once compiled enables the Paediatrician to make an informed diagnosis. This proforma (or elements of the proforma) will be shared with parents, children and young people, the GP and other professionals involved in the ongoing support and care of the child or young person. **Discrepancies (NICE Guidance):** If there are discrepancies at any point during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, the clinician will highlight these in the Proforma and consider gathering additional information from other sources and/or carrying out further autism-specific observations in different settings, such as the school, nursery, other social settings or at home (via expanded FPoC) **Core Information Captured (NICE Guidelines):**  
- Parent's or carer’s concerns and, if appropriate, the child's or young person's concerns  
- The child or young person's experiences of home life, education and social care  
- A developmental history*  
- Assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours* |
| It has already been recognised that a standard approach to assessment is required and a proforma is being develop. In addition, FPoC use a standard Proforma at triage which is printed out in CAMHS. By expanding the Proforma to cover all stages of the new process and ensuring that the proforma can remain electronic across service providers a simplified assessment can be created that can be shared with all stakeholders, is updated immediately, requires no additional inputting, avoids unnecessary duplication and ensures a consistent approach to assessments across Calderdale. Children, young people and families; the ASD Service and those populating the proforma should all be consulted on its development and outputs. **NICE Guidelines:** Provide parents or carers, GP (and if appropriate, the child or young person) with a copy of the autism diagnostic assessment. This should explain the findings of the assessment and the reasons for the conclusions drawn. With parental or carer consent (and the consent of the child or young person if appropriate), share the profile with key professionals involved in the child's or young person's care, including those in education and social care. This is so it can contribute to the child or young person's individual education plan and needs-based management plan |
- A medical history, including prenatal, perinatal and family history, and past and current health conditions
- A profile of the child’s or young person’s strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context

*Focusing on developmental and behavioural features consistent with ICD-10 or DSM-5 criteria (consider using an autism-specific tool to gather this information)

### Estimated Costs of Service

NB: The calculations below are heavily reliant on assumptions and estimates and the information should only be viewed as indicative of the potential costs and efficiency savings.

#### Estimated total resource hours per referral

Based on the information provided, the following hours per child or young person are estimated below:

The current Early Years process is the most resource hungry at approximately 23 hours per referral, although the school age process currently only includes 2 assessments which is below to NICE guidance.

The future state process is much shorter, driven by a reduction in the number of professionals involved in the process, a reduction in the number and duration of appointments and meetings, a reduction and centralisation of administration tasks and the impact of introducing a streamlined electronic proforma.

<table>
<thead>
<tr>
<th>Role</th>
<th>Early Years Current State (hrs)</th>
<th>School Age Current State (hrs)</th>
<th>Future State (hrs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic Practitioners</td>
<td>0.3</td>
<td>0.3</td>
<td>0.3</td>
</tr>
<tr>
<td>FPoC Support Workers</td>
<td>0.5</td>
<td>5.0</td>
<td></td>
</tr>
<tr>
<td>FPoC Coordinator</td>
<td>0.8</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Assistant Psychologist</td>
<td>3.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Psychologist/ Educational Psychologist</td>
<td>3.6</td>
<td>6.8</td>
<td>3.0</td>
</tr>
</tbody>
</table>
### Estimated Total Resource Hours Per Referral

<table>
<thead>
<tr>
<th>Role</th>
<th>Band</th>
<th>Hourly Rate</th>
<th>Early Years</th>
<th>School Age</th>
<th>Future State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic Practitioners</td>
<td>Band 6</td>
<td>£15.68</td>
<td>£5.2</td>
<td>£5.2</td>
<td></td>
</tr>
<tr>
<td>FPoC Support Workers</td>
<td>Band 3 - 4</td>
<td>£9.93</td>
<td>£5.0</td>
<td>£49.7</td>
<td></td>
</tr>
<tr>
<td>FPoC Coordinator</td>
<td>Band 6 - 7</td>
<td>£16.21</td>
<td>£13.5</td>
<td>£16.2</td>
<td></td>
</tr>
<tr>
<td>Assistant Psychologist</td>
<td>Band 4</td>
<td>£10.87</td>
<td>£41.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Psychologist/Educational Psychologist</td>
<td>Band 8c</td>
<td>£31.60</td>
<td>£215.9</td>
<td>£94.8</td>
<td></td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>Band 5 - 7</td>
<td>£15.68</td>
<td>£55.9</td>
<td>£94.1</td>
<td>£47.0</td>
</tr>
<tr>
<td>Paediatrician</td>
<td>Band 9</td>
<td>£45.70</td>
<td>£271.1</td>
<td>£68.5</td>
<td></td>
</tr>
<tr>
<td>Nurse (Physical Assessment)</td>
<td>Band 5</td>
<td>£12.81</td>
<td>£33.3</td>
<td>£6.4</td>
<td></td>
</tr>
<tr>
<td>Admin</td>
<td>Band 4</td>
<td>£10.87</td>
<td>£33.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist Teacher</td>
<td>Estimated</td>
<td>£16.75</td>
<td>£59.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Development Assistant</td>
<td>Band 5?</td>
<td>£12.81</td>
<td>£45.7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Estimated Total Cost Per Referral**: £578.5, £375.3, £287.8
Estimated Cost to Deliver Assessments based on current demand

School age reported that they received 144 referrals for ASD Assessment in 2017. Early Years reported that they have 42 children waiting for an assessment and a 12-month waiting list suggesting that there were 42 early years ASD referrals last year.

Current State:

Early Years = £24,297.90 (42 referrals x £579 per referral)
School Age = £54,047.43 (14 referrals x £375 per referral)
Total Cost = £78,345.33

Future State:

Total Cost = £53,534.87 (186 referrals x £288 per referral)

NB: The calculations above are based on a series of assumptions and are indicative only. The calculations are not fully costed, nor do they include training, supervision etc. In addition, they are based on professionals being 100% productive and not taking other forms of authorised or unauthorised leave.

It is strongly recommended that the professionals involved in the current process are involved in adding the detail to the future state map and challenging the time and cost assumptions to increase the accuracy of the calculations.
Appendices

Appendix 1: Local Documentation

Calderdale CCG Engagement with families, children, parents and carers Report

Autism Spectrum Condition (ASC)
Engagement with families, children, parents and carers

Report of Findings

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<td>4</td>
<td>What do we already know</td>
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<td>Engagement methods and approaches</td>
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</tbody>
</table>
1. Purpose of the report

The purpose of this report is to present the findings from a piece of engagement work with families, children, parents and carers of children with Autism. The report explains the approached used to engage people, the findings from the engagement and the questions asked to engage people.

The report provides a background to current services and also describes the findings from previous engagement.

2. Background

The provision of Children's Autism Spectrum Disorder (ASD) service in Calderdale and Kirklees needs to be reviewed, as there is increasing evidence that the current diagnostic process is not fit for purpose and waiting times are extremely long. There have been a number of MP’s letters in relation to waiting times and complaints in relation to the outcomes of the diagnostic process from individual parents. There have also been representations from parent’s groups in Kirklees suggesting the current provision is not fit for purpose.
There has been a piece of work undertaken in Wakefield to relation to redesigning ASD services. This has been done in partnership with all agencies and developed in line with the NICE guidance in relation to ASD assessment. Subsequently a proposed model has been developed to transform the ASD process in Wakefield, Wakefield CCG.

**What are the CCGs aiming to achieve?**

The CCGs are aiming to review the clinical pathway for Children’s Autism Spectrum Disorder (ASD) to identify any areas for improvement in order to deliver improved quality and value for money that improves patient outcomes.

Their objective is that the outcomes will be consistent across the delivery footprint whilst being delivered in a way that suits the differing needs of the population.

The specific tasks that now need to be undertaken for Kirklees and Calderdale are the following:

- Confirm the existing pathway for ASD, involving specific meetings with all agencies involved with ASD diagnosis.
- Review the existing ASD Pathway against the NICE guidance
- Highlight the gaps in the current pathways and model, and make clear recommendations in relation to a new model for Kirklees and Calderdale based on NICE guidance

3. **Legislation**

**Health and Social Care Act 2012**

The White Paper, ‘Equity and excellence: Liberating the NHS’, and the subsequent Health and Social Care Act 2012, set out the Government’s long-term plans for the future of the NHS. It is built on the key principles of the NHS - a comprehensive service, available to all, free at the point of use, based on need, not ability to pay. It sets out how the National Health Service (NHS) will:

- Put patients at the heart of everything it does
- Focus on improving those things that really matter to patients
- Empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services.
It makes provision for CCGs to establish appropriate collaborative arrangements with other CCGs, local authorities and other partners, and it also places a specific duty on CCGs to ensure that health services are provided in a way which promotes the NHS Constitution – and to promote awareness of the NHS Constitution.

Specifically, CCGs must involve and consult patients and the public:

- in their planning of commissioning arrangements
- in the development and consideration of proposals for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and
- in decisions affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact.

