



NATIONAL
CHILDREN'S
BUREAU



COUNCIL
FOR DISABLED
CHILDREN

LIIA

LONDON
INNOVATION &
IMPROVEMENT
ALLIANCE



Collaborative Commissioning, Creative Support

By Caroline Coady and Sorrel Norwood

September 2022



Table of contents

Executive Summary	3
Introduction	7
Methodology	9
Phase 1: Quantitative data gathering and understanding the context	9
Phase 2: Qualitative data gathering – exploring the current system	11
Phase 3: Co-develop options and recommendations	12
Understanding the cohort of children and young people	13
Children and young people's experiences	15
Birth – Infancy (0–4)	15
Childhood (5–11)	16
Adolescence (12–15)	18
Approaching Adulthood (16–18)	19
Developing a shared vision for London	20
Developing commissioning options for London	22
Prevention	22
Managing emerging crisis	24
Supporting young people with the most complex needs	31
Recommendations	33
Appendices	38

Executive Summary

Context

The Council for Disabled Children (CDC), part of the National Children's Bureau (NCB), were commissioned by the London Innovation and Improvement Alliance (LIIA) to carry out research to understand the needs of and provision for children and young people with Autism, a Learning Disability and/or Social, Emotional and Mental Health (SEMH) need who are also Looked After Children or at risk of significant family breakdown and/or unplanned hospital admission. It is particularly pertinent in light of the financial challenges that high-cost low incidence (HCLI) needs are creating for local authorities nationally and the implications on the outcomes for children and young people. The purpose of this work was to develop potential commissioning options and recommendations that prioritise both prevention of avoidable crisis, and better support for children and young people who present in crisis at services across the system to inform phase 2 of this work.

Methodology

This research involved delivery of a three-phase methodology, involving both quantitative and qualitative elements and culminating in this final report.

Quantitative data was gathered through an analysis of the existing Pan-London Snapshot developed by LIIA and the CDC SEND Data Dashboard; twelve individual reviews of children's journeys; a review of Service Mapping Tools across a sample of representative London boroughs; three virtual focus groups with key stakeholders, including parent carers and; a virtual co-production workshop.

Key findings

Understanding the cohort of children and young people

- **Variation and disproportionality** – Following our review of available data sets we found significant variation of the prevalence of autism and SEMH needs across the region. It is possible these variations are indicative of wider discrepancies in the identification and diagnostic pathways for children and young people in this cohort. It may also reflect wider challenges with interpretation of presentations, leading to ethnic disproportionality in the identification of SEN.
- **EHCPs** – There is clear increasing demand for new EHCPs in London, particularly for the 5–10-year-old cohort who represent 49% of new plans. The majority of new requests are for children and young people attending mainstream schools (78%).
- **Key shared characteristics** – The data on young people attending residential special schools in the Pan-London snapshot highlighted that they were overwhelmingly male, typically placed during adolescence, and disproportionately from racialised backgrounds. It is likely that these findings are indicative of the wider cohort of children and young people with these needs in London.
- **Gaps in the data** – There are significant gaps in our knowledge about this cohort of children and young people, particularly related to their intersecting needs and their engagements with other services such as CAMHS. There is a clear need to develop new mechanisms to collate and share locally held data on a regional and/or ICS footprint to inform analysis and commissioning models.

Children and young people's experiences

- **Birth-Infancy (0-4)** – Children and young people are seen by many professionals at this stage of their lives, however the opportunities for early intervention and multi-agency support are often not acted on. For those with identified needs, the available services for support before the age of 5 such as short breaks are limited and sometimes only accessible through a social work assessment. There is also a critical lack of information and support for the whole family.
- **Childhood (5-11)** – As children progress into childhood there should be greater opportunities for cross-agency intervention, with education taking a leading role. However, children often go undiagnosed or are on long waiting lists for support precluding the capacity for holistic engagement. For young people who do receive an EHC plan at this time, there are still barriers to securing engagement from health and social care. During this time children and young people also experience a critical escalation point at the step up to secondary school, which is noted as a significant escalation point by stakeholder across the system where there is a lack of appropriate wrap around support to mitigate risk.
- **Adolescence (12-15)** – there is a recognised risk of increasing escalation during adolescence as our data analysis highlight the average age at placement to a residential special school was 13. This risk is particularly high for young people who have not received a formal diagnosis and whose families are struggling to access the necessary support. Additionally, although there are some measures for access to support (such as Annual Health Checks for young people with LD over 14) these are not well utilised and represent a missed opportunity for support. For young people who are accessing support, there are also challenges with the arbitrary limits set on these services.
- **Approaching Adulthood (16-18)** – A lack of alignment between Children's and Adult's Services and late engagement with planning for adulthood is undermining the need to support young people to build independence as they approach adulthood.

Developing a shared vision

- There is a need to codify a shared vision on outcomes for this cohort of children and young people at a regional level to support equity of experience across London. Developing shared principles and key ways of working across London will enable the region to build commissioning options which are able to focus on both prevention and crisis management, thereby improving sufficiency, value for money and outcomes for children.
- This shared vision should build on the model of care set out in the Lenehan Review (2017), 'Good intentions, good enough?' which highlight the key elements of an effective service for this cohort of children and young people.



Developing commissioning options for London

Prevention

- **Early identification of need** – opportunities for developing frontline staff to identify behaviour and presentations early, including an understanding of masking, is critical to ensure children and young people access the right support as early as possible.
- **Diagnosis** – significant waiting times and delays to entering the diagnostic pathway are preventing joined-up support being made available to families before the reach crisis.
- **Cross-agency engagement** – siloed working across the key agencies involved in children and young people's lives is preventing effective cross agency collaboration or appropriate information sharing.

Managing emerging crisis

- **Exclusions and school placement breakdown** – these can be traumatic for children and young people and compound existing challenges they may be facing due to unmet needs. Emphasis needs to be placed on tracking attendance issues early and considering the role of neurodiversity in unexplained absences to enable appropriate support to be put in place.
- **The role of other agencies** – multi-agency intervention is critical to managing crises and can support effective de-escalation and there is a need to build on existing best practice in this area across London.
- **Risk and accountability** – the move to the ICS model provides new and important opportunities to re-establish accountability lines across key partners. Additionally, the roll out of the Keyworker function will support effective crisis management and multi-agency approaches to risk.

Supporting children and young people with the most complex needs

- For some young people, the complexity of their needs means they will always need access to residential support. There will also always be young people who do reach crisis and need an emergency placement as a result. To keep these children and young people safe in the placements that they need we need to ensure sufficiency, value and appropriateness of placements across London. This will require ongoing work between LIIA, the Pan-London Commissioning Programme and providers across London to manage evolving demand across London.

Recommendations

In order to develop a pan-London commissioning approach that meets the needs of this cohort of children, we have suggested a series of comprehensive recommendations.

Recommendation 1 – Identify and engage key partners across London at a regional, ICS and local level who should be engaged in phase 2 developments and potential related finance streams.

Recommendation 2 – Develop a data and evidence strategy for London to ensure accurate information on the needs of children and young people and the sufficiency of suitable provision that can inform future commissioning for this group of children.

- Develop a comprehensive data dashboard containing data across education, health and care to underpin development of regional and ICS level strategy across London.
- Develop an approach to identification and monitoring of children and young people who may need cross-agency support through an integrated pathway.
- Undertake a pan-London review of the available provision as part of a provision sufficiency and gap analysis, with the direct engagement of providers.

Recommendation 3 – Identify potential regional, ICS and LA commissioning approaches to improve sufficiency, suitability and quality of interventions and provision for this group of children.

- Based on the output from recommendation 2, identify regional commissioning priorities and seek opportunities to influence ICS strategy development in relation to this group of children and young people.
- Develop and disseminate knowledge and understanding of what works for children and young people with Autism and Learning Disabilities and/or SEMH.
- Engage with providers to improve their confidence in developing targeted new and innovative provision.

Recommendation 4 – Strengthen the approach to workforce development and sufficiency.

- Explore opportunities to integrate findings on workforce and sufficiency related to Learning Disability and Autism into wider LIIA workstream on workforce.

Recommendation 5 – Identify opportunities for broader integration with wider work across London and nationally in relation to this group of children and young people.

Introduction

The Council for Disabled Children (CDC), a part of the National Children's Bureau (NCB), was commissioned by the London Innovation and Improvement Alliance (LIIA) to undertake research into needs and provision for children and young people with Autism, a Learning Disability and/or Social Emotional and Mental Health (SEMH) needs, who are also Looked After Children or children at risk of significant family breakdown and/or unplanned hospital admission. This work is part of the Pan-London Placements Commissioning Programme, which was established by ALDCS to improve sufficiency. This piece of work sits within the context of the financial challenges that local authorities are facing due to high-cost, low incidence placements nationally, and ongoing issues with a provider-led market. Isos' Under Pressure report highlights a growing pressure of children and young people with high-cost low incidence (HCLI) needs, requiring more specialist provision¹. Recent data also shows a clear rising demand for services as well as a growing prevalence of Autism and SEMH in London², putting additional pressure on a system which is already struggling and not facilitating consistent and well-managed de-escalation for children and young people reaching crisis.

'Data published by the DfE shows that nationally the percentage of children with EHCPs or on SEN support whose primary need is autism grew from 8.8% in 2016 to 10.3% in 2018. In Inner London, however, the rate grew faster and from a higher level rising from 9.9% to 12.7%. In Outer London the trend was slightly less marked but still above national averages, growing from 9.3% to 11.1%. One borough described how over 40% of the EHCPs they issued last year were for ASD with complex needs and that the waiting time for an autism diagnosis was now 2 years.'

In line with findings in the Under Pressure report, CDC's Director Dame Christine Lenehan's review, *These are our children* (2017)³, identified a failure to provide appropriate support and care early to a small group of children in each local area, leading to out-of-borough residential placements as the perceived long-term solution. The current financial system 'appears to reward crisis but disincentivises early intervention' (Lenehan, 2017). Many of the same contextual and demographic factors are seen across both children's social care and SEND. These children are impacted by both geography and capacity, often resulting in being separated from their families, with no effective assurance or monitoring in place to bring them back home.

As part of this review, Lenehan also recommended that practical action should be taken by Government Departments to make the system better able to co-ordinate care, support and treatment for children and young people with complex needs (and behaviour that challenges) involving mental health needs and learning disabilities and/or autism. One of the specific recommendations that came out of this report was the development of an effective model of care for this cohort of children, particularly post-ATU (Assessment and Treatment Unit). The report also acknowledges that the facilitation of this would require the engagement of the Department for Education, Transforming Care Partnerships, the Association of Directors of Children's Services, and the Local Government Association.

1 Isos Partnership, *Under Pressure: an exploration of demand and spending in children's social care and for children with special educational needs in London*, 2019

2 Council for Disabled Children, *SEND Data Dashboard*, 2022

3 Dame Christine Lenehan, *These Are Our Children*, 2017

'In order to provide the range of support needed there needs to be ownership underpinned by clear joint commitment at the highest level with cross-agency agreements on access to the service, costs and funding.'⁴

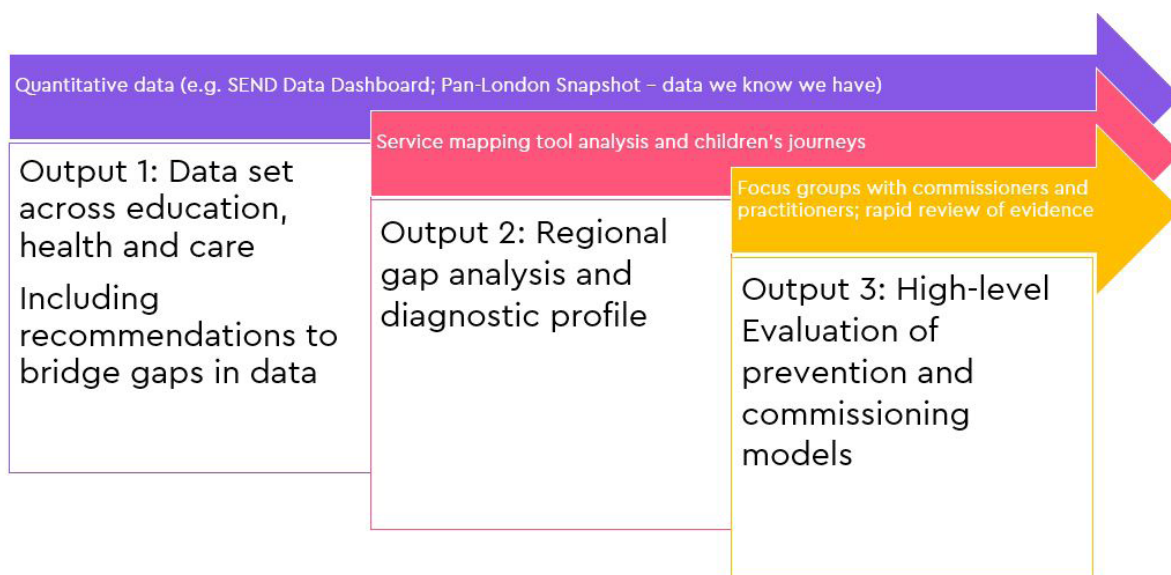
This all points to the need for improved commissioning options that prioritise both prevention of avoidable crisis, and better support for children and young people who present in crisis at services across the system. The focus of this project was therefore to develop commissioning options and recommendations that will improve outcomes for this cohort of children and young people.

4 Ibid

Methodology

This project was designed to explore possible collaborative commissioning options children and young people who have Autism, a Learning Disability and/or SEMH and who are Looked After Children or children at risk of significant family breakdown and/or risk of unplanned hospital admission.

This involved delivery of a three-phase methodology, involving both quantitative and qualitative elements culminating in a final report, which is described in detail below.



Phase 1: Quantitative data gathering and understanding the context

Preliminary Data Analysis

As part of the quantitative data gathering, evidence was analysed and interrogated from two key sources. The first was the Pan-London Snapshot, developed by the Pan-London Commissioning Programme, which holds data on placements commissioned across London. The second was CDC's existing 0–25 Multi-agency SEND Data Dashboard which includes a range of national datasets and enables comparisons of local area and region-level data across agencies. Where possible we sought to triangulate the data from these two sources with other publicly available SEND specific datasets to identify any trends or gaps in the data.

CDC intended to analyse child level data in the existing Pan-London snapshot, on the top quartile by cost of placement. This was originally designed to be supplemented by an analytical framework to identify answers to some key variables such as race, gender identity, socio-economic status, country of origin/language, and predictive factors, including when issues first emerged. However, there were significant barriers to accessing the full breadth of data required.

Challenges with accessing data

The first challenge was that there were critical missing fields in the child level data provided through the Pan-London Snapshot that prevented some of our lines of analysis. This included primary or wider needs and diagnoses, socio-economic status, gender identity and country of origin/language. We did attempt to receive this additional data from Local Authorities directly, however without a pre-existing DPIA agreement this proved challenging to secure within the timeline of the project.

Furthermore, some of the national data will not be updated in the timeline of this project and that which exists may be up to and including 2019. Whilst this is challenging it also means that any concerns related to data being skewed due to the pandemic will be mitigated. We have continued to triangulate data and focus group feedback as it becomes available/published to ensure trends and themes identified are relevant to the current context.

Consequently, the Steering Group agreed to accept the limitations of the current data with a view to CDC developing clear recommendations and an approach to future phases of this work building on the dynamic sufficiency project work ongoing in the region. Child-level analysis was completed based on the Pan-London Snapshot for those in residential special school as a proxy in the absence of data on needs, triangulating this with relevant data from the SEND Data Dashboard.

Developing a Sample of LAs

Although the quantitative data had clear gaps, it informed the development of a framework to define a representative sample of local authorities across two primary criteria to approach in the next phase (Figure 1). The sample was also balanced in terms of size, deprivation, commissioning partnerships, Inner/Outer London and ethnic diversity. This ensured that we could use qualitative data to supplement our initial analyses, including by enabling us to explore individual cases across the breadth of the system.

Rates of looked after children		% SEND with ASC/SEMH higher than national av. ⁵		
		Low	Medium	High
	High	Hackney	Greenwich (ASC) Croydon (ASC) Hammersmith and Fulham (ASC) Lambeth (ASC) Lewisham (ASC) Southwark (ASC)	Haringey (ASC) Islington (ASC) Barking and Dagenham (SEMH)
	Medium		Bromley (SEMH) Enfield (SEMH) Hillingdon (ASC) Hounslow (SEMH) Newham (ASC) Bexley (ASC)	Tower Hamlets (SEMH) Wandsworth (SEMH) Sutton (ASC)
	Low	Ealing Harrow Havering Redbridge Brent (ASC)	Kingston upon Thames (ASC) Richmond upon Thames (ASC) Merton (SEMH) Waltham Forest (ASC) City of London (SEMH) Westminster (SEMH)	Barnet Camden (SEMH) Kensington and Chelsea (ASC)

Figure 1 – Sampling Framework Table

⁵ In this table a High rating refers to Autism and SEMH above nat. average or Autism or SEMH above nat. average and the other is at least equal to nat. average. Medium refers to either measure above the and other below; both at the nat. average. Low refers to Autism and SEMH below; one below and one equal to.

Phase 2: Qualitative data gathering – exploring the current system

Phase 2 consisted of the qualitative fieldwork activity which included:

Individual Case Reviews

A reflective sample of children's profiles were developed following our initial data analysis and as set out in the table below (Figure 2).

Gender and age at placement	Status
Male aged 13-16 (x6) With ASD/LD or SEMH	Accessing Community Support
	On DSR
	In placement (Tier 4 or residential)
Male aged 8-10 (x3) With ASD/LD or SEMH	Accessing Community Support
	On DSR
	In placement
Female aged 13-16 (x3) With ASD/LD or SEMH	Accessing Community Support
	On DSR
	In placement
Female aged 8-10 (x3) With ASD/LD or SEMH	Accessing Community Support
	On DSR
	In placement

As a result, the journeys of 12 children (Appendix 3), from 11 of the 15 sample local authorities, were mapped and illustrated anonymously to explore the experience of the system for children, young people and families. This included three young people on their local Dynamic Support Register (DSR), five young people accessing community support and four young people with experience of either a residential or inpatient setting.

Figure 2 – Profile samples for individual case reviews.

An initial analytical framework was developed (Appendix 2) for professionals from each of the sample authorities to complete through an online survey and this was followed up with conversations with the lead practitioner who completed the submission, predominantly social workers or children's commissioners, to pick up any gaps in data where necessary. This survey was disseminated to the DCS of each sample authority who then cascaded it to the relevant teams to complete.

Services/Pathway audit

To supplement the children's journeys, we also carried out a services/pathway audit focused on developing a clearer picture of current service provision and the pathways that this cohort follow across London. There were two key stages including:

- The dissemination of a spreadsheet to local commissioners within the sample local authorities across the region to map the systems in the local areas for identifying and meeting needs of children with Autism, a Learning Disability and/or SEMH who are at risk of hospital admission or residential placements, and the current service offer in place in their local area. We received nine completed tools back.

- Three virtual focus groups with key stakeholders (including Operational Practitioners, Strategic Practitioners and Parent Carers) to gain a range of perspectives on the strengths, gaps or developments in provision which could best support this cohort. For the professional groups, this included an initial presentation on the Serious Case Review 'David' to frame the context of the work.

Colleagues in the Steering Group and LIA supported us to co-recruit participants for the focus group sessions.

Phase 3: Co-develop options and recommendations

After collecting the qualitative and quantitative data, a development workshop was delivered with representatives from 3 local authorities where effective practice had been identified through the work strands above, as well as other regional colleagues and parent carer representatives. Attendees of this workshop included:

- Parent Carers
- Social Workers and Team Managers
- Children's Commissioners
- Autism Lead – NHSE LD&A Programme
- Improving Quality Lead – NHSE LD&A Programme
- Head of Youth Offending Service
- Children with Complex Needs Service Lead

The workshop focused on bringing together senior leaders, commissioners, parent carer representatives who participated in the previous focus groups, service managers and members of London ASD/LD/Tier 4 Steering Group to develop a shared vision, share reflections on positive local interventions and to test emerging recommendations from the analysis for the final report.



Understanding the cohort of children and young people

In order to define and map trends in need across the region, analysis of data held in the SEND data dashboard was carried out at national, regional and local level as well as analysis of the pan-London snapshot. Findings were triangulated with relevant national datasets to set out what is known about this cohort of children and young people and to explore effective data indicators and gaps in data to inform the development of a framework of indicators for a regional dataset across education, health and care [see appendix 1].

Figure 3 below sets out the regional variation in prevalence of Autism, LD and SEMH based on the SEND data dashboard.

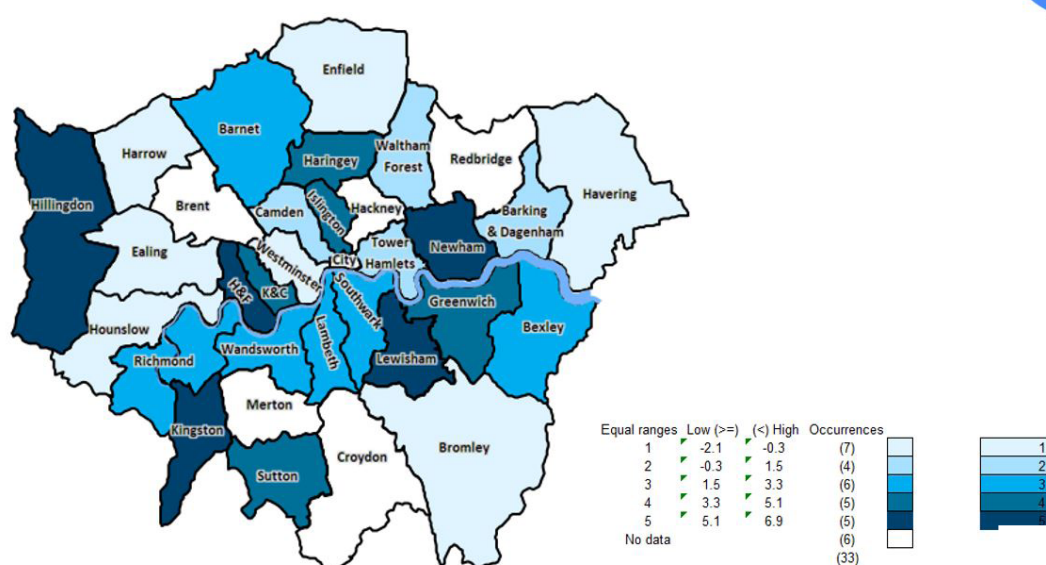


Figure 3 – Map of regional variation of Autism across London.

There is significant variation in the prevalence of Autism across the region. This variation is also reflected in Speech, Language and Communication needs and for Social, Emotional and Mental Health needs.