The Act also updates Section 244 of the consolidated NHS Act 2006 which requires NHS organisations to consult relevant Overview and Scrutiny Committees on any proposals for a substantial development of the health service in the area of the local authority, or a substantial variation in the provision of services.

The Equality Act 2010

Section 149 of the Equality Act 2010 states that a public authority must have due regard to the need to a) eliminate discrimination, harassment and victimisation, b) advance ‘Equality of Opportunity’, and c) foster good relations. It unifies and extends previous disparate equality legislation. Nine characteristics are protected by the Act, which are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation.

The NHS Constitution

The NHS Constitution came into force in January 2010 following the Health Act 2009. The constitution places a statutory duty on NHS bodies and explains a number of patient rights which are a legal entitlement protected by law. One of these is the right to be involved directly or through representatives:

- in the planning of healthcare services
- the development and consideration of proposals for changes in the way those services are provided, and
• in the decisions to be made affecting the operation of those services

4. What do we already know

There has been previous engagement in Calderdale on services to support children and families/carers with autism. Findings from the engagement are set out below and the key points are highlighted.

In 2013 Calderdale National Autistic Society (NAS) members reported on some of the key issues, these are highlighted below:

• **Levels of knowledge and expertise about autism**

• Parents told us how professionals did not appear to have a full understanding of autism or how to communicate with their child.

• **Access to assessment**

• Parents told us about referrals being dismissed, with parents concerns not taken seriously and/or parenting skills being questioned – also without even meeting with the child or the parents.

• Parents have been told their child cannot be assessed as they are not ‘priority case’. (What are the criteria for ‘high’ or ‘low’ priority cases, and how does this affect decisions regarding assessment for autism?)

• When a referral is dismissed, families say they are not offered any other support, nor are they signposted or referred to other services for support.

• After it has been decided that an assessment is needed, families say they are experiencing long waiting times.

• In sheer frustration some parents are opting for private assessment, although the diagnosis is not then recognised by local professionals.

• Without diagnosis families are unable to access appropriate educational support and other therapy services (e.g., the Autism Spectrum Conditions (ASCs) team).

• **Diagnosis**

• Parents have reported concerns about the quality of the assessment process.
Post assessment support and the management of autism

Parents report being discharged post diagnosis and told that Child Adolescent Mental Health Service (CAMHS) do not provide a service for children with ASCs.

Parents report that they are not signposted to the ASC team or other agencies e.g. speech and language therapy, occupational therapies for sensory needs experienced by most children with autism, or local and national support organisations.

If the assessment does not result in a diagnosis, parents say they are not offered any other support for the child and are not referred or signposted to other services.

Parents then say they are ‘passed from pillar to post’ trying to find the support they need.

From this work NAS recommended that:

All staff working within CAMHS tiers 2, 3 and 4 must have basic training in autism, and have access to specialist advice.

Specialist autism capacity is made available within all tiers 2, 3 and 4 CAMHS.

Autism appropriate tier 4 services must be available at a regional level.

Relevant health and local authority strategic planning tools record data that includes the full range of needs for children with autism, including their mental health problems.

Health and local authority commissioning must take specific account of CAMHS waiting times, rates of return and family outcomes for children with autism.

Commissioners must demonstrate their commitment to involving children and families/carers affected by autism in planning and delivering local CAMHS.

Each area to develop specific pathways for mental health support for children and families/carers with autism.

Commissioners ensure that local CAMHS have the capacity to provide 24-hour support to children and families who need it.
Four engagement events were delivered across the Calderdale and Huddersfield in 2014. Of these, one was held solely for local ASC professionals and the remaining three events were for members of the public and current service users, Voluntary and Community Sector (VCS), providers and key stakeholders. These events were held in different locations to ensure feedback was gained from across the three CCG areas. The event for Calderdale was held on Thursday 23 October at Calderdale Parents & Carers, Halifax.

More than 60 people attended the four events across the district, however Calderdale events were not well attended and so local views were lost in the engagement process. The key themes from the engagement is highlighted below:

- Local services are delivered by extremely passionate and dedicated staff.
- Participants reported that there is some satisfaction that the overall service is good once people suspected of having autism are finally seen for an assessment. Examples of good practice occurred when assessments were delivered across multi-disciplinary teams and in conjunction with school services.
- A lack of a single point of contact for families from the outset was seen as the biggest difficulty. This resulted in inconsistent services, breakdown in communications between both the service and parents and between the service and other providers in the intended pathway and ultimately delays in service provision from initial assessment through to the transition of diagnosed children through the ASC service pathway.
- Long, sometimes extended, waiting times for an assessment appointment or specific services are a frustration for families and carers. In some cases, assessment appointment took years, rather than the few months recommended by NICE quality standards for autism, to be given.
- A lack of clear pathways in general was noted as were disparities, i.e. where experience was dependent on who is assessing the child with suspected ASC.
- Participants reflected on a ‘pillar-to-post’ experience where they were referred to and from different contact points, e.g. GPs, schools, CAMHS or VCS groups.
- Some parents self-diagnose their children, leading to missed opportunities for access to services or missed diagnosed comorbidity condition.
- Lack of support for those waiting for assessment or diagnosis but also post diagnosis was noted as an aspect that does not work well in the current service, with respondents noting the need for information, support and being enabled to help their child.
- Linked to the above, respondents noted the need for professionals to ensure that children, young people and their families have the necessary information about local services to access the support they required.
- Equally, in some cases, assessment did not necessarily result in a diagnosis. This left families in an uncertain situation – no diagnosis, but child demonstrating symptoms and families having to follow this up again.
- The need for training for professionals was also noted and this was linked both to understanding conditions as well as the manner in which they communicate with service users and their families.
• A single point of contact for parents and significantly improved assessment waiting times were consistently commented on across all engagement events and in surveys.
• Transparency, and better explanation, of a functioning ASC pathway with more capacity and resources to deliver the services.
• Better working together and communication at all stages, especially with parents and between multi-agency teams.
• Awareness raising in schools through improved training for school staff.
• Awareness raising for GPs and other healthcare professionals.
• Improved communication, and hand-off, between ASC service providers, especially as children transitioned between them, e.g. Post-16+

5. Engagement methods and approaches

The approach to engagement was to use a survey which asked four questions. The intention was to gather information about the current service and listen to people’s views about the services they receive in general. This means that participants can tell us anything they want us to know and allow us to identify key themes.

The method of circulation was to deliver the survey both electronically and as part of 1:1 interviews. The survey was circulated to approximately 800 parents on the Calderdale Parents and Carers database.

In order to ensure we engaged fully we also:

• Included details of the survey on the Calderdale parents and carers bulletin
• Directly emailed those all members of Calderdale parents and carers
• Spoke to parents at coffee mornings / support groups
• Spoke to parents at the ASC coffee morning

In addition, the survey was circulated via local authority colleagues delivering services to children with autism and their families/carers and through the children and young people’s participation project to engage with young people directly.

6. Findings from the Engagement

Respondents were asked four open questions. It should be noted that some respondents provided more than one comment in their response. These are detailed below.
Thinking about your experience of the current Autism Spectrum service please tell us:

6.1 What works well?

24 participants responded to this question by providing open ended comments. The points raised included the following:

- Four respondents were unable to think of anything that worked well.
- Six respondents found the support that they got from Calderdale parents and carers/NAS helpful.
- Three respondents were happy with the support that they received from school.
- The ASC team was mentioned positively by seven respondents. Respondents valued the support that their child got in school from the ASC team – this support included helping ‘key workers to deal with certain types of behaviour’, ‘the ASC team came and gave an information session to my child’s classmates. This worked very well and coffee mornings.
- Respondents were also happy with the service they received from speech and language, the Special Educational Needs team and Central Street.
- One respondent felt that at diagnosis they ‘were treated with respect’. They went on to say:

  ‘I didn’t feel that I battled and they listened to what we were saying. All the meetings were brilliant. They all knew how to deal with my son i.e. speech and language knew what he hadn’t understood.

6.2 What could be improved?

24 participants responded to this question. Again, many respondents made multiple comments. The points raised included the following:

- CAMHS service was mentioned by nine respondents. This related to both the diagnostic process and additional support needed by their child in addition to their ASC needs.
- Waiting times were mentioned by several respondents. One child waited seven years for a diagnosis, following the initial identification of the child’s additional needs to an ASC diagnosis. It was also mentioned that there was a lack of support for both parents and children during the assessment/diagnosis process. One parents suggested that there should be:

  ‘More support for parents, children and teaching staff during diagnosis phase of autism’.  

Another respondent stated that

‘The whole process takes too long and it breaks down. I was constantly having to act as a go
between, between CDU and CAMHS. I was having to chase them.’

As one respondent pointed out, this can mean there is a lack of early intervention.

- Four respondents had negative experiences of DCT. They found it was quite difficult to
access their services due to the high threshold and restrictive criteria.
- A number of respondents stated that they would welcome support at home. Most of the
services are provided within an education setting and this means that families feel
unsupported at home. For many families, it is at home where their children have their
meltdowns.

‘You get a diagnosis and the support provided is for the school. Who do I go to if there are
issues at home? There is nobody who offers you support at home. If it was medical we would
have nurse to chat to. For example, a friend who has a child with diabetes has a diabetes nurse
to speak to if there are any difficulties’.

- Communication problems were raised by many respondents. This ranged from
communication with parents to communication between professionals.

‘Communication with CAMHS was quite dreadful. It wasn’t communicated to us that a Doctor
had left. I had to chase appointments with CAHMS for my son’s blood tests so that he could
get his prescription of ADHD medication’. [This child has ASC and ADHD]

One respondent also mentioned the problem of a language barrier, where the parent’s first language
was not English.

- Other things that respondents felt could be improved was support and training to staff in
mainstream schools [3], transition to adult services [2], provision for those who live outside
Halifax centre [1], joined up working of services [1], lack of clubs/provision for children with
ASC [1], lack of home visits during assessment process [1] and having to take children out of
school for appointments [1].
- There was one respondent that was disappointed with CAMHS as there was no reciprocal
arrangement in place for their foster child who had been fostered from outside of
Calderdale.
6.3 Is there anything else you would like to tell us about your experience of the service?

Participants were invited to specify anything else that they would like to tell us about the services. 21 participants responded to this question. Again, many respondents made multiple comments. The following were raised:

- ‘CAMHS is shocking and offer medication with no other services’.
- Respondents felt that they were passed around from one to service to another with no one taking responsibility.
- There was concern that cost cutting was reducing the services that were available and that the voluntary sector had to fill the void.
- Support disappears as children get older.
- The waiting time was too long. One child reached five during the assessment process and was then passed from the Paediatrician/CDU and placed on another waiting list for CAMHS which meant the wait for assessment started again.
- Two respondents mentioned the need to keep telling your story again and again. This gets very frustrating for parents.

‘Having to tell your story 30 times. It is emotionally draining to have to go through everything again and again. The frustration that creates....Life is hard with a child with additional needs and then you have to battle with services....At every appointment you are constantly having to prove what you need and fight for what needs to be in place’.

- One respondent felt very uncomfortable during the assessment process as she had to discuss her son’s negative behaviour in front of him. She felt ‘uncomfortable and awful for him.
- One respondent had a child who had a high level of anxiety, which had resulted in self-harming and Urticaria, but did not meet the threshold for CAMHS.
- If children do receive support in school from outside agencies, i.e. occupational therapy, it is not always fed back to parents.
- Respondents are also concerned about what services will be available to their child once they have left school.
- There were positive comments about support following diagnosis

‘we were given a six-month window to speak to (name removed) and he did reassure us many times’ and ‘they were very helpful at Central Street. You felt supported’.

- One respondent stated that they have no services and the only help they get is from special school. Comments about the school were very positive

‘[As parents] we feel disappointed, let down, not believed and unsupported. It has taken us a year to get school to accept that our daughter needs support. When they contacted the ASC team, they were reportedly told that they were unable to become involved because they were already running at full capacity and did not have the necessary resources. It felt very cold, like we were being carried along on a conveyor belt. The whole process seemed very ‘medical’
with our daughter having to fit into tick boxes (we were openly told that “she doesn’t tick enough boxes to get a diagnosis”.

- Difficulty if your child is schooled outside Calderdale [in Kirklees]. The child is not able to attend an ASC social group as he isn’t on the system for Calderdale ASC team.
- Another respondent had a positive experience but did state that:

  ‘The diagnostic process was long, but not as long as others have [nine months]. Whilst I was doing the Insider’s Guide I met other parents who really struggled to get a diagnosis. I think having a ‘Looked After Child’ meant that things were pushed forward when he needed extra support’.

- There were comments that services didn’t always look at the impact on the rest of the family:

  ‘We have had to continually fight for funding i.e. short breaks through the panel. They don’t look at how it affects the rest of the family. We have three hours of short breaks but I have to travel there on public transport and it gives little time for me and my other child to spend time together.’

6.4 Thinking about the future what would a good service look like?

24 participants responded to this open-ended question and the suggestions on how a service could be improved going forward included the following:

- Ensure families can access the support needed i.e. Disabled Children’s Team
- Flexible direct payments including overnight.
- Listening to the voice of parents and ensuring a good support network for families.
- Ensure that school staff have a basic understanding of ASC
- ‘A good service would need to be very proactive getting the information out to possible users about the support available’.
- Services need to available across the whole of Calderdale, not just central Halifax.
- ‘Support for parents at home such as having a link worker to off load to, explain worries to, signpost to services, help with creation of visual timetables, suggest strategies’.
- A single point of contact/a named contact/ a single point of access/phone support
- People believing parents.
- More person centred/child centred. Tailored to the individual needs of the child and the family.
- ‘It would be based clearly on the social model of disability and demonstrate clear understanding of how autism/Asperger Syndrome presents in girls.’
- ‘Good communication, honesty and transparency’.
• Providing support for those who are undergoing assessment and do not yet have a diagnosis.

7. **Equality and Diversity**

Out of the 24 people who responded to the questionnaire, 22 people completed or partially completed equality monitoring forms. The forms have been analysed and the data is available, the equality monitoring form is also included (see Appendix 2).

The overall findings from the equality monitoring forms were that:

- There were much fewer men
- Lesbian, gay and bisexual people were not represented
- There were a number of carers who completed the survey one to one, but this was not recorded for those who undertook the survey online

The questionnaire was aimed at and intended to and engage a broad range of people, representative of protected groups. From the completed responses received and one to one interviews delivered the findings do not fully reflect current service users.

68% of the respondents were female and 18% were male. 13% preferred not to say.
42% respondents were Christians, whilst 47% stated they had no religion. 5% were Muslim.
95% of the respondents were White British and 5% were Asian – Pakistani

8. Overall findings and common themes

The emerging themes for the engagement work are;

- Communication – it was felt that there was a general lack of communication. This included communication between services which meant that there was no ‘joined up’ working; communication with parents – informing them of services available and what services their child may be accessing through school.

- Waiting time for assessment/diagnosis. There was a consensus of opinion that the waiting times were too long. During this time there is no support for the child or family.

- Families would welcome support at home. The current support that most children receive is education/school based. The ASC team will work with children about issues that may present themselves at home, but this is generally for a specific piece of work. Parents are very satisfied with the support they do get from the ASC team. There are many issues in families with siblings and there is no support available.

- The support from the ASC team is really valued by families. However, this is only available to those who have a diagnosis. For those who do not have a diagnosis or are undergoing the assessment procedure this is felt to be a gap. Parents feel that they are left in a black hole and ‘that gap is torture’.

- Respondents only want to have to tell their story once. By joining up services and sharing information with health and social care organisations and the third sector

- Provide basic training/awareness of ASC for mainstream school staff including lunchtime supervisors/play supervisors

- Access to support and advice from fully skilled and trained workers and acknowledging that parents and carers could also be up skilled and trained

9. How the findings will be used and next steps
The findings from the engagement activity will be added to any existing engagement which has already taken place in Calderdale. The feedback from this and any other engagement activity will be used to inform and develop future services.

This will include:

- Sharing the report of findings from the engagement at a commissioners’ workshop in December 2015.
- Use the findings to inform the future service specification for ASC services.
- Provide feedback to families, children, parents and carers on the outcome of the engagement activity and the next steps.
Appendix 2: Value Stream Mapping

Value Stream Mapping and how to read a Value Stream Map

Value stream mapping is a paper and pencil tool that helps you to see and understand the flow of material and information as a product or service makes its way through the value stream. Value stream mapping is typically used in Lean, it differs from the process mapping of Six Sigma in four ways:

- It gathers and displays a far broader range of information than a typical process map.
- It tends to be at a higher level (5-10 boxes) than many process maps.
- It tends to be used at a broader level, i.e. from receiving of raw material to delivery of finished goods.
- It tends to be used to identify where to focus future projects, subprojects, and/or kaizen events.

A value stream map (AKA end-to-end system map) takes into account not only the activity of the product, but the management and information systems that support the basic process. This is especially helpful when working to reduce cycle time, because you gain insight into the decision-making flow in addition to the process flow.  

Reading the Value Stream Map

The Value Stream Map starts in the top right-hand corner with the family

Follow the flow of information from right to left as the family move through various providers and professionals until their child’s referral is received as an ASD Assessment referral

Follow the journey of the child and young person’s referral from arriving as an ASD Assessment Referral to an outcome being received (bottom left to bottom right)

The boxes represent core processes or handoffs in the process (both value-adding and non-value-adding). The information within the boxes relates to

71 https://www.isixsigma.com/dictionary/value-stream-mapping/
School Age Current State Map

School Aged+ ASD Assessment – Current State Value Stream Map (Updated 01/03/18 based on FPoC Feedback)
Early Years Ideas, Questions and Opportunities

The below table lists the ideas, questions and improvement opportunities identified during and after the value stream mapping exercise. During the initial value stream mapping exercise, we were able to assign a control and impact to the improvement opportunities that were identified.