Some local areas reporting higher than national average levels of SEMH report lower than average ASD and the opposite is also true which may indicate a reporting discrepancy in the way in which ASD/SEMH are identified, diagnosed and recorded. It may also be reflective of the issue of ethnic disproportionality in the identification of SEN (Strand and Lindorff, 2018)⁶. The study highlights the challenge that, whereas some types of SEN have a clear medical/biological basis, others e.g. SEMH/MLD, rely on the interpretation of behaviours and/or attainment by a wide range of different professionals, such as Teachers. Inappropriate interpretation of ethnic and cultural differences is identified as a contributing factor to the ethnic disproportionality of identification of SEN and may be linked to the variation of reported prevalence across London.

⁶ Steve Strand and Ariel Lindorff, Ethnic disproportionality in the identification of Special Educational Needs (SEN) in England: Extent, causes and consequences, 2018

In addition to the data above, the pan-London snapshot identifies 98 children placed in residential special school based on the top quartile by cost. This is 1.25% of all children in London with an EHCP and 8.5% of those in special school settings with an EHCP.

In 2021/22, 78% of new EHCPs in London are for children and young people in mainstream settings and 11.5% are for children and young people in special schools (both day and residential). This is a 4.7% increase in EHC plans for children and young people in special schools for 21/22. 49% of new EHC plans were for children aged 5–10 years old and an additional 20.4% were for young people aged 11–15.

Despite a lack of data on the residential special school provision available in London it is clear from the challenges highlighted in the London Children, London Lives report that there is insufficient residential or specialist provision to meet the needs of this cohort of young people within their communities.

The dataset of children and young people attending residential special schools⁷ in the Pan-London Snapshot demonstrated several key shared characteristics. Firstly, they tend to be overwhelmingly male, with only 25% of the 98 children with completed data reported to be female. They were also broadly placed whilst they were in their adolescence, with an average age at placement of 13 years old. They were disproportionately from racialised backgrounds, with 50% of the cohort from Black, Asian or Mixed-Race backgrounds. Although the residential special school proxy was adopted, based on concurrent work in this area and the findings of the London Children, London Lives⁸ report, it is likely that these findings are indicative of the wider cohort of children and young people with Autism, a Learning Disability and/or SEMH in residential placements.

The children's journey mapping conducted as part of our qualitative evidence gathering, highlighted some key areas where different approaches to identification, assessment and intervention may have led to different outcomes. This will be explored in more detail later in the report.

Gaps in the data

When reviewing these two data sources, there were significant gaps in our knowledge about this cohort. Firstly, we were missing basic data on a child or young person's primary needs in the Pan-London snapshot and although we had some reflections of primary needs within the CDC SEND Data Dashboard there was a missing granularity. It would also be useful to have a picture of their combination of needs to provide a fuller picture of the individual. Other additional factors it would be useful to analyse could include data on levels of exclusions and whether they are known to other services like CAMHS, which will be held at a local level.

A clear thread that runs throughout this report is the need to collect and track data related to this cohort at a regional, system and local level to understand the fluctuations in needs and any trends emerging. We are currently missing a lot of critical data which would enable us to see the fuller picture of need in London and therefore adapt any future commissioning solution to meet changing needs. There is a need to create mechanisms to share any locally held data for regional/system level analysis. A possible solution for this will be explored further in the recommendations.

7 A necessary proxy due to the data gathering challenges outlined in the methodology section.

8 Council for Disabled Children and Isos Partnership, London Children, London Lives: Understanding under-utilisation of London's residential provision by London children, 2022

Children and young people's experiences

Evidence suggests that children and young people's needs and experiences of services will vary greatly across the life course and that in different stages of development any commissioning option



In addition, across these various stages, there are key escalation points where risk of crisis increases significantly. These are largely tied to critical points of transition such as the step up from early years settings to primary school, from primary to secondary school and to further education, employment or training (EET) from 16 onwards, as well as the transition from Children's to Adults services at 18.

Birth – Infancy (0–4)

During this period, children are seen by a variety of professionals at various health and development reviews. This professional oversight should create many opportunities for early identification and support, however for many families this does not appear to transpire or lead to the necessary supports being put in place. This is partly due to the siloed nature of these early checks and the disconnected information sharing pathways between different agencies.

In addition, even for those whose needs are identified early, the available services are more limited for this age group with many disabled children's teams offering limited support pre-5 years old. Short break activities may only be available with a social work assessment or may be restricted to provide activities for children over the age of 8 which can limit options for support.

Lack of accessible post-diagnosis information and support can be confusing and overwhelming for families. During this period there may be particular challenges related to parental mental health and/or sleep deprivation which require agencies to identify, sign post to, or provide support necessary to meet the needs of the whole family.

In the parent carer focus groups parents noted a distinct gap in support to enable them to continue to care for and support their children and young people. Some of these gaps were linked back to missed opportunities for diagnosis and holistic early support in infancy and primary school.

Escalation points

During this time children and young people will also experience the transition to primary school from nursery which could act as a key intervention point and opportunity for cross-agency engagement if appropriate early identification and support mechanisms are in place.

Missed opportunities

- Lack of early identification and post-diagnosis information and support
- Lack of early cross-agency engagement
- Lack of information and support for the whole family

An example to consider is Barnet Early Autism Model (BEAM), a specialist autism home-based service for families of pre-school children under five with a confirmed diagnosis of autism by a paediatrician. The specialist team works together with families to provide effective support around the transition into educational settings. This includes direct work with the child to model appropriate strategies and learning activities which can then be further explored by the parents or carers. They also provide support to parents and carers by helping them to develop skills to manage their child's behaviour, promoting communication and providing information on educational settings to support the family to make the best choice for them. Barnet is currently considering expanding the service offer to increase the age range supported (BEAM+). Alongside the BEAM programme, Barnet Education and Learning Service (BELS) also provides significant support to families at this key transition point. This includes a recently produced Transition to Reception Autism Support Plan⁹, comprising of 2–3 visits to support staff in the setting and the young person to adjust. This commitment to early intervention and targeted support is enabling professionals to hold risk at key escalation points and minimise the impacts of these transitions.

Childhood (5–11)

As children and young people progress into childhood there may be key changes in their support needs, as well as further opportunities for cross-agency interventions. Education will play a key role in identifying and supporting needs during this phase. Initially this should lead to SEN Support in school and reasonable adjustments under the Equality Act duties to ensure that children's needs are being met. It may also include health related therapies such as speech and language, occupational therapy, physiotherapy and/or support for sensory needs.

However, due to a range of challenges which will be explored in this report, children often continue to go undiagnosed or spend long periods of time on waiting lists for assessments and support. The challenges of a lack of collaborative working and misaligned systems continues with school staff and school nurses potentially being the key practitioners consistently engaged. This creates further missed opportunities to intervene holistically.

Where a diagnosis does exist and emerging needs are becoming more complex and/or challenging it is possible that a referral for an Education, Health and Care needs assessment would take place during this phase and where this results in an EHC plan this should act as the trigger for more effective collaboration between agencies. However, in practice, local authorities continue to report challenges in engagement and input from both health and social care.

The local offer is intended to support families to identify community activities and support however parent carers and professionals report significant challenges in being able to access information about universal services that are able to support children with autism, LD and/or SEMH.

It was clear in the parent carer focus group that there is an awareness from parents that some supports and provisions may already be available, however there are challenges in terms of parents being able to easily access the services without the adequate information. Professionals reflected that this should be the role of the local offer in each Borough but this is clearly not experienced in reality. One practitioner said there was an urgent action to standardise the local offers across London to reduce the 'postcode lottery for access to services and quality of local offer' that currently exists.

In relation to social care and pathways to short breaks, this can be similarly complicated sometimes requiring a full social work assessment through a disabled children's team. Despite the fact that all disabled children are defined as 'in need' and there is a duty to assess the local thresholds in place can make this difficult to access without a formal diagnosis and for some children and young people in this cohort they end up in a perpetual cycle between early help teams and mainstream social care teams where practitioners do not necessarily have the skills, knowledge or experience to be able to effectively meet their needs.

Escalation points

The step up from primary to secondary school at age 11 presents a significant transition point which can lead to rapid escalation in needs or behaviours that challenge. There is high anxiety across stakeholders about the lack of appropriate wrap-around support to be provided at this point to mitigate the challenges which may arise.

Missed opportunities

- Limited availability and access to inclusive universal supports through the local offer
- Limited awareness of roles, responsibilities and pathways across education, health and care
- Limited availability and access to wraparound support e.g. proportionate short breaks pathways and needs-led eligibility approaches
- Missed opportunities to collaborate across-agencies

Adolescence (12–15)

As young people approach adolescence it is recognised that the risk of escalation becomes higher, our analysis of the pan-London snapshot highlighted that the average age at placement to a residential special school was 13 years old and of the young people who escalated to crisis in the children's journey maps, all are currently in the adolescent age range. Consequently, this is where the bulk of demand for specialist provision for high-cost low incidence needs sits. This is a particularly challenging time for those young people who are yet to receive a diagnosis with the compounding factors of limited or inappropriate support throughout childhood, families who are exhausted from trying to navigate the system and get their voices heard and listened to by professionals, emerging physical health needs that can accompany puberty, and mental health needs that may also be in response to trauma experienced due to a lack of early identification of need and the subsequent lack of appropriate support. Despite this being the one of our most vulnerable cohorts, anecdotal evidence suggests they are typically ending up in some of our worst provision (including expensive bespoke packages) due to a lack of available, appropriate services.

For the older cohort of children with learning disabilities, they are entitled to Annual Health Checks from the age of 14 onwards which should act as the opportunity for health engagement for young people, excluding specialist support where necessary. These checks should be a vital intervention point to identify changing mental health needs and to reduce health inequalities. However, there are ongoing challenges with encouraging young people to take up this offer. CDC have recently undertaken some work for NHSE/I focused on increasing uptake and quality of annual health check. Through this work we know that young people at or approaching crisis are unlikely to use this resource so there is a clear need to think about how we increase engagement and use these check as part of a future preventative solution.

At this point the trigger for more holistic intervention is often the breakdown of a school placement. Whether this is described as an exclusion or the school being unable to meet needs the end result is the same, children and families in crisis and struggling to engage with of the cross-agency support that becomes available at this point.

One practitioner in the co-production workshop articulated a perception held in some sectors of the workforce that it is sometimes too late to provide positive support and that services are holding children and young people in crisis rather than managing de-escalation effectively or utilising positive strategies at the edge of care level to mitigate risk and avoid crisis.

Where children and young people are known to social care they may have been in receipt of short break support however, the escalation of short breaks cycles through a set menu of options, reacting to crisis, and are often subject to varying and arbitrary limits on levels of support. Children and young people's care package will often extend to include residential short breaks at this time but due to limits, such as maximum 6 overnights per month, in local policies often due to lack of capacity in services or lack of funding in a particular budget, families are left feeling they have no choice other than long term residential specialist placements. Where this happens, the costs can be seen to increase ten-fold and the outcomes can be much poorer. There is a significant gap in provision at this level.

As well as the challenges set out above, there are also an increasing number of contextual risks and young people with undiagnosed SEN and SEMH needs who have become isolated due to school breakdown can become victims of criminal exploitation leading to further trauma and complexity in identifying need and providing effective support.

Missed opportunities

- Missed opportunities for cross-agency collaboration
- Lack of oversight and monitoring of this group of young people
- Lack of support for the whole family to continue caring
- Lack of trauma-informed practice and consistent approaches to de-escalation from crisis
- Limited capacity for more bespoke and creative solutions that can genuinely respond to the needs of young people and families
- Large gap in provision in between 'day special school and overnight short break' and residential special school

Approaching Adulthood (16–18)

The final critical period is the journey into adulthood. Feedback from the parent carer focus group identified a need to build independence and robust wrap-around support early to enable young people to live fulfilling lives. Unfortunately, parents felt that support dropped off at this point and professionals also reflected that better alignment was needed between Children's and Adult Services, as well as the further education sector, from the earliest point but particularly in the period between 16 and 18 for those young people still living at home.