<table>
<thead>
<tr>
<th>Pre-Assessment</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>The team felt that additional visits to children at home/setting prior to assessment may aid the assessment decision making process.</td>
<td>High</td>
<td>Low</td>
<td><strong>Reject proposal:</strong> Although this would add further insight and would help add additional information to the assessment it would add extra processing time rather than reducing waiting times.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing time allocated to staff to support the Complex Communication Process to reduce waits</td>
<td>Low</td>
<td>High</td>
<td><strong>Accept:</strong> The proposed future state will deliver a number of efficiency savings that will make the process more effective. However, the process is reliant on it being sufficiently resourced.</td>
</tr>
<tr>
<td>Ensure that there is cover for staff holidays – currently if a critical member of the team is away or absent the assessments do not happen.</td>
<td>Low</td>
<td>High</td>
<td><strong>Accept:</strong> It is strongly recommended that significant consideration is given to the multiple ‘single points of expertise’ that currently exist within the pathways. It is essential to the pathway’s resilience that it does not rely on individuals with a particular interest but rather becomes a part of a number of professionals shared responsibility.</td>
</tr>
<tr>
<td>Provide an all year-round service. Currently the service conducts Complex Communication Assessments during term time only</td>
<td>Low</td>
<td>High</td>
<td><strong>Accept:</strong> Whilst school observations can only be conducted during term time, there is no reason whilst all other aspects of the pathway can’t remain operational throughout the year.</td>
</tr>
<tr>
<td>Is there an opportunity to do achieve a faster turnaround from referral to assessment if those that were more obviously on or not on the autism spectrum received a diagnosis earlier in the process? For example, if the</td>
<td>High</td>
<td>Medium</td>
<td><strong>Hold:</strong> This proposal is not included within the final future state map; however, this may provide additional efficiency savings once the future state has been achieved.</td>
</tr>
</tbody>
</table>
Paediatrician is able to diagnose autism during the initial meeting, why leave that child and family waiting a year to conduct a time consuming observational assessment that simply confirms what was already known? This would reduce the number of children requiring the observational assessment which would reduce their wait times also. Concerns were raised over quality and equity.

<table>
<thead>
<tr>
<th>There appears to be more professionals involved than are required by NICE best practice guidelines. Only using the 3 that are required would free up resource to support the process elsewhere.</th>
<th><strong>Accept:</strong> This has been incorporated within the future state map</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the service provides assessments during term time only then only allow leave during school holidays</td>
<td><strong>Hold:</strong> This proposal is not included within the final future state map as the future state is a year-round service; however, if the decision is made to keep the ASD Assessment process to term time only then it is recommended to consider changing contracts to only allow staff to take holiday during school holidays to avoid further disruption to the pathway.</td>
</tr>
<tr>
<td>Is there an opportunity to video the observation sessions – this could aid recollection and be a record that could be used in place of extensive notes recording the detail of the session. Allowing those writing up their findings to focus on diagnosis and recommendations and less on evidencing their decision?</td>
<td><strong>Hold:</strong> This proposal is not included within the final future state map; however, this may provide additional efficiency savings once the future state has been achieved.</td>
</tr>
<tr>
<td>Use returned Proformas rather than F2F meeting with other professionals. The current process requires any number of professionals to attend and contribute to the post observational meeting. Is this an expensive luxury</td>
<td><strong>Accept:</strong> This has been incorporated within the future state map</td>
</tr>
</tbody>
</table>
and could it be replaced by a proforma submitted by professionals prior to the assessment?

Currently 91% of assessments produce a decision with the remaining 9% requiring a second assessment later. Is one in ten not receiving an outcome an acceptable failure rate or are their improvements that could be made to improve that number?

Is this a Gold Standard Process and is that required? The Early Year team appear to provide an assessment involving many different professionals and provide a bespoke and nuanced for every assessment. This is extremely time-consuming and expensive. If the time-quality-cost triangle is considered, where each is a competing factor that adversely affects the others (e.g. a faster process will typically either be at extra cost or at the expense of quality) have the Early Years team got the balance right? In the absence of any significant new money and with a 1 year wait, would families prefer a less nuanced time-consuming assessment quicker or would they rather wait for the current offering?

<table>
<thead>
<tr>
<th>Report Writing and Output</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whilst time is required to write up findings, the decision regarding the diagnosis is made on the day of observations. Rather than make the parents or guardians wait an additional 10 days, there is an opportunity to provide feedback and diagnosis on the day. This will simplify the process, enable feedback to be given whilst the case is fresh in the minds of the professionals and allow the phone call</td>
<td>High</td>
<td>High</td>
<td><strong>Accept:</strong> This has been incorporated within the Future State Map</td>
</tr>
</tbody>
</table>
to parents to occur after the report is compiled.

Currently reports are typically written up at home in the professional’s own time. The team felt that having time allocated within their role to write reports was more appropriate.

Feedback sessions are currently 45 minutes. There was felt to be an opportunity to reduce the time taken/allocated for feedback sessions to 30 min

Reviews to run parallel to feedback sessions

What are the opportunities to simplify and expedite the assessment process for those children certain to get a diagnosis? Is there an opportunity to double up feedback for children who are certain to get a diagnosis? Concerns were raised over quality and equity of a fast track service

<table>
<thead>
<tr>
<th>Whole</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase Resources/ Staff Capacity to better meet demand (more time needed)</td>
<td>Low</td>
<td>High</td>
<td>Accept (in conjunction with the efficiency savings identified within the future state map)</td>
</tr>
<tr>
<td>The service should be commissioned &amp; acknowledged within CHFT &amp; Calderdale Council</td>
<td>Low</td>
<td>High</td>
<td>Accept</td>
</tr>
<tr>
<td>Official agreements in place i.e. contracts in relation to time allocated to support the Complex Communication Assessment process</td>
<td>Low</td>
<td>High</td>
<td>Part-Accept: Official Agreements should be to provide sufficient staff to achieve service levels rather than a set amount of resource agreed up front</td>
</tr>
<tr>
<td>Succession planning needed. The process needs a skilled workforce and there are a number of single points of expertise currently within the process</td>
<td>Low</td>
<td>High</td>
<td>Accept: It is strongly recommended that significant consideration is given to succession planning and the multiple ‘single points of expertise’</td>
</tr>
</tbody>
</table>
that pose an additional risk to the process. That currently exist within the pathways. It is essential to the pathways resilience that it does not rely on individuals with a particular interest but rather becomes a part of a number of professionals shared responsibility.

Better relationship and knowledge sharing (about the process & CDS) between CHFT and the LA, High, Low, Accept

It was mentioned that other areas within the country have dropped providing ASD Assessments altogether. What would be the impact of NOT assessing EY children? There is a package of support already offered to early years children prior to assessment. If that support continues then saved resource could be reallocated to the support the school age assessment process. In addition, by the time these children were assessed there would be significantly more prior professional involvement and knowledge which would make the school age assessment easier.

Reject as not consistent with NICE Guidelines nor the stated wishes of parent, carers and service users. Adopting a multi-agency pathway support model based on needs would potentially reduce focus on assessment/diagnosis if support offered all along the pathway.

What would be the impact of agreeing a consistent approach between both ASD assessment providers (CDS & CAMHS), Low, High, Accept the future state is for a single assessment model that cuts across boundaries and delivers some economies of scale and increased flexibility.

School Age Ideas, Questions and Opportunities

The below table lists the ideas, questions and improvement opportunities identified during and after the value stream mapping exercise. During the initial value stream mapping exercise, we were able to assign a control and impact to the improvement opportunities that were identified.

<table>
<thead>
<tr>
<th>Referrals</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrals could be reduced if there was a greater understanding and awareness</td>
<td>Low</td>
<td>Medium</td>
<td>Hold: Not included within the proposed future state, however</td>
</tr>
</tbody>
</table>
of ASD, as a disorder and its various presentations, across the wider Calderdale workforce opportunities to educate referrers should be exploited. Many professionals require a little knowledge on a lot of subjects, and while it would benefit the process for there to be a greater understanding across referrer groups, it may prove impractical to due to how they are distributed and variety of potential referrers into the service.

It would benefit children and young people if there was Increased ASD Training for Schools so CYP would not have to wait for a diagnosis before the school was implementing appropriate support packages and reasonable adjustments. Many professionals require a little knowledge on a lot of subjects, and while it would benefit the process for there to be a greater understanding across referrer groups, it may prove impractical to due to how they are distributed and variety of potential referrers into the service.