By this point many of the more complex young people are living away from home, sometimes at a distance, in residential special schools or have been admitted to inpatient hospital settings due to mental health crises. For some this may be the right thing however for those who have experienced late identification of needs, school breakdown and multiple placements it will be due to avoidable crisis that repeated failures across systems have neglected to prevent.

Escalation points

The move into adulthood is not just a point in time and there may be many different transitions across services, this could include the transition into Adults' social care services. However, due to significant differences in the criteria for support between children's and adults', for some this may be a transition to community support. Planning for preparing for adulthood outcomes should start from year 9 at the latest to enable young people and families to be prepared for fulfilling adult lives regardless of whether they are at home or in a specialist residential setting.

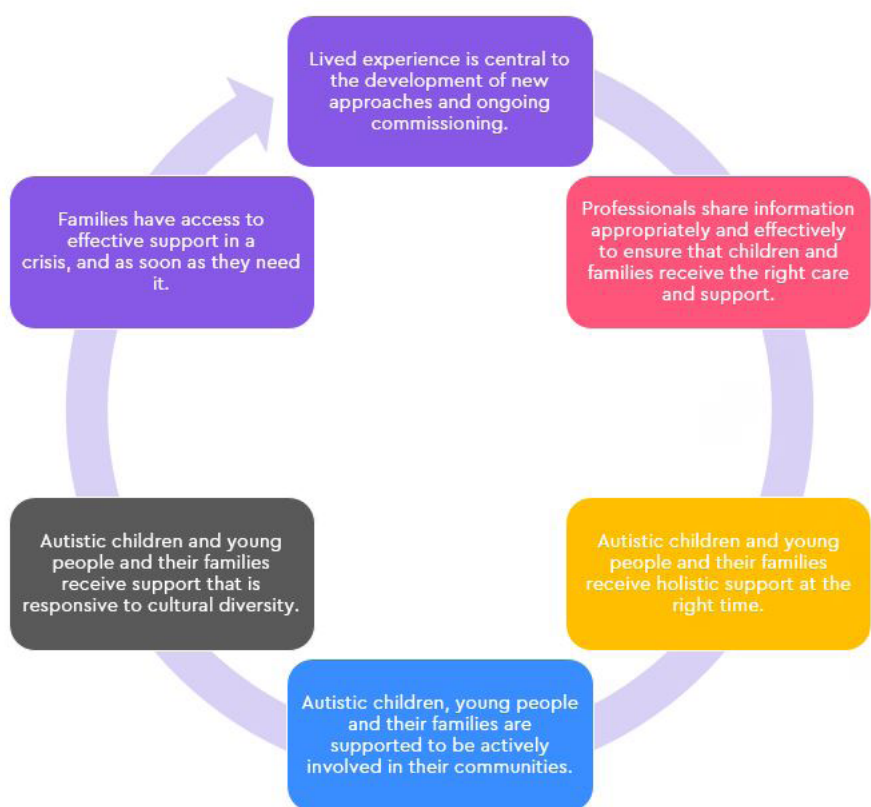
Missed opportunities

- Misaligned services and supports across children's and adults' services
- Late engagement with planning for adulthood
- Lack of support for the whole family to continue caring
- Lack of trauma-informed practice and consistent approaches to de-escalation from crisis
- Limited capacity for more bespoke and creative solutions that can genuinely respond to the needs of young people and families

Developing a shared vision for London

Individual partners across the system already have a clear vision about the outcomes being sought for children and young people with Autism, a Learning Disability and/or SEMH and how provision should support them to achieve this. However, this vision needs to be codified at a pan-London level to support equity of experience across the region. Developing this regional shared vision will help build in commitment from professionals across the workforce in developing new commissioning options that improve outcomes for this group of children and young people.

During the co-production workshop participants were encouraged to consider the impact or change they hope to see as a result of developing Pan-London commissioning options. Some of the impact statements that professionals and parent carers suggested included:



Developing these shared principles and key ways of working across London will offer the best opportunity to build on existing opportunity and levers in the system locally, regionally and nationally, to build commissioning options which are able to focus on both prevention and crisis management thereby improving sufficiency, value for money and outcomes for children.

What is a good model of care?

The Lenehan Review, 2017 – 'Good intentions, good enough?'¹⁰ – explored how examples of effective practice for this group of children and emphasised the importance of a shared vision for what good looks like. One example was Gloucestershire LA, who were attempting to build a "whole system around the child" for children and young people with SEMH through their intensive recovery intervention service.

This is similar to North Yorkshire's No Wrong Door service, providing dedicated short term and emergency residential placements and/or specialist foster care support, integrated with mental health, physical and sexual health support, education, employment and training activities through day provision, and support for parents and carers.

In addition, These are our children (Lenehan, 2017) highlighted the elements a service should provide which strongly resonate with the feedback from the focus groups and co-production session:

"A service should provide:

- Early diagnosis;
- Post-diagnosis support including specialist parenting classes;
- Strong early links with education services;
- An agreed CYPMHS (children and Young People's Mental Health Services)/Learning Disability approach which is focussed on prevention/early intervention and which involves schools;
- A Positive Behaviour Support programme which is consistent across settings;
- An early warning system potentially linked to key worker/named clinician models;
- Family support which looks at the whole family;
- Wrap-around support which looks at good multi-agency intervention approaches;
- Education which recognises and understands behaviour as a form of communication and seeks to fully include the child in school life, in the least restrictive way;
- Education, Health and Care (EHC) plans which are a genuine vehicle for bringing "whole child" planning together which take a whole life approach and focus on what matters to the child and their family;
- Good therapeutic short breaks service which provide positive opportunities for young people and support in management to caregivers and others;
- Joint commissioned residential services which should have both health/education and care inputs and serve as an outreach support service.
- An Intensive support service to manage crisis and support community living; and
- An understanding of the additional effective role that inpatient units play."



¹⁰ Dame Christine Lenehan, Good intentions, good enough?, 2017

Developing commissioning options for London

Prevention

Early identification of needs

Early identification of needs, including those that may arise as children grow older, is fundamental to ensuring that children and families are able to access the right support at the right time to prevent avoidable crisis. CDC's national work in this area suggests that for children with a combination of complex health needs and ASD/LD a diagnosis may come shortly after birth or before the age of 2 however, where health/physical needs are not present diagnosis can come much later and often after significant challenges for parent carers and families who end up as the 'navigators' of a series of complex systems that are not well aligned. In addition, parents also raised their concerns about the challenges with locating and navigating existing services before a crisis which might have helped avoid escalation.

Reflections from the practitioner focus groups highlighted the challenges of ensuring that frontline staff have the appropriate knowledge of behaviours and presentations linked to this cohort of children and young people in order to be able to identify emerging needs early. One professional reflected that the system seems to seek to define a specific profile or set of needs associated with this cohort of children and young people but this can obscure identification for those who have a different presentation or whose presentations primarily occur within the family home. This was also picked up by parent carers who raised concerns about families not being believed when professionals haven't seen the behaviours themselves.

The masking of behaviours can further compound these challenges, particularly among girls. Although evidence around masking is currently limited, it is defined as a social survival strategy involving 'the conscious or unconscious suppression of natural responses and adoption of alternatives across a range of domains including social interaction, sensory experience, cognition, movement, and behaviour'¹¹. The implications of this are that frontline staff may not recognise the need for specific adjustments to support children and young people, resulting in missed opportunities for providing support early.

This speaks to a need for greater training and support for staff to understand behaviours and presentations so they can provide appropriate early support to children and young people with Autism or a Learning Disability.

An example of this working in practice is the Drumbeat Outreach Service in Lewisham. This service is made up of 14 specialist teachers and advisors who offer support, advice and training to children, families and professionals across the borough. This includes work in all mainstream education settings, funded by the local authority through a Service Level Agreement (SLA). The support includes targeted workshops on specific themes and good practice, resources and accredited training as part of the Autism Education Trust's (AET) schools programme. Parents in the co-production workshop spoke highly of this model and the impacts it had on their children. Although one professional raised the issue that services like Drumbeat need to be accessible for all children who reside in the borough including those who attend non-maintained, out of borough and independent schools.

¹¹ Pearson and Rose, A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice, 2021

Diagnosis

For many local areas formal diagnosis is seen as the only route into statutory services which can cause considerable delays in ensuring joined up support is available before families reach crisis. Across the 12 children's journeys 75% of children had received a diagnosis by the age of 11 with five receiving their diagnosis by the age of 5. Despite the majority of the children and young people in the sample having some level of additional needs identified in their early learning and health checks the waiting lists for diagnostic pathways were also a challenge with one child waiting 3 years.

For two thirds of the children in the sample this means that a potentially substantial part of their primary education will have taken place without a clear understanding of their needs. Three of the young people did not receive a diagnosis until adolescence and this was linked to a marked escalation in need that led to either an exclusion or admittance to an inpatient setting where diagnosis was confirmed. For these young people, diagnosis and subsequent access to appropriate support came too late in their journey leading to traumatic experiences of the system for both them and their families.

The older cohort of children with Learning Disabilities are entitled to Annual Health Checks from the age of 14 onwards. These checks could be a vital intervention point to identify changing or emerging mental health needs and to reduce health inequalities. However, there are ongoing challenges with encouraging young people to take up this offer. CDC have recently undertaken some work for NHSE/I focused on increasing uptake and quality of annual health check. Through this work we know that young people at or approaching crisis are unlikely to use this resource so there is a clear need to think about how to increase engagement and use these checks as part of a prevention pathway.

Cross-agency engagement

While some parent carers at the focus group highlighted missed opportunities for diagnosis and holistic early support in infancy and primary school as set out above, others spoke to a wider lack of join up between professionals. Of the children in the sample whose early learning and health checks identified some level of additional need only 50% reported that other agencies were involved following these checks. Even where multiple agencies can be seen to be involved there is limited evidence of join up leading to opportunities for shared information, understanding of family needs and holistic support being missed.

When needs have been identified and children and families are referred for assessment the misalignment of pathways continues. Different timelines for assessment processes across agencies and different thresholds for engagement with services can mean that planning and decision making continues to take place in siloes without effective cross-agency collaboration or appropriate information sharing.



In Barnet, the local authority has acknowledged that there is a specific group of children and young people with Autism that were struggling but were largely missed by other interventions as they did not have the more profound needs and were seen to be coping. These young people were revolving around various Social Care and Early Help services but cases were continually closed as there was no specific intervention being delivered for the family. This was in spite of these children experiencing increased escalations of mental health presentations, late diagnoses and exclusions. To ensure that these children did not escalate to crisis before support reached them, Barnet developed a Specialist Autism Team (0–25) whose role is to pick up these children early and provide wrap-around social care support to prevent children needing an emergency placement. The team has now generated positive links with education and health colleagues, allowing for multi-agency working.

Things to consider

Early identification of needs across education, health and care is fundamental to ensuring that children and young people can access the holistic support they need to thrive and to prevent avoidable crisis. In order to improve early identification across London, these solutions could be considered:

- Train frontline workforce in:
 - The indicators of autism, LD and SEMH and how they can be experienced by children and young people
 - How different presentations may be seen in girls, specific ethnic groups and different settings (e.g. family home vs school)
 - The opportunities in the pathway to engage other agencies early to ensure the holistic needs of the child and family are understood e.g. SENCO identification of potential SEN support needs linked to ASD/LD could trigger a notification to relevant health partners (including CAMHS where appropriate) and social care colleagues for short breaks or signposting to mainstream/universal supports via the local offer.
- Explore a mechanism to identify and track children and young people with a view to preventing needs from escalating. For example, extending the DSR to include children and young people before they are in crisis/edge of care and explore collaborative cross-agency approaches to prevent avoidable crisis

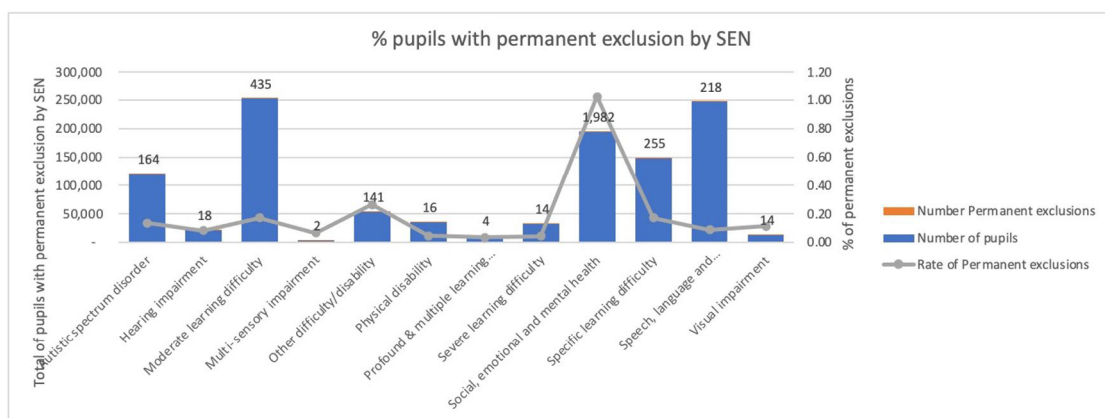
Managing emerging crisis

The 12 children's journeys emphasised some critical points in the system where missed opportunities to identify, assess and support can lead children and young people into a cycle of repeated crisis and reactive emergency provision.

Exclusion and school placement breakdowns

At a national level persistent absence and early exclusion are a known contributory factor to high cost specialist placements that do not always lead to the best outcomes. Although the full breakdown of local/regional data was not available in relation to this the child journey activity findings are aligned with that of the national data picture, which tells us that:

- SEMH is the most common need among persistent absentees, followed by MLD



75% of the children and young people from the journey mapping activity have had recorded periods out of school. Of those 37.5% were Black British and 25% were mixed ethnicity suggesting further disproportionality within the system. The reasons for periods out of school vary including:

- challenges related to transition to a specialist school placement as a result of a placement/care move;
- fixed-term and permanent exclusions;
- periods in A&E;
- an education setting 'breaking down';
- needing to quickly seek a new residential placement after becoming looked after; and
- admission to a mental health unit.

One young person had a nine-month absence as her carers struggled to decide about a specialist secondary school placement. Although she received home tuition during this time, it raises the question about the lack of suitable placements that the system could tolerate this long absence from an education setting.

Another key theme that came through was the relationship between exclusions or 'school breakdowns' and children and young people experiencing crisis. Exclusions and periods outside of education can be traumatic for children and young people compounding the challenges they may be facing due to unmet needs. This is particularly true for children and young people who experience multiple exclusions. One young person was reported to have been excluded three times between the ages of 13 and 15 due to challenges with managing behaviour. Alongside this he had experienced three residential placements and five foster care placements. In several of the children's journey maps there were no references to exclusions, however some children were noted to have several 'school breakdowns' or residential school placement changes. While the reasons for some of these changes are not noted, several professionals recorded these as being linked to an escalation in the child's behaviours or the school being no longer able to meet need. Where these 'breakdowns' are not being recorded as exclusions this means the children and young people are also missing the same protections and trauma-informed approaches that would be utilised after an exclusion for other cohorts.

In the co-production workshop, one professional flagged the need to understand attendance issues early and to provide support to children, young people and their families to avoid unnecessary suspensions and exclusions which could lead to greater harm. In particular, professionals should seek to unpick unexplained attendance issues and consider whether neurodiversity might be a fundamental reason behind a child being a school refuser. This was reiterated by a parent carer in the focus group who said that following the pandemic, her son's bedroom had become a safe space and he was really struggling to get back to school as a result of his anxiety and this is leading to his poor attendance. However, no support has been offered to enable her son to effectively transition back into a school setting. There is a need for further work with colleagues in education to understand issues with attendance and to ensure that staff are able to recognise the range of underlying issues that may cause this.



The role of other agencies

As set out above, for several young people an exclusion or placement breakdown in early adolescence was the trigger for identification of their needs. During absences from education, other agencies were often involved including social care, CAMHS and specialist intervention teams for those already in a crisis setting such as the Autism and Intellectual Disability Intensive Intervention Team (AID-ITT), a pan-London service provided by SLaM and based in Maudsley Hospital. Whilst this engagement is crucial in responding to crisis it is important to consider how earlier multi-agency intervention might have prevented escalation and potentially supported more effective planning for a school placement that could meet needs.

Stakeholders have reflected on the importance of bolstering mainstream support, particularly as one parent shared their concern that the pandemic had knocked back some of the progress already made in this area. Schools are a critical partner in safeguarding these children and young people and they need to be able to signpost and refer early but this isn't happening at the moment. One professional in the operational practitioners focus group reflected that schools are not currently understanding the wider context of the family. This was supported by feedback from the parent carer group as one parent reiterated that we need to adopt a whole-family approach when engaging with children and young people, rather than viewing them solely through a reductive disability lens. This would enable planning for holistic support and increase access to respite.

It is important to note that even when identification and engagement happens well the consistency and quality of the intervention that takes place as a result may still not deliver the level of holistic support needed to prevent future crisis. 11 of the 12 children whose journeys were mapped were reported to have received some early support interventions from education, health and care agencies. However, the extent of these interventions ranges greatly. For some they experienced relatively comprehensive early interventions through bespoke services, however for others they accessed less intensive supports such as one-off CAMHS interventions and some SEN support in their primary school.

These wider responses may also be linked to the varying ways that children and young people come to the attention of other agencies. For example, 66% of the children whose journeys were mapped had historic engagement with social care and many had been subject to either a Child in Need (CIN) or Child Protection (CP) plan. However, they have come to the attention of social care through a variety of different mechanisms, including:

- Early Help Assessment
- Short Breaks Assessment
- CwD Registration
- Children and Families Assessment
- Admittance to a Mental Health Unit/Crisis
- Section 47 Enquiry
- Strategy Discussion
- Police Notification

At some point in their lives, 10 out of 12 of the young people had been on a CIN plan, and, of those 10, three had escalated to a CP plan. It should also be noted that two young people bypassed CP and jumped straight from a CIN plan to being looked after.

This also suggests a complex picture of potential challenges in the family lives of the young people which is also aligned with some of CDC's wider national work on children and young people with ASD, LD and SEMH in residential special schools. The challenges of unpicking whether their needs are as a result of their ASD/LD or a response to difficult and traumatic experiences at home is complex even for experienced practitioners. Similarly, it is important to acknowledge that where effective early support is not available for the whole family this can also have an impact on parental mental health and wellbeing leading to wider concerns. When needs escalate, families need to be able to access proportionate, specialist services. However, for many families these services are unable to meet the specific needs of this cohort of children and young people.

One parent reflected that after a particularly difficult mental health escalation they were offered 16 sessions by CAMHS but at the time her daughter was too young to actively participate in the discussion and reflection process and needed access to art or music therapy instead. Yet, this was unavailable locally and therefore necessary mental health support was missed. The parent reflected that she had been pleased to receive the offer of multiple sessions but for her child but this lack of specific adaptations meant they could not realise the benefits: 'CAMHS is amazing but it is limited in its ability'. One practitioner agreed that better access to Neurodevelopmental CAMHS would be an enabler but currently only a few local areas have access to this.

CAMHS commissioning was also highlighted in the operational practitioners focus group with a professional reflecting that some individual services aren't living up to their potential because of issues with sub-contracting some elements to poorer quality providers. In practice, this means that the staff aren't always appropriately trained or embedded in the local system leading to reports that exist in isolation and don't lead to appropriate wraparound care for this cohort of children and young people. The professional went on to add that these challenges with local practice meant that they were failing to address root causes but instead focusing only on some of the symptoms.

When it came to Short Breaks provisions, only five families were able to access this. There is some evidence that for the families who were able to access this that it was increased in line with need, including progressing up to overnight stays for three of the children. However, these are predominantly very small-scale packages. The approach to accessing short breaks appear to be overly process-driven and means many families bypass short breaks entirely or are unable to access a package that allows meaningful intervention. This may also be due to the varying criteria to access short breaks across areas. For some LAs they will form part of an early help offer and low-level support can be accessed without a formal social work assessment however for others, particularly overnight residential short breaks, a section 17 assessment will be required and dependent on the level of overnight support agreed this may lead to a child having looked after status.

This is not to say that there aren't examples of good early intervention in London already. A practice example that came through from the Service Mapping Tool is the soon to be launched Rebuilding Bridges programme in Camden, which is funded by the Respite Innovation Programme.

The Rebuilding Bridges programme is a community-based support for children with SEN and SEMH aged 4–18 who are not engaging with or are refusing school, not accessing short breaks services, attending an alternative curriculum or at risk of exclusion or placement breakdown. The programme is centred on providing respite and holistic, joined-up support to families through 1:1 support and mentoring, small group work, a weekly parent support group and direct interventions from a clinical psychologist. By providing holistic wrap around support which takes into consideration of the needs of both the child or young person and the wider family, this programme will seek to provide necessary preventative support to avoid crisis.

Risk and accountability

For professionals working with children and young people approaching crisis, a frequent concern raised is around crisis management. Particularly, the question of who holds overall risk and accountability in the system and how this is discharged in the best interest of the child or young person. Frequently, the risk is held at a social care level but there are obligations for all partners to enable effective crisis management in a multi-agency approach to risk. What we see for this cohort of children and young people is that there are a lot of professionals around them who hold some responsibility but very few who hold overall accountability. This is particularly true when professionals are engaged from different disciplines, necessitating the involvement of different commissioners. There is safety in keeping children and young people under the same commissioners, and going forward this is likely to be under an ICS footprint. However, it is important to consider the integration of education and social care in this to ensure there is consistency across approaches and a simple ability to track where children and young people are known across the system.

Whilst there are current triggers for multi-agency conversations within the existing pathways, particularly through the DSR and CETR, these are only as good as the person chairing them. To effectively utilise the value of these conversations there is a need for constant enforcement and accountability.



The keyworker function is already being shown to support this in practice, and SELECT (South East London's Keyworker Programme) has been routinely shared as an area of best practice in our conversations with stakeholders. In particular, stakeholders have been impressed by its capacity to enable effective holding of accountability across involved partners and ensuring the ethos of multi-agency working is lived up to.

The Keyworking function for children and young people with Learning Disability and/or Autism recently introduced through the NHS Long-Term Plan is useful to reflect on in conversations around risk as they have an important role to play in holding space to manage risk amongst busy practitioners and enforcing decisions to ensure adequate accountability is dispensed. In the Keyworker Guidance developed by CDC and NHSE, the keyworker role is stated to be an important response to enable families to 'get the right support at the time and that local systems are responsive to meeting their needs in a holistic and joined up way'¹². A practitioner in our focus groups shared that they had seen in practice that the keyworker role has led to reductions on DSR. However, they also stated that there is a need to think critically about how this would sit in the geography of London to ensure it plays a consistent role in levelling out disparities of experience across the region.