<table>
<thead>
<tr>
<th>FPoC Triage</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shortages within the FPoC team were identified as an area that if addressed would be of high impact and would speed up the process.</td>
<td>Low</td>
<td>High</td>
<td><strong>Accept:</strong> In the future state the FPoC team is grown and its role would be significantly expanded to incorporate administration; diary management; workload coordination and value stream management.</td>
</tr>
<tr>
<td>There is currently no opportunity to see the child within the current FPoC referral process. There is phone-based consultancy that occurs within the triage process and although face to face may be preferable it was felt it would add little additional benefit to the process.</td>
<td>Medium</td>
<td>Low</td>
<td><strong>Reject:</strong> This is not required in the future state.</td>
</tr>
<tr>
<td>If a joint referral is received for both SALTS and FPoC these get rejected until SALTS have assessed for ASD. The SALTS assessment the Child or Young Person receives is significantly more thorough and robust than the FPoC triage process so there are good reasons why FPoC may wait for this assessment. However,</td>
<td></td>
<td></td>
<td><strong>Accept:</strong> This has been incorporated into the future state so that all referrals will receive a SALT assessment early in the process.</td>
</tr>
</tbody>
</table>
this means that the eventual wait to assessment will be greater for those children referred to SALTS and FPoC than those referred directly to FPoC only.

SALTs assessments use GADS/GARS assessment tools, however no other referral source conducts sufficient assessment prior to referral. If non-SALTs referral then parents and school are contacted by FPoC and asked questions relating to the ‘Triad of Impairments’

Accept: A consistent approach is required so that all children and young people receive an assessment based on their needs and not on the route into the pathway.

An electronic proforma based around ‘Triad of Impairments’ has been created by the FPoC team. This proforma is completed by FPoC and sent to CAMHS via the weekly Review Meeting but because they work off different systems this is printed out by CAMHS and updated manually.

Accept: An electronic proforma available to all assessors and key professionals in its original form is required in the future state. In addition, it is essential that electronic systems are able to communicate to each other where there are different systems operating.

If all case notes systems could communicate better the proforma could remain an electronic document which would improve record keeping and traceability and could reasonably be expected to help speed up the process through the removal of unnecessary rework.

Accept: Service level agreements should be established across all providers. These would be actively monitored and managed by the expanded FPoC team and reported to commissioners quarterly or by exception if there was a breach. In addition, internal thresholds should be established with contingency plans to avoid breaching service level agreements.

There is no SLA established between FPoC and CAMHS.
Currently reported ‘Wait to Assessment’ times start at point triaged referral is passed from FPoC to CAMHS and not the point the CYP is referred into FPoC - This is driven by lack of communication between 2 provider organisations case notes systems but creates an additional hidden wait that is experienced by the CYP and their family.

Accept: Reported waits must begin at the point of the referral being received into FPoC and end at the point the family are given the outcome of the assessment. This will more accurately reflect the service users experience and will avoid hidden waits. Waits between individual steps in the process should be known and actively managed by the expanded FPoC to ensure the achievement of a ‘wait to assessment’ target of within 3 months

<table>
<thead>
<tr>
<th>Initial ASD Screening</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
</table>
| There are a range of screening activities that currently occur between FPoC ASD Review Meeting and the Waiting List sift. This includes:  
• Meetings with parents  
• Gilliam scale (GARS)  
• School Observations  
There is already work underway looking at avoiding this unnecessary rework, but it is unclear at moment what percentages could avoid elements of this so it is difficult to determine if the impact of this change will warrant the effort to implement. |  |  | Accept: The proposed future state aims to remove all duplication from the assessment process |
| Why do we do this process at the beginning and repeat it at the end as data is out of date? Could this be moved to become part of final assessment. Unclear what benefit this stage gives the process. |  |  | Accept: The proposed future state aims to remove all duplication from the assessment process |
| The delay between FPoC ASD Review Meeting and Waiting List Sift is currently 8 weeks. What would this delay look like if the extended triage is dropped because sufficient information |  |  | Accept: The proposed future state aims to remove all duplication from the assessment process |
exists to move the child or young person directly onto the waiting list?

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>It would aid the Assessment Process if the child or young person’s</td>
<td>High</td>
<td>High</td>
<td><strong>Accept:</strong> It is anticipated that an electronic Proforma would contain this</td>
</tr>
<tr>
<td>development history was available in a standardised semi-structured and</td>
<td></td>
<td></td>
<td>information in a manner that enabled as quick as possible a population of key</td>
</tr>
<tr>
<td>computerised format.</td>
<td></td>
<td></td>
<td>information.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>This may link into the challenges faced by FPoC with their electronic proforma</td>
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<td></td>
</tr>
<tr>
<td>There is currently no Paediatrician on the MDT. The group felt that</td>
<td>Medium</td>
<td>High</td>
<td><strong>Accept:</strong> The future state requires that a paediatrician is one of 3 standardised</td>
</tr>
<tr>
<td>although there needed to be a ‘doctor’ on the MDT they advised that</td>
<td></td>
<td></td>
<td>assessments that contribute to the final diagnosis/non-diagnosis.</td>
</tr>
<tr>
<td>NICE guidance suggest that this could be a Paediatrician or a Psychologist</td>
<td></td>
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<tr>
<td>and doesn’t have to be a Paediatrician.</td>
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<tr>
<td>Use Autism Diagnostic Observation Schedule (ADOS) as part of the</td>
<td>Medium</td>
<td>High</td>
<td><strong>Part Accept:</strong> The future state is consistent should be built around a</td>
</tr>
<tr>
<td>standard assessment process. The current process is if there is no</td>
<td></td>
<td></td>
<td>standardised diagnosis criteria and standardised process for diagnosis. This may</td>
</tr>
<tr>
<td>agreement at MAT meeting then the ADOS will be used.</td>
<td></td>
<td></td>
<td>be ADOS although this would require further investigation and agreement across</td>
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<td></td>
<td></td>
<td></td>
<td>parties.</td>
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<tr>
<td></td>
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</tr>
<tr>
<td>How are complex cases managed and assessed: LD, Attachment, ADHD –</td>
<td>Medium</td>
<td>High</td>
<td><strong>Accept:</strong> This assessment process should be available where possible to all</td>
</tr>
<tr>
<td>Comorbidity shouldn’t always exclude ASD.</td>
<td></td>
<td></td>
<td>regardless of potential comorbidity.</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>More professional resources need to reduce waiting times. Taking into</td>
<td>Low</td>
<td>High</td>
<td><strong>Accept</strong> in conjunction with the efficiency savings identified within the</td>
</tr>
<tr>
<td>account improvement opportunities, it was felt by the group that</td>
<td></td>
<td></td>
<td>future state map</td>
</tr>
<tr>
<td>under-resourcing was the single biggest hurdle to improving wait to</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>assessment times and addressing this would have the single biggest impact</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>upon wait times</td>
<td></td>
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</tbody>
</table>
The additional resources to support the assessment process could be somewhat addressed by all members of the MDT being integrated into one team (trust) - SALT, Psychiatry, Psychology and Educational Psychology etc. integrating all involved into one trust would reduce complexity, remove rework, enable better tracking of referrals and reporting of true wait times and provide economies of scale.

| Reintegrate Educational Psychology back within the Multidisciplinary Team and Assessment Process. Could the Clinical Psychology Assessment be replaced by an Educational Psychology Assessment? | Low | Medium | **Part Accept**: Sufficient psychology resource is required to support this process. Educational Psychologists are a resource that should not be discounted from this process. NICE Guidance states the multidisciplinary group should include a:
- paediatrician and/or child and adolescent psychiatrist
- speech and language therapist
- clinical and/or educational psychologist |

| The agreed process for Calderdale school years Autism Assessments is for 3 professionals to conduct separate assessments and to feed this into a Multi-Agency Team meeting. In reality only 2 assessments per child or young person are currently being conducted. This is reportedly because Paediatrics are from a separate trust which have begun charging for support and so are no longer supporting the process. | Low | High | **Part Accept**: The future state does not dictate whether this pathway should be provided by a single trust or multiple trusts, rather a commitment by services to a multi-agency, integrated approach. However, all barriers to seamless team working must be removed and a consistent service provided to all. Currently the involvement of three separate providers and two assessment processes represent a significant challenge. **Accept**: The future state is for each child to be seen and assessed by three professionals (SALTs; Psychology and Paediatrics) |
The team suggested the Core assessments required were:
- Clinical Psychology Assessment
- Medical Assessment (Paediatric or Psychiatrist)
- SALTS Assessment

The grade of professionals conducting assessments is based on the grades of professionals within the team rather than because that is the banding required. It was felt that a team of lower grade professionals could support this process and would cost less. E.g. Clinical Psychology assessment current being completed by an 8c but could be done by Band 6

It was stated during the meeting that although the assessments take place these assessments are not recorded in writing or otherwise as there is insufficient time. This could pose a significant compliance risk as professionals will be unable to provide any evidence of why a decision is made if it is challenged

The stakeholder group felt that assessments needed at least 3 professionals to give wider perspective. This was raised in relation to the revelation that currently only 2 people contribute to the MDT Assessment and neither is a Paediatrician

Accept: Services should be commissioned and paid for based on the most appropriate level for the work required.

Accept: Observations and findings must be written up. It is proposed that the Proforma will enable much of the report writing to happen during or directly and quickly after an appointment.