It is important to remember that the ICS model provides opportunities to re-establish how accountability lines are maintained across partners. It also creates the opportunity to collectively commission for the small groups who are at risk of hitting crisis in individual boroughs. Thereby pooling resource, expertise and services in an efficient and effective way to meet children and young people's needs more effectively.

12 Council for Disabled Children and NHSE, Keyworking Function Guidance, 2021

Things to consider

There is a clear need for a system which can both prevent escalation of needs and manage de-escalation of needs at crisis. This requires not only a skilled, holistic response from professionals across agencies but also sufficiency of the appropriate and creative wraparound supports that can bridge the void between planned local area provision and emergency or long-term residential settings. Solutions may include:

- Improve information and access to inclusive universal supports through the local offer
- Improve sufficiency of appropriate creative wraparound support e.g. short break support for families when they need it (including overnights), flexible offers that can increase and decrease flexibly with need without families being terrified that support will not be available again if not used in a less difficult period.
- Improve access to wraparound support e.g. proportionate short breaks pathways and needs-led eligibility approaches.
- Improve awareness of roles, responsibilities and pathways across education, health and care to enable practitioners to join up effectively.
- Develop and embed the role of the Keyworker.

Supporting young people with the most complex needs

For some young people, preventative strategies as outlined above will not avoid escalation to crisis, particularly young people who are already on that pathway within the current system. There is therefore a clear need to restructure support for children and young people who have already reached or are imminently approaching crisis to enable them to experience the best outcomes possible. It is imperative that we keep children and young people safe in emergency placements if they need them, by ensuring sufficiency, value and appropriateness of placements across London. We know from LIIA's previous work on under-utilisation of London's provision that it is critical that we endeavour to keep young people close to home in suitable, high-quality placements so we can continue to provide the necessary multi-agency support¹³. However, a recent review of sufficiency strategies across London indicated that, due to challenges of supply, commissioning decisions are 'sometimes made based on availability rather than evidence-based on effectiveness of placements'¹⁴.

For practitioners, a significant issue that was raised was the challenges related to finances. Particularly, the cost of placements within a provider-led market impacting on their ability to source appropriate placements for this cohort of children and young people. However, cost was not the only issue attributed to providers. Professionals raised their concerns about the challenge of being able to find a provider who is willing to accept the high levels of risk that often are necessitated when finding a placement for a child or young person with this complexity of need. This challenge with risk aversion in providers was identified in the London Children, London Lives report which found that 'providers are less inclined to take on young people with more complex needs, including those with deprivations of liberties, as they are unsure whether their behaviour may impact on their Ofsted rating'.

13 CDC and Isos Partnership, London Children, London Lives, 2022

14 Suh and Holmes, Review of sufficiency strategies in London, 2020

In the context of the challenges set out above, the issues of placement sufficiency and stability for this cohort of children and young people must be addressed. For many young people who end up needing a residential special school placement, there are challenges identifying an appropriate setting that can meet needs and provide holistic support. Practitioners have regularly reflected that they would like to place these children and young people with foster carers, however they are not able to identify anyone who can meet these needs. One notable gap is in foster carers who have the necessary knowledge of contextual safeguarding and trauma-informed practices. In the words of one practitioner this means the 'default has always been specialist residential placements'. According to the London Children, London Lives¹⁵ report, commissioning approaches for these residential placements across different London Boroughs vary greatly. However, analysis showed 'a pattern of placements that involves high levels of spot-purchasing in a large number of boroughs'¹⁶. Often this spot-purchasing comes at the risk of placing children and young people outside of the local area, removing opportunities for the essential family work to facilitate a move back home where possible.

Many young people profiled in the children's journey maps have experienced a lack of stability with their placements, with one young person having had 4 placement changes and a 5th in progress. The role of the market and providers is crucial in mapping and developing the right provision for this group of children in London. The evidence gathered through the Service Mapping Tools points to there being a distinct gap in provision for emergency placements for children and young people with Autism, a Learning Disability and/or SEMH. In particular there were challenges with accessing residential settings that were able and willing to hold the level of risk associated with these young people. Consequently, there is a need for ongoing, transparent conversations with providers about the demand and requirements across London and their capacity to manage risk.

Things to consider

Without a sufficiency of the appropriate placements in London, children and young people will continue to experience placement breakdowns and poorer outcomes. Any future commissioning solution needs to enable placement stability by having the sufficiency of placements at the right level that can manage the complexity of needs that this group of children and young people present with. Solutions may include:

- Developing a mechanism for more in-depth conversation with providers across London to understand sufficiency and suitability of placements in order to meet the needs of young people within London provision.
- Addressing the gaps in placements and provisions to ensure the right supports are available at the right time across London.
- Ensuring a clear read across of any future work to recommendations set out in the London Children, London Lives¹⁷ report on under-utilisation of London's provision and the ongoing work on a pan-London vehicle for engagement with the providers being led by LIIA.

15 CDC and Isos Partnership, London Children, London Lives, 2022

16 Ibid

17 Ibid

Recommendations

To effectively improve outcomes, reduce long term spend on inappropriate placements, and prevent avoidable crisis for children and young people with autism, a learning disability and/or SEMH leaders, practitioners and partners across Social Care, Health and Education will need to work together to ensure that agencies seeking to support these children and families have a better, evidence-based understanding and opportunities to identify needs earlier; effective cross-agency monitoring via an integrated pathway; and high quality provision delivered by a skilled and knowledgeable workforce.

As part of phase 2 of this piece of work, the Pan-London ASD/LD/Tier 4 Steering Group should retain a specific focus on several key areas to enable the development of clear commissioning options that will have an impact on the existing commissioning challenges identified throughout this report. This will include data and the way it is used to inform future market development, analysing the sufficiency of existing provision and the workforce around it in relation to this particular cohort of children and young people, and the ways in which providers are engaged to ensure the market is sufficiently receptive to the needs of children and young people with Autism and Learning Disabilities and/or SEMH most at risk of requiring a high-cost, low-incidence placement.

In order to develop commissioning options for London which enable prevention of avoidable crisis and better support for children and young people who will continue to present in crisis at services across the system, we suggest the following recommendations are taken forwards:

Recommendation 1 – Identify and engage key partners across London at a regional, ICS and Local level who should be engaged in phase 2 developments and potential related finance streams

- Consider the role and key interfaces of the five ICSs in the next phase of work.
- Consider how to align and embed the role of the Keyworkers and learning from the national pilot programme.
- Consider how to align and integrate work being led by the Learning Disability and Autism Partnerships in London.
- Identify and map existing finance streams and potential funding opportunities at a local, regional and national level.

Recommendation 2 – Develop a data and evidence strategy for London to ensure accurate information on the needs of children and young people and the sufficiency of suitable provision can inform future commissioning for this group of children

Develop a comprehensive data dashboard containing data across education, health and care to underpin development of regional and ICS level strategy across London.

As part of phase 2 of this work and building on LIA's Dynamic Sufficiency project, LIA should coordinate necessary child-level data collection (as set out in Appendix 1), providing the required detail on needs to inform future commissioning approaches. ALDCS to approve development of

pan-London data dashboard to enable necessary analysis.

- Building on the existing Pan-London snapshot, the dataset should include data on primary and secondary needs for all children and young people in high-cost, low-incidence placements, as well as further information on additional factors including whether they are excluded or missing from education, whether they are on a LAC, CiN or subject of a CP plan, whether they present with behaviour that challenges and whether they are known to CAMHS or other mental health services. These missing data points (Appendix 1) were identified through our review of existing data sets and indicators and their inclusion will enable a more comprehensive picture, at both ICS and regional level, of the complexity of needs children present with in crisis and ensure a more targeted approach to future commissioning designed to meet those specific needs.

Develop an approach to identification and monitoring of children and young people who may need cross-agency support through an integrated pathway

- Consider the role the Dynamic Support Register (DSR), or a similar process, could play in a preventative pathway. The LDA programme, and specifically the DSR element of it, has the potential to significantly improve the pathway to cross-agency support for this group of children and young people. Leading to improved outcomes, a reduction in long term spend, and improved value for money. To be effective in these ambitions the DSR should be a whole-system approach jointly owned by Health, Social Care and Education as part of a preventative pathway to support.
- As part of the consideration of how to align and integrate the work being done by the LDA programme as set out in recommendation 1, engage with the London LDA partnership to identify and build on examples of more mature DSR process which are linked up with education and social care.
- The Steering Group should ensure they explore opportunities to influence the DSR development work linked to the ambitions of the Building the Right Support action plan¹⁸ on DSR processes, which states that every ICS must design an effective process that engages the multiagency and multidisciplinary team that know the child or young person and their family circumstances and seek to prioritise shifting the thinking away from being purely about admissions avoidance and consider a new focus on children and young people entering an integrated pathway at green and working with the intention of preventing them from ever escalating to amber.

Undertake a pan-London review of the available provision as part of a provision sufficiency and gaps analysis, with the direct engagement of providers.

- As part of phase 2 of this work, the Pan-London ASD/LD/Tier 4 Steering Group should work with provider collaboratives to lead on mapping existing support offers across education, health and care, to establish their capacity to deliver provision that supports both early intervention and crisis support for this group of children and young people.
- Over time the development work on the data dashboard, as set out above, will inform better evidence-based understanding of the needs of this group of children, young people and families enabling more effective identification of shortfalls in available provision.

18 Department of Health and Social Care, Building the Right Support action plan, 2022

Recommendation 3 – Identify potential regional/ICS/LA commissioning approaches to improve sufficiency, suitability and quality of interventions and provision for this group of children.

Based on the output from recommendation 2, identify regional commissioning priorities and seek opportunities to influence ICS strategy development in relation to this group of children and young people.

- As part of phase 2 of this work, the Pan-London ASD/LD/Tier 4 Steering Group should engage representatives from the five ICS footprints across London to ensure there is a clear read-across to the newly developing ICS strategies ahead of the November 2022 publication timeline and establish a commitment to working in partnership on delivering the strategy where appropriate.
- Future development should include an action plan to prioritise implementation of cross-agency approaches to commissioning, with a focus on developing targeted offers to provide earlier support to this group of children and young people. Consideration will need to be given to whether particular approaches should be at a place (local) level, sub-regional (ICS) level or regional level, whilst also having regard to forthcoming national evidence and recommendations as set out in recommendation 5.

Develop and disseminate knowledge and understanding of what works for children and young people with Autism and Learning Disabilities and/or SEMH

- Building on the identified practice examples in this report and on formal evaluation of effective interventions or approaches for children and young people with Autism, a Learning Disability and/or SEMH (e.g. BEAM or Ealing's Brighter Futures Intensive Engagement Model) develop a mechanism to enable commissioners and providers in local areas across the region to replicate or scale up evidence-based models of support and intervention.
- Given the identified need to help and advise commissioners who are holding the risk for these children at crisis point, we recommend that the next phase of work considers what the solution might be to meet this need across London and whether this is at place level or sub-regional (ICS)/regional level. This may include encouraging take up of the Learning Disability and Autism commissioner qualification which is to be further rolled out as announced in the Autism Strategy¹⁹.