Accept: The future state is for each child to be seen and assessed by three professionals (SALTs; Psychology and Paediatrics)

<table>
<thead>
<tr>
<th>Outputs</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>The team felt that providing training for practitioners or supervision for people working with ASD would be high impact.</td>
<td>Medium</td>
<td>High</td>
<td>Initially Hold but given priority need Accept: Although not included within the proposed future state for the ASD Assessment pathway this activity is needed as a priority (previous and current consultation outcomes and proposal of FPoC/ CAMHS staff needs) and will be...</td>
</tr>
</tbody>
</table>
Currently the team provide a yes/no answer as the key output of the assessment. This is different to the more nuanced output from the Early Years Process. The team felt that providing a greater differentiation of diagnosis, more clinical detail/pointers or advice to services following MDT assessment would be highly impactful. However, this would be more time consuming and resource heavy than current processes and could not be implemented without further damaging already significant wait times or requiring additional resources.

Families would like more information from Assessment on what next and less information on what we did. Early Years tend to provide long reports with lots of ‘what we did’, school age tend to provide yes/no diagnosis with little detail.

<table>
<thead>
<tr>
<th>Post Assessment</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAMHS could offer post diagnosis treatment:</td>
<td>Medium</td>
<td>High</td>
<td><strong>Out of Scope</strong>: Out of scope of this review although efforts should be made to fill any gaps in services available post assessment and contained in recommendations</td>
</tr>
</tbody>
</table>
| • Medical  
• Psychological  
• Behavioural | | | |
| Working more closely with other agencies who work with ASD (Training/research & Development) | Medium | Medium | **Accept**: The future state is based around borderless working and a clear understanding of the processes customers (children and young people; ASD service; schools and GPs etc.) |
| Offer an enhanced (new) specialist support for families, CYP, school & other agencies as part of overall | Low | Medium | **Out of Scope** of this review but contained in recommendations due to the significance of need |
| process (post assessment) e.g. band 6 nurse |  | across the system and in CAMHS; although efforts should be made to fill any gaps in services available post assessment. |
| Psychiatry not commissioned to provide post diagnostic ASD care |  | Out of Scope of this review but an opportunity for resource development |
| School still required to apply for support |  | Accept: With parental or carer consent (and the consent of the child or young person if appropriate), the ASD Service should contact the school and other key professionals involved in the child's or young person's care |

<table>
<thead>
<tr>
<th>Whole</th>
<th>Control</th>
<th>Impact</th>
<th>Proposed Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is clear that even with making improvements to the existing process there are not enough staff to support the current demand and assessment process. However:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>- Where are more staff needed?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Where are higher trained/skilled staff needed?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- What can lower skilled staff do?</td>
<td>Medium</td>
<td>High</td>
<td>Accept in conjunction with the efficiency savings identified within the future state map</td>
</tr>
<tr>
<td>Increased capacity across the board.</td>
<td>Low</td>
<td>High</td>
<td>Accept in conjunction with the efficiency savings identified within the future state map</td>
</tr>
<tr>
<td>All aspects of the process – from triage, screening, MDT assessment to be done by one unitary team – currently undertaken by Northpoint, SWYFT &amp; CHFT</td>
<td>Low</td>
<td>High</td>
<td>Part Accept: The future state does not dictate whether this pathway should be provided by a single trust or multiple trusts. However, all barriers to seamless team working must be removed and a consistent service provided to all. Currently the involvement of three separate providers and two assessment processes represent a significant challenge</td>
</tr>
<tr>
<td>Clinical Psychologist only working 1.5 days per week creates a single point of expertise and is insufficient to support the assessment process.</td>
<td>Accept: It is strongly recommended that significant consideration is given to the multiple ‘single points of expertise’ that currently exist within the pathways. It is essential to the pathways resilience that it does not rely on individuals with a particular interest but rather becomes a part of a number of professionals shared responsibility.</td>
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<td></td>
</tr>
<tr>
<td>Process doesn’t make sense that there are different processes and waits for Early Years and School Age</td>
<td>Accept: The future state is for a single pathway for all children and young people</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can this process be simplified / shortened for CYP who are obviously on the Autism spectrum?</td>
<td>Hold: This proposal is not included within the final future state map; however, this may provide additional efficiency savings once the future state has been achieved.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*ADOS-G: Autism Diagnostic Observational Schedule - Generic: The ADOS-G is a semi-structured assessment of communication, social interaction, and pervasive developmental disorders (PDD). The ADOS-G consists of standard activities that allow the examiner to observe the occurrence or non-occurrence of behaviours that have been identified as important to the diagnosis of autism and other pervasive developmental disorders across developmental levels and chronological ages. The ADOS provides data from direct observation of the subject's behaviour. Based on the individual's behaviour, the subject will be found to meet either the cut off for Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) or the cut off for Autism.  

<table>
<thead>
<tr>
<th>Changes</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appt with Paediatrician Booked</td>
<td>Create a single point of contact that triages and administers the value stream to provide consistency to the assessment process regardless of age of child or young person or service provider</td>
</tr>
<tr>
<td>Incorporated within ‘FPoC &amp; Diary Management Coordinator Team’ role</td>
<td></td>
</tr>
<tr>
<td>Appointment with Paediatrician</td>
<td>It appears that the current initial Paediatrician screening assessment may be an unnecessary screening process as the review team were advised that the Paediatrician always agrees to Complex Communication Assessment?</td>
</tr>
<tr>
<td>The initial meeting with the Paediatrician is moved to after SALTs and Psychology Assessments and replaces the Paediatrician’s current involvement in the observation sessions.</td>
<td>The Paediatrician conducting an initial assessment and being involved in the observation session or means that Paediatrics are involved in 2 separate assessments for ASD. This is extra processing and reducing this to one will free up expensive resource to support the school age process.</td>
</tr>
<tr>
<td>Monthly Planning (Review of Names)</td>
<td>Assessment bookings and request for information handled by FPoC so this stage is not required.</td>
</tr>
<tr>
<td>Not included within Future State Map</td>
<td></td>
</tr>
<tr>
<td>3 weekly Planning (Request for Info)</td>
<td>Additional information is requested as part of the FPoC Triage Process for school age assessments. Expanding this process to cover all ASD referrals will provide an economy of scale with the administration tasks and provide a consistency of approach.</td>
</tr>
<tr>
<td>Incorporated within ‘FPoC &amp; Diary Management Coordinator Team’ role</td>
<td></td>
</tr>
<tr>
<td>Contact Parents (1 day out)</td>
<td>Expanding this process to cover all ASD referrals will provide an economy of scale with the administration tasks and provide a consistency of approach.</td>
</tr>
<tr>
<td>Incorporated within ‘FPoC &amp; Diary Management Coordinator Team’ role or replaced with automated text reminders</td>
<td>Automating this process so text messages are triggered one day out from all appointments would free up additional resource.</td>
</tr>
<tr>
<td>Joint Observation Sessions:</td>
<td>Joint observation sessions will become an exceptions process where the information required to make an assessment cannot be obtained by individual assessments as per future state core process.</td>
</tr>
<tr>
<td>• Team Briefing (Pre- Appt)</td>
<td></td>
</tr>
<tr>
<td>• Complex Coms. Assessment</td>
<td></td>
</tr>
<tr>
<td>Activity</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Exceptions process</td>
<td>Not required unless part of exceptions process. If required the meeting will consist of 2 professionals rather than 6. Exceptions process will involve Psychologist and Paediatrician rather than 6 professionals as SALT assessment will occur prior to this meeting and only 3 professionals are required (NICE Guidelines) to reach a diagnosis. Freed up resource can be utilised in offering additional support for children or young people.</td>
</tr>
<tr>
<td>Joint Observation Sessions</td>
<td>Not required. FPoC will request additional information from professionals (see ‘3 weekly Planning (Request for Info)’ above) Additional professionals will only be involved in ASD assessments if there are gaps or discrepancies (as per NICE Guidance) see future state ‘ASD Proforma’ characteristics. Freed up resource can be utilised in offering additional support for children or young people.</td>
</tr>
<tr>
<td>Report Writing</td>
<td>Time required to write reports significantly reduced by Proforma. Core information updated during assessments or potentially automatically via dictation software or by FPoC Admin team via audio recordings from professionals. Freed up resource can be utilised in offering additional support for children or young people.</td>
</tr>
<tr>
<td>Compile Reports</td>
<td>Not required. Proforma incorporates all information into a single electronic document that requires no additional compilation.</td>
</tr>
<tr>
<td>Lead Reviews Report</td>
<td>Not required/ incorporated within individual professional’s preparation for conducting their element of the assessment. This step existed so that the Paediatrician could refamiliarize themselves with the case prior to meeting with the family to provide a diagnosis or otherwise from the completed report. As a diagnosis is provided by the Paediatrician immediately after they have completed their final assessment there is no requirement to refamiliarize themselves.</td>
</tr>
<tr>
<td>Feedback to Parents (F2F)</td>
<td>Streamlined version incorporated within Future State Process. Feedback is provided by the paediatrician immediately after they have completed their final assessment rather than by 2 professionals as per current process.</td>
</tr>
<tr>
<td>Phone Parents</td>
<td>Incorporated into the core Future State Process but reassigned to ASD Team. Best Practice value add that is designed to answer any questions that parents may have and should be rolled out across all ASD Assessments in Calderdale.</td>
</tr>
</tbody>
</table>
By reassigning to the ASD Team, they can answer any questions the family may have about Autism and the diagnosis, as well as talk about available support and next steps*.