¹⁹ Department of Health and Social Care, The national strategy for autistic children, young people and adults: 2021 to 2026, 2021

Engage with providers to improve their confidence in developing targeted new and innovative provision

- Based on the improved understanding of sufficiency through the provision mapping activity, the Pan-London ASD/LD/Tier 4 Steering Group should work with existing and new providers to identify and inform commissioning options and support increased provider confidence to develop new provision that is able to hold and manage risk safely whilst effectively meeting the needs of this cohort of children and young people. This may include options such as residential special schools at a regional/ICS level as well as preventative multi-agency wraparound support for the whole family at an ICS/local level.
- In the future development of residential settings for this group of children and young people, the group should have regard to the forthcoming recommendations from the National Child Safeguarding Practice Review Panel's review into safeguarding children with disabilities and complex health needs in residential settings with a particular focus on mechanisms to provide effective quality assurance and improved core standards in residential placements for this group of children and young people.

Recommendation 4 – Strengthen the approach to workforce development and sufficiency

Explore opportunities to integrate findings on workforce and sufficiency related to Learning Disability and Autism into wider LIAA workstream on workforce.

- Review the scope for integrating findings related to workforce and sufficiency from this report into existing LIAA workstream underway on workforce. We recommend that any future work undertaken to develop a workforce development and sufficiency strategy considers the findings of this report and has regard to the implications of the particular needs of this cohort of children and young people.
- Engage with the London LDA partnership to consider the workforce implications of embedding a whole-system approach to the LDA programme including cross-agency ownership of the DSR, six monthly reviews and the operational CETR.
- Building on particular workforce interventions highlighted in this report, including the Autism in Schools project from Autism Education Trust and Drumbeat Outreach, explore the opportunities for regional or ICS level approaches to workforce sufficiency and development specifically linked to the needs of this group of children. This should include consideration of training opportunities in trauma informed practice and contextual safeguarding as part of any future approach to the recruitment, training and retention of residential care staff and foster carers to enable these commissioned services to be upskilled and supported to meet the specific needs of this cohort of children and young people, enabling them to remain closer to home in line with recommendations from London Children, London Lives²⁰.



Recommendation 5 – Identify opportunities for broader integration with wider work across London and nationally in relation to this group of children and young people

Throughout the activity in phase 2 of this work the Pan-London Steering Group should have regard to both the emerging recommendations and potential linked funding streams of the:

- Forthcoming National Child Safeguarding Practice Review Panel's review into safeguarding children with disabilities and complex health needs in residential settings.
- Emerging learning from the DfE/NHSE Short Break Innovation Programme targeted at prevention/de-escalation support for this group of children and young people (London Borough of Camden is involved).
- Role of Family Hubs in generating different ways of working and providing pre-diagnosis support, family support and other early interventions for this specific cohort of children.

Appendices

Appendix 1 – Review of quantitative and qualitative datasets and indicators

Data Sources	Key relevant indicators	What this data currently tells us/ why it's useful	What's missing?	What the data could tell us and the impact
Nationally collected data sources – Used to support regional data reviews				
CDC SEND Data Dashboard – Commissioning tool that brings together national data relevant to education, health and social care, to help local areas to understand local need; performance; and outcomes. Co-produced with local SEND partners including parent-carer representatives.	Local Profile – SEN <ul style="list-style-type: none"> No. of pupils with SEN by where the pupil attends school Pupils by primary type of need 	Variation of local % of pupils with SEN vs. national average helpful in unpicking disparities in line with local data on deprivation, ethnicity etc. No. of pupils in special schools is useful in exploring availability of placements locally. Variations of primary needs vs. national average also helps us look at regional and local disparities and levels of need.	Data on type of specialist placements by borough. In exploring high cost specialist placements, local data could provide a much fuller picture in terms of: <ul style="list-style-type: none"> What combination of SEN (i.e. not just primary SEN – CYP in high cost placements have complex needs)? What additional factors e.g. excluded, LAC, CiN, challenging behaviour, known to CAMHs etc would provide a fuller picture, if data can be matched? SEN2 data on CYP for whom the LA is responsible would generally be more useful for this analysis (to inform commissioning) than School Census, which reflects where children attend school rather than where they live. 	Although the CDC SEND Data Dashboard provides significant useful information to inform commissioning across local areas, triangulation with local collected data is required to provide a cohesive picture of local need, performance and outcomes. Exploring options for data linkage with pan-London data collections could be useful.

	<p>Local Profile – CIN</p> <ul style="list-style-type: none"> • CIN by disabilities recorded • % CIN episodes with a disability recorded 	<p>Variation of number of CIN compared to actual level of need outlined in Local Profile – SEN to unpick missed opportunities for early identification and support. Prevalence of specific disabilities within recorded CIN in a local area – Autism consistently highly prevalent. % of children in need episodes with a disability recorded vs total number of episodes to see regional variations in recorded engagement at this stage.</p>	<p>Missing comparison with LAC SEN profiles – data available from DfE on SEN profile of CIN and LAC (who maintain a longitudinal matched dataset, following the CiN Review)</p>	
	<p>Local Profile – MHSDS-LD</p> <ul style="list-style-type: none"> • CYP in contact with mental health services (by MH provider) • LAC and CYP with a CPP referrals (by CCG) • National LDA stats (Transforming Care/ Assuring Transformation) • National LD activity commissioned by CCGs, specialist hubs) (by TCP, CCG or Region) 	<p>Limited relevant intelligence comes through this given the lack of LA breakdown but it does helpfully indicate the prevalence of mental health needs across providers in London.</p>	<p>None of this data can be broken down at LA level so would need to match to local data collected in London to pull out useful data on SEN cohort (possibly through data linkage and matching using NHS numbers).</p>	

	<p>Governance and Assurance</p> <ul style="list-style-type: none"> CYP with EHC plans or LD/ASD and personal budgets (by CCG) National absence and exclusions data, broken down by primary SEN Quarterly Tribunal Statistics (CYP with EHC plans) 	<p>% of CYP with EHC plans by LA (including breakdown across primary and secondary school) is useful contextual data for specialist placements.</p> <p>National absence and exclusions data is a useful contextual dataset given persistent absence from education's role as a contributory factor to specialist placements.</p> <p>National data on SEN appeals per need available can show areas of growing demand which is useful as appeals often lie behind high cost placements.</p>	<p>Data on CYP with EHC plans or LD/ASD and personal budgets would be useful to explore at an LA level given their role in providing families with flexibility and avoiding residential placements</p> <p>National data on absences and exclusions needs to be triangulated with local data.</p> <p>Data on appeals needs to be triangulated with more recent LA and regional data to assess ongoing trends and any variations across London.</p>	
	<p>Section 251 Benchmarking</p> <ul style="list-style-type: none"> High needs budget compared to similar LAs 	<p>Useful data to include in high cost placements framework, including top-up funding to non-maintained and independent specialist schools, as well as top-up spending on other schools and the SEN support. These data are also available broken down across the London region (i.e. comparing spending between boroughs).</p>		

<p>Child health/ Young People profiles (Office for Health Improvement and Disparities)</p> <p>- To help local authorities and health services improve the health and wellbeing of children and tackle health inequalities. Available for each upper-tier local authority and for each clinical commissioning group (CCG) in England. Data is also readily available via the PHE website.</p>	<p>Different indicators exist across the Child and Maternal Health data sets but these include:</p> <ul style="list-style-type: none"> • Hospital admissions for mental health conditions (<18s) • Hospital admissions for self-harm (<18s) • Hospital admissions for injuries (0–14 yrs/14–25) 	<p>These indicators are all widely used in local JSNAs to explore trends in children and young people's health and mental health.</p>	<p>None of this data is specific to children and young people with SEN and therefore serves to illustrate the wider national picture for children and young people in general only.</p>	<p>Given the broader scope of this dataset, it should continue to be used as a contextual reference only.</p>
<p>Office of the Children's Commissioner - recent briefing on mental health services, indicators and data sources – useful insights on sources and quality of MH data.</p>	<p>Uses data from Five-Year Forward View for Mental Health (FYFVMH) dashboard including indicators:</p> <ul style="list-style-type: none"> • % CYP accessing mental health services during year as a proportion of CYP with a diagnosable mental health condition • Time between referral and treatment <p>Also includes indicators such as:</p> <ul style="list-style-type: none"> • Numbers of children referred to and accessing CYPMHS 	<p>Useful contextual information on how mental health services are being delivered to children and young people. The local area maps enable us to review London's provision in line with other similar regions across the UK.</p>	<p>This data set only presents data for children's mental health services funded by the NHS, therefore it doesn't include services like school-based counselling or services provided by local authorities (which may be supported by the NHS but not considered NHS funded). This may also impact on scores as CCGs that spend more on external or prevention-based services at the expense of NHS provided CYPMHS may underperform on indicator scores based solely on CYPMHS datasets.</p>	<p>This data needs to be triangulated with locally held data where possible to establish meaningful regional analysis.</p>

	<ul style="list-style-type: none"> Numbers of children referred that were not accepted into treatment during the 2020/21 financial year, as proxied by the numbers not receiving two contacts with CYPMHS Average waiting times Spending on children's mental health 			
LGInform¹ – local area benchmarking tool created by LGA.	<p>Comprehensive data set including a variety of indicators already included in other data sources, as well as:</p> <ul style="list-style-type: none"> Persistent absentees – SEN pupils with a statement (10% of sessions) Persistent absentees – SEN pupils without a statement (10% of sessions) 	The data includes regional and LA breakdowns and enables comparisons to similar LAs/regions.	N/A	N/A

¹ LAIT (local authority interactive tool) also provides similar benchmarking with similar indicators.

Regional and Local data that is already collected				
<p>Pan-London Snapshot – evidence and data that the Pan London Commissioning Programme has gathered from regional colleagues to identify regional variations and gaps in provision.</p>	<p>Child-level data on the top quartile by cost of placement</p> <p>Number of special school pupils by ethnic group</p> <p>No. of children placed in residential special school</p> <p>Inner vs Outer London compared to national average by special educational need</p> <p>Total pupils by LA (All and SEN)</p>	<p>Proxy of exploring data held on children and young people placed in residential special schools used due to gaps in data as no data on need is held for the child level data. Through this we can see:</p> <ul style="list-style-type: none"> • Placing LA • Age • Gender • Ethnicity • Start date in placement • Placement type (e.g. residential special school, children's home) • Weekly cost of placement 	<p>The existing child-level data set doesn't capture LAC status, primary or wider needs/ diagnosis, gender identity, socio-economic status, country of origin/ language and any DSR data.</p> <p>Using this proxy, we also have no available data on children and young people pre-placement.</p>	<p>This data set could be significantly more useful if child-level data was triangulated and matched with other sources. Capturing specific child-level data on needs and known contributory factors to high-cost placements will enable London to commission services that are more targeted to the specific needs of this cohort of children and young people.</p> <p>We suggest the focus of the future regional and ICS level data collection remains on the identified gaps in the previous column (see Recommendation 1). This would help to identify the scope and evidence base for commissioning alternative models of support which may help avoid demand for residential placement and escalation to inpatient units in crisis.</p>

New/experimental data sources				
Autism Statistics Quarter 1 2019–20 to Quarter 1 2021–22 (NHS Digital) - These statistics present a group of measures on waiting times for autism spectrum disorder diagnostic pathways, based on the time between a referral for suspected autism and the first care contact associated with that referral.	Some key indicators from this dataset include: <ul style="list-style-type: none"> • No. of new referrals for suspected autism • Proportion of new referrals for suspected autism having an autism diagnosis recorded • Proportion of new referrals for suspected autism waiting for a diagnosis but had a care contact recorded • No. of new referrals for suspected autism receiving a first appointment in 13 weeks or less • No. of new referrals for suspected autism receiving a first appointment between 13 weeks and 26 weeks • No. of new referrals for autism receiving a first appointment more than 26 weeks 	Provides useful national context on autism referral pathways for children and young people.	This dataset doesn't include child development centres and most CYP pathways will be here. Additionally, for referrals without a care contact, it is not possible to know how long they have been waiting. Also, although it does have data on ethnicity, this isn't broken down by age group.	This national context should continue to be analysed against local authority data to unpick specific regional challenges around waiting times and the implications this has on delayed access to support services and demand for high-cost, low-incidence placements.