*see ASD Service: Information and support

<table>
<thead>
<tr>
<th>ASD Team Support</th>
<th>Out of scope of the review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incorporated within Future State Map</td>
<td></td>
</tr>
</tbody>
</table>

### Changes to Process (School Age)

<table>
<thead>
<tr>
<th>Changes</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Early Years</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Changes</strong></td>
<td><strong>Rationale</strong></td>
</tr>
<tr>
<td>FPoC Referral Logged</td>
<td>Create a single point of contact that triages and administers the value stream to provide consistency to the assessment process regardless of age of child or young person or service provider</td>
</tr>
<tr>
<td>Incorporated into the core Future State Process</td>
<td></td>
</tr>
<tr>
<td>FPoC Referral Triage</td>
<td>The future state takes a predefined structure of assessments based around a prescriptive gate keeping system: FPoC (triage); SALT (assessment); Physical Health (assessment); Psychology (Assessment); Paediatrics (Assessment). No weekly meetings to review ASD referrals are scheduled although discussions may occur on a case by case basis</td>
</tr>
<tr>
<td>Incorporated into the core Future State Process</td>
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<tr>
<td>FPoC ASD Review Meeting</td>
<td></td>
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<tr>
<td>Part incorporated within the expanded FPoC process</td>
<td></td>
</tr>
<tr>
<td>Initial Screening</td>
<td>Already identified by the service as unnecessary and a duplication of work elsewhere in the value stream</td>
</tr>
<tr>
<td>Not included within Future State Map</td>
<td></td>
</tr>
<tr>
<td>Sift Waiting List (Prioritisation)</td>
<td>Single process for all referrals. Any amendments to that process due to prior professional involvement will be determined by the Enhanced FPoC team</td>
</tr>
<tr>
<td>Not included within Future State Map</td>
<td></td>
</tr>
<tr>
<td>Assessment Request (10 - 12 weeks out)</td>
<td>Active diary management coordinated by the FPoC team negates the need for clinicians to manage and arrange</td>
</tr>
<tr>
<td>Not included within Future State Map</td>
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</tr>
</tbody>
</table>
their own meetings and schedules; freeing up clinicians to concentrate on clinical work

**ASD Assessment (Clinical Psychologist)**
Incorporated into the core Future State Process

One of 3 core ASD assessments recommended by NICE guidance

**ASD Assessment (SALT)**
Incorporated into the core Future State Process

One of 3 core ASD assessments recommended by NICE guidance

**ASD MAT Assessment Meeting**
Not included within Future State Map

With a proforma created where each assessment builds upon the findings of the previous professional there will be no need for a MAT Assessment unless there are discrepancies or contradictory findings

**School Contact ASD Team**
Not included within Future State Map

ASD Service call parents or guardians within a week to 10 days of receiving a diagnosis to answer questions from the assessment and discuss and agree a support package and next steps. The ASD Team will aim to gain parental (and if appropriate, child or young person) consent to contact the school to agree any necessary support.

**ASD Team Intervention**
Incorporated within Future State Map

Out of scope of the review

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**ASD Service: Recommended Information and support package**

<table>
<thead>
<tr>
<th><strong>ASD Service: Information and support</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide children and young people with autism, and their families and carers, with information about autism and its management and the support available on an ongoing basis, suitable for the child or young person's needs and developmental level. This may include:</td>
</tr>
<tr>
<td>• contact details for local and national organisations that can provide:</td>
</tr>
<tr>
<td>o support and an opportunity to meet other people, including families or carers, with experience of autism</td>
</tr>
<tr>
<td>o information on courses about autism</td>
</tr>
<tr>
<td>o advice on welfare benefits, rights and entitlements</td>
</tr>
<tr>
<td>o information about educational and social support and leisure activities</td>
</tr>
<tr>
<td>o information about services and treatments available</td>
</tr>
<tr>
<td>o information to help prepare for the future, for example, transition to adult services.</td>
</tr>
<tr>
<td>• Make arrangements to support children and young people with autism and their family and carers during times of increased need, including major life changes such as puberty, starting or changing schools, or the birth of a sibling.</td>
</tr>
<tr>
<td>• Explore with children and young people with autism, and their families and carers, whether they want to be involved in shared decision-making and continue to explore these issues at regular intervals. If children and young people express interest, offer a collaborative approach to treatment and care that takes their preferences into account.</td>
</tr>
</tbody>
</table>
• Offer children and young people with autism support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.
Appendix 4: NICE Benchmark

<table>
<thead>
<tr>
<th>NICE Guidance</th>
<th>Pre School Service - evidence</th>
<th>School Age Service - evidence</th>
</tr>
</thead>
</table>
| The assessment within 3 months of the referral to the autism team | No - waiting time of approx. one year | No waiting time of approx. 3 years  
Wait newly referred first screened via ADS pro forma - wait 6 months  
Multi agency list is beyond 3 years |
| A case coordinator in the autism team should be identified | Not formally identified. The Psychologist currently coordinates care. | |
| **Autism diagnostic assessment:** | | |
| detailed questions about parent's or carer's concerns and, if appropriate, the child's or young person's concerns | Collated as part of the assessment process | Collated as part of the assessment process |
| details of the child's or young person's experiences of home life, education and social care | Collated as a part of the assessment process | Yes, collated as part of the assessment process. Visit and/or information from education contributes to the assessment process |
| a developmental history, focusing on developmental and behavioural features consistent with [ICD-10](https://www.who.int/classifications/icd/en/) or [DSM-5](https://www.psychiatry.org/patients-and-families/dsm) criteria (consider using an autism-specific tool to gather this information) | Collated within initial screening and assessment process | Yes. Collated as part of the information gathering element of the assessment process. Psychologist undertakes as part of full assessment if not already undertaken. |
| assessment (through interaction with and observation of the child or young person) of social and communication skills and | Undertaken at initial assessment appointment as part of paly based assessment | Observations arranged as required in school or within clinic setting. |
behaviours, focusing on features consistent with ICD-10 or DSM-5 criteria (consider using an autism-specific tool to gather this information)

<table>
<thead>
<tr>
<th>Item</th>
<th>Undertaken at initial screening assessment</th>
<th>No Paediatric input into assessment process currently. Will incorporate health related reports. Will take a history from family</th>
</tr>
</thead>
<tbody>
<tr>
<td>a medical history, including prenatal, perinatal and family history, and past and current health conditions</td>
<td>Undertaken at initial screening assessment</td>
<td>No Paediatric input into assessment process currently. Will incorporate health related reports. Will take a history from family</td>
</tr>
<tr>
<td>a physical examination</td>
<td>Undertaken at initial screening assessment</td>
<td>As above. Not undertaken.</td>
</tr>
<tr>
<td>consideration of the differential diagnosis</td>
<td>Yes</td>
<td>Yes. Key part of the assessment process.</td>
</tr>
<tr>
<td>systematic assessment for conditions that may coexist with autism</td>
<td>Yes, as part of assessment process</td>
<td>Yes. Key part of the assessment process.</td>
</tr>
<tr>
<td>development of a profile of the child's or young person's strengths, skills, impairments and needs that can be used to create a needs-based management plan, taking into account family and educational context</td>
<td>Yes, referrals to relevant support services undertaken at initial screening and Family Support Plan undertaken as part of assessment</td>
<td>No diagnostic letter sent to parents/carers. Letter addresses potential issues around diagnosis and maps DSM criteria to that consideration</td>
</tr>
<tr>
<td>communication of assessment findings to the parent or carer and, if appropriate, the child or young person.</td>
<td>Yes, feedback meeting with parent/carer and letter</td>
<td>Yes, diagnostic outcome letter sent to parents and relevant professionals</td>
</tr>
<tr>
<td>Perform a general physical examination and look specifically for: skin stigmata of neurofibromatosis or tuberous sclerosis using a Wood's light signs of injury, for example self-harm or child maltreatment/congenital anomalies and dysmorphic features including macrocephaly or microcephaly.</td>
<td>As part of initial screening assessment by Paed</td>
<td>No without a medical input currently</td>
</tr>
<tr>
<td>Do not routinely perform any medical investigations as part of an autism diagnostic assessment, but consider the following in individual circumstances and based on physical examination, clinical judgment and the child or young person's profile:</td>
<td>As part of initial screening assessment by Paed</td>
<td>No medical input</td>
</tr>
</tbody>
</table>
genetic tests, as recommended by your regional genetics centre, if there are specific dysmorphic features, congenital anomalies and/or evidence of a learning (intellectual) disability electroencephalography if there is suspicion of epilepsy.

| If there are discrepancies during the autism diagnostic assessment between reported signs or symptoms and the findings of the autism observation in the clinical setting, consider: gathering additional information from other sources and/or carrying out further autism-specific observations in different settings, such as the school, nursery, other social settings or at home | As part of initial screening assessment by Paed | Observation within another setting is arranged if required as part of the pathway. To be reviewed at a later stage - is part of the process if unsure of diagnosis or discrepancy occurs this is built into plan of care as outlined in the CAMHS ASD flowchart. |

**Diagnosis**

| Use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-5 criteria. | Yes, from initial screening, child play based observation session, feedback with parents carers and multi-agency / multi professional input | Yes, SALT assessment, Paed and other professional report if available. |

| After the autism diagnostic assessment, discuss the findings, including the profile, sensitively, in person and without delay with the parents or carers (and if appropriate, the child or young person). Explain the basis of conclusions even if the diagnosis of autism has not been reached. Use recognised good practice when sharing a diagnosis with parents, carers, children and young people. Provide parents or carers (and if appropriate, the child or young person) with a written report of the autism diagnostic assessment. This should | Planned feedback session with parents/ carers arranged as part of the assessment process Information offered of support services as part of Family Support Plan and written report outlining elements of diagnostic assessment given to parents / carers and child’s network with permission from parents/ carers. | Final outcome / decision meeting occurs with the professionals and parents. Diagnosis outcome letter sent to parents/ carers Information shared to relevant professionals and GP Child is discharged from CAMHS unless ongoing work within CAMHS team. |
explain the findings of the assessment and the reasons for the conclusions drawn. Share information, including the written report of the diagnostic assessment, with the GP.
With parental or carer consent (and the consent of the child or young person if appropriate), share the profile with key professionals involved in the child’s or young person’s care, including those in education and social care.
With parental or carer consent and, if appropriate, the consent of the child or young person, make the profile available to professionals in education (for example, through a school visit by a member of the autism team) and, if appropriate, social care. This is so it can contribute to the child or young person’s individual education plan and needs-based management plan.

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<thead>
<tr>
<th>Diagnosis not autism spectrum disorder: child is referred them to appropriate services based on their profile.</th>
<th>As above - according to level of need with or without a diagnosis</th>
<th>Child is discharged from CAMHS unless ongoing work within CAMHS team. Referred to other services as appropriate</th>
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<tbody>
<tr>
<td>Diagnosis uncertain: Consider keeping the child or young person under review, taking into account any new information. If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary): continued uncertainty about the diagnosis disagreement about the diagnosis within the autism team</td>
<td>As above</td>
<td>There is a review process outlined in the assessment pathway Child is discharged from CAMHS when second opinion/alternative assessment required. Second opinion generally requested from parents not clinician-based requests.</td>
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</tbody>
</table>
disagreement with parents or carers, or if appropriate the child or young person, about the diagnosis
a lack of local access to particular skills and competencies needed to reach a diagnosis in a child or young person who has a complex coexisting condition
a lack of response as expected to any therapeutic interventions provided to the child or young person.

| Autism spectrum disorder diagnosed | Child referred to ASD school team with permission from parents/carers. Seen within six-week timeframe
Information on support services offered as part of Family Support Plan
Information about another support services offered | No.
No post diagnostic service available for specialist CAMHS perspective. Discharge at the point of diagnosis unless already open for pre-existing issue within tier 3 CAMH
Child referred to ASD school team with permission from parents/carers. Seen within six-week timeframe
School aged service hold a database of school aged children. ASD team with link in with the school if requested by the school.

| Information and support | Information on support services offered as part of Family Support Plan
Further support offered as part of referral to LA ASD Team | Further information offered by giving information about Unique Ways service (formerly Parents and Carers) offer information, advice, support, advocacy and training for parents and carers of children with any kind of additional need.

Provide children and young people with autism, and their families and carers, with information about autism and its management and the support available on an ongoing basis, suitable for the child or young person's needs and developmental level. This may include:
contact details for local and national organisations that can provide:
support and an opportunity to meet other people, including families or carers, with experience of autism
information on courses about autism
advice on welfare benefits, rights and entitlements
information about educational and social support and leisure activities
information about services and treatments available
information to help prepare for the future, for example, transition to adult services.
Make arrangements to support children and young people with autism and their family and carers during times of increased need, including major life changes such as puberty, starting or changing schools, or the birth of a sibling.
Explore with children and young people with autism, and their families and carers, whether they want to be involved in shared decision-making and continue to explore these issues at regular intervals. If children and young people express interest, offer a collaborative approach to treatment and care that takes their preferences into account.
Offer children and young people with autism support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.

Information pack being developed to be sent to all families
Information resources, services for children and families both locally and nationally.
## Appendix 5: Action Plan

### Calderdale Review of ASD CAMHS Service Action plan

**Progress key:**

<table>
<thead>
<tr>
<th>Not commenced</th>
<th>Action commenced</th>
<th>Action completed</th>
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<table>
<thead>
<tr>
<th>No.</th>
<th>Action</th>
<th>How it is delivered?</th>
<th>Person responsible / Lead</th>
<th>Progress</th>
<th>Comments/ detail re progress</th>
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<tbody>
<tr>
<td>1</td>
<td>Development of the Commissioning Process:</td>
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<td>1.1</td>
<td>It is essential that the delivery of both the ASD Assessments and the ongoing programme of support are explicitly commissioned using clear integrated commissioning processes</td>
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<td>1.2</td>
<td><strong>Data Driven Decision Making:</strong> Data and management information must be routinely, accurately and consistently collected across all provider organisations (health and local authority) to enable the development, implementation, ongoing maintenance and fully accountable and transparent commissioning.</td>
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<td>1.3</td>
<td><strong>Fully Funded and fully resourced ASD Assessment Process:</strong> In conjunction with undertaking the opportunities to reduce waste within the system it is essential that the team responsible for delivering the pathway is sufficiently funded and resourced to meet current and future demand.</td>
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<td>1.4</td>
<td><strong>Single Core Assessment Pathway within an integrated team:</strong> Agree a single assessment pathway that will simplify communication processes, balance waiting times and deliver a more equitable service regardless of age. Bring together the early years and school age services as one pathway under one caseload coordinator to enable improved economies of scale as resource is pooled. It is not necessary for this pathway to be operated by a single provider, although it must be operated in a seamless and boundary-less way that has the wider team integrated and able to work in an open and</td>
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1.5 **Development of an accountable process:** The pathway development includes a quantifiable process to continue to identify and measure activity and resource allocation to ensure a cost-effective service.

1.6 **Integrated ASD Assessment and Intervention Pathway:** The initiation of the package of support from the ASD Service should be incorporated into the assessment process to ensure a seamless transition along the pathway from assessment to support.

1.7 **Signposting and External Support:** Signposting and additional packages of support should form part of the pathway and be made in a consistent and timely manner based on the needs of the child or person and their family.

1.8 **Simplified Assessment Process:** Agree a simplified assessment process based on NICE guidance that
removes duplication and unnecessary professional involvement.

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<tr>
<th>20</th>
<th><strong>Workforce Development:</strong></th>
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<tr>
<td>2.1</td>
<td>Undertake a comprehensive training needs analysis and subsequent training programme that is targeted at ensuring there is sufficient knowledge and expertise across the whole system to support children with ASD and their families with awareness, identification, assessment, support and therapeutic interventions within a Thrive/ tier less system framework.</td>
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</tbody>
</table>

| 2.2 | All workforce development to be underpinned by a whole system staff competency framework in relation to working with children, young people with ASD and their families. |

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<thead>
<tr>
<th>3.0</th>
<th><strong>Team Re Design</strong></th>
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<tr>
<td>3.1</td>
<td><strong>Proactive Caseload Management:</strong> Allocate a single point of responsible (non-clinical) for proactively managing the pathway and matching resources to demand to support timely diagnosis and flow</td>
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3.2 **Single Subject Matter Experts and Succession Planning:** Currently single points of expertise are causing multiple bottlenecks and leaving the process vulnerable to absence and attrition. It is essential that the core assessment roles within the pathway are shared across a number of individuals.

3.3 **Diary Management:** Centralise triage and administration functions to create a team of process and pathway experts with the ability to coordinate referrals across functional and trust boundaries. This team would handle all external communications and booking activities, chasing information etc. which will free up additional clinical time currently tied up in these activities.

3.4 **ASD Assessment Proforma:** Utilise an electronic proforma, consistent with nice Guidance/ DSM 5/ ICD 10 to cover all stages of the new process that can be shared with all stakeholders. The
**3.5 Sequentially Scheduled Professional Involvement:** SALT, Physical, Psychological and Paediatrics assessments conducted in a logical order based on how to best build an understanding of the child or young person, professional availability and cost, and ensuring the right professional is available at the right time for the child and young person and their family.

**3.6 Physical Health Examination:**
Introduce a nurse led physical examination after the SALT ASD Assessment to perform a general physical examination and systematic assessment for conditions that may coexist with autism or may be misdiagnosed as Autism.
| 3.7 | **Diagnosis:** Combine the Paediatrician ASD Assessment with the communication of assessment findings to the parent to remove unnecessary additional delay |