<p>CDC SEND Data Bulletins – In response to the lack of robust data available on children and young people with SEND for local services across the country, the Council for Disabled Children has published a series of SEND Data Bulletins designed to share learning and improve data on disabled children and young people.</p>	<p>N/A</p>	<p>Provides useful examples of LAs who have implemented effective multi-agency data approaches e.g. Bradford, Middlesbrough and Plymouth.</p>		<p>It is suggested that regard is paid to the learning examples outlined in the SEND Data Bulletins to generate conversations on approaches taken across other regions to use data to inform more effective planning and identification of gaps in provision.</p>
--	------------	---	--	---

Appendix 2 – Analytical Framework for Children's Journey Mapping

About the young person

- What is the young person's current age?
- What is the young person's ethnicity?
- What is the young person's gender identity?
- What is their home London Borough?

Identification of needs

- What early learning and health checks took place and what did they report? (open text)
- Were any other agencies involved following these early learning and health checks? (Y/N/I don't know)
- Did they have their annual health check? (Y/N/I don't know)
- At what age did they receive a formal diagnosis? (Number)
- Were they on a waiting list for a diagnostic pathway? (Y/N/I don't know)
- If so, how long had they been waiting? (Number)
- Were they on the learning disability register? (Y/N/I don't know)
- Were they on the DSR and if so at what rating? (Y/N/I don't know)
- Are there records of A&E attendance? (Y/N/I don't know)
- If so, how many times and when? (Number)
- Were they admitted to tier 4 inpatient care? – under what circumstances (e.g. under Mental Health Act) (Y/N/I don't know)
- If so, how many times? (Number)
- Are there any records of periods out of school? (Y/N/I don't know)
- If so what were the reasons? (open text)
- Were any other agencies involved (e.g. Health/Social care)? (open text)
- Are there any records of early exclusions? (Y/N/I don't know)
- If so at what age was the first exclusion? (number)
- How many times has the child been excluded? (number)
- What was the child or young person's age at their first change of school? (number)
- How many times have they come to the attention of children's social care? (number)

Assessments and plans

- At what stages did the child or young person (and their family) receive social care involvement? (assessment undertaken, this may also include early help assessments) [open text]

- At what age was their first statutory EHC needs assessment and EHCP? (number)
- Has there been historical social care involvement in the child or young person's family? (Y/N/I don't know)
- At what age was their first assessment? (number)
- At what age were they first allocated a social worker? (number)
- Have they been subject to a Child in Need plan and/or Child protection plan? (Y/N/I don't know)
- If so, under which category; (neglect; emotional; physical; or sexual abuse)? (tick box)
- How long were they on the (CIN/CP) plan? (number)
- Did the young person become looked after and if so by which route? (tick box)
- Voluntary arrangement – under section 20 of the CA 1989
- Care Order
- Emergency protection order (then potentially subject to care proceedings; interim care order/care order)
- Police Protection order (then potentially subject to care proceedings; interim care order/care order)
- Via a tribunal judgement
- Not looked after

Support and provision

- Was there any early support intervention from education, health and care agencies, including any family support? (open text)
- Did they access Short Break provision? (Y/N/I don't know)
- If so, what type of short break provision; e.g. day, evening, overnight, weekend activities, in the CYP's own home, the home of an approved carer, or in a residential or community setting?
- Were they receiving any of the following health support/treatment: (Tick all that apply)
- A form of Positive Behaviour Support therapy or similar
- Physical, occupational, Speech/language, sensory therapy
- Health commissioned short breaks
- Specialist Support from CAMHS
- Support from Community Learning Disability Team
- Receiving Personal Health Budget
- Medication
- Support from Dietician/Nutritionist or other diet/nutrition support
- Any Family Carer Support- including Healthy Parent Carer programme
- Was there a health element and/or social care element of an EHC Plan or other form of multiagency plan – CIN, CP, LAC etc. (Y/N/I don't know)
- If so, what was it, and do we know if it actually delivered/happened?

Additional questions for those already in residential placements

Visits and Reviews

- Did annual reviews take place in a timely way? (Y/N/I don't know)
- Who attended? (open text)
- Any change of provision (as well as placement)? (open text)
- If so, was it genuinely responsive to the nature of the difficulties or was it just a matter of finding a different place for doing the same thing? (open text)
- Across placements, how often were they visited and by whom? (open text)
- How often have they been visited by parents/family? (open text)
- Were any concerns raised? (Y/N/I don't know)

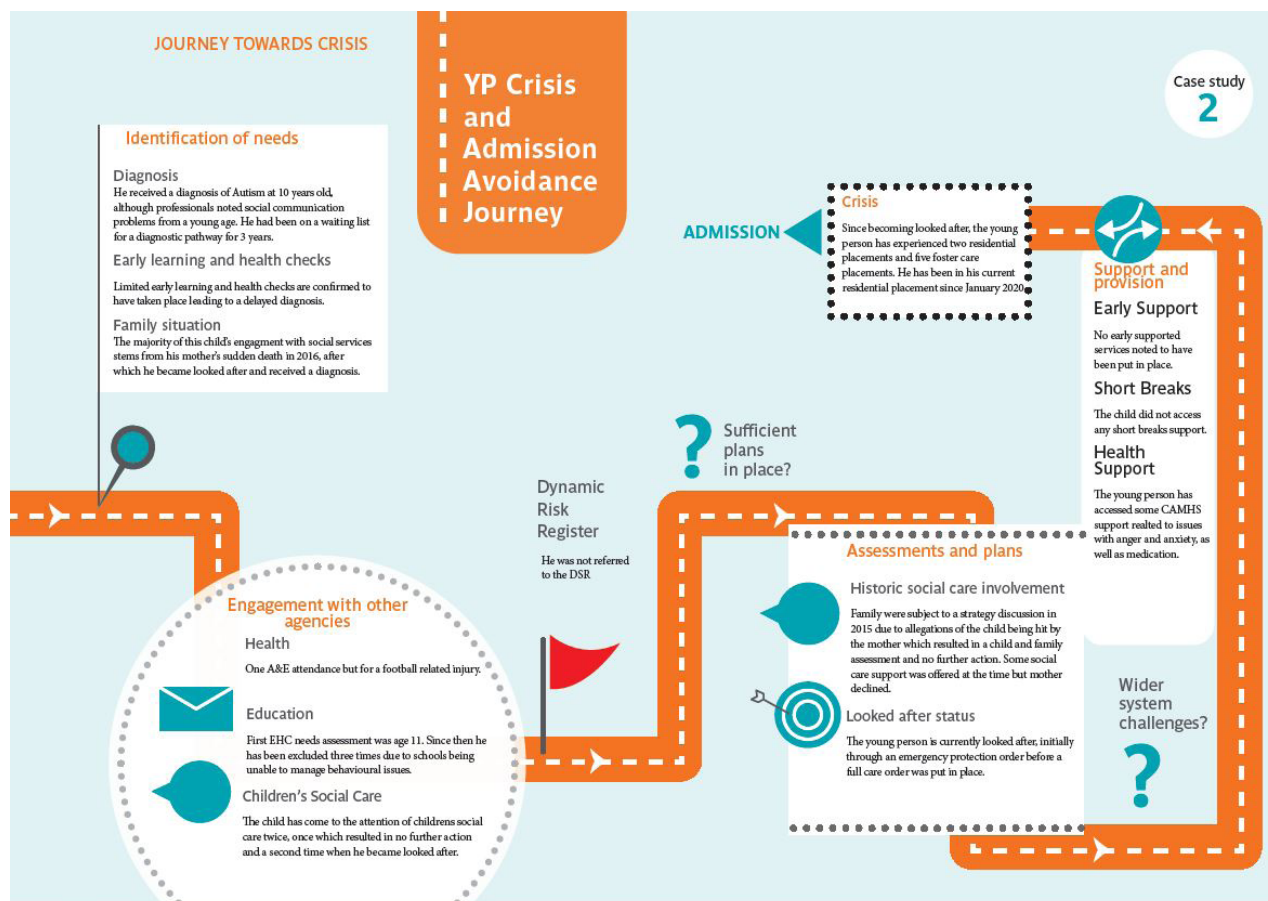
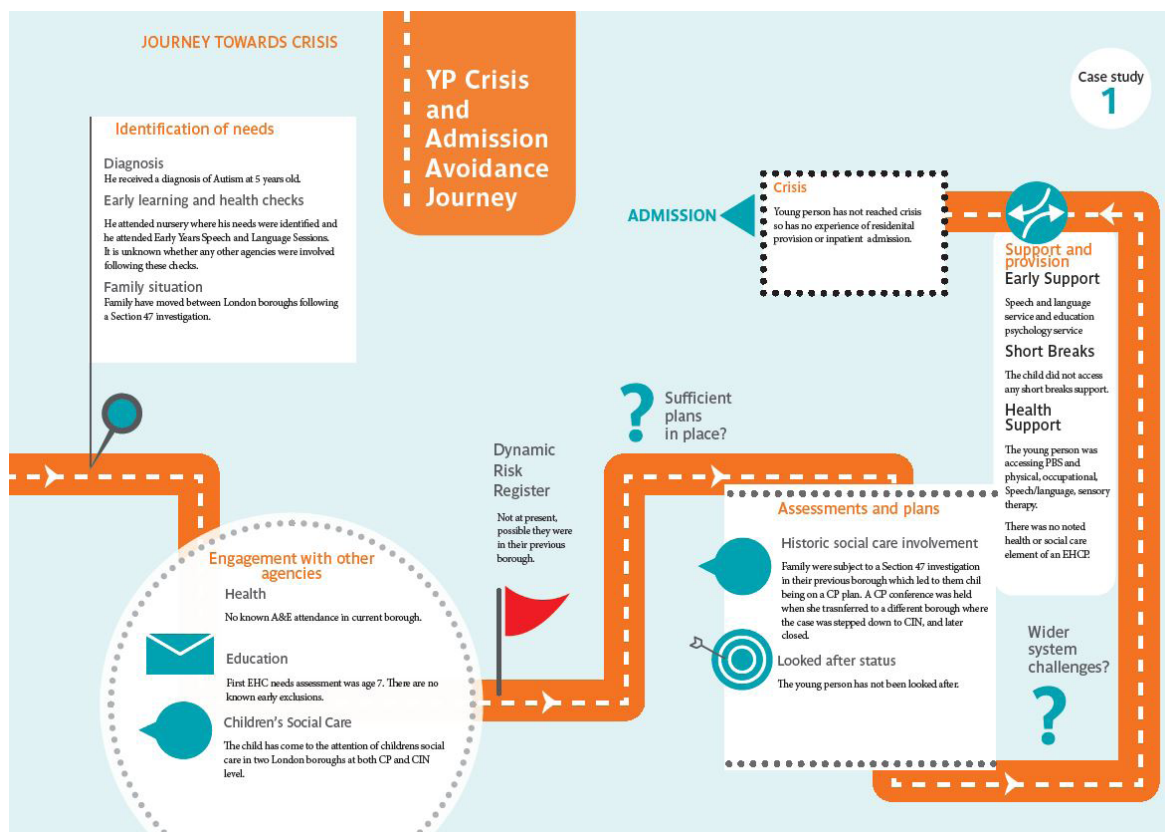
Additional questions for those with experience of inpatient settings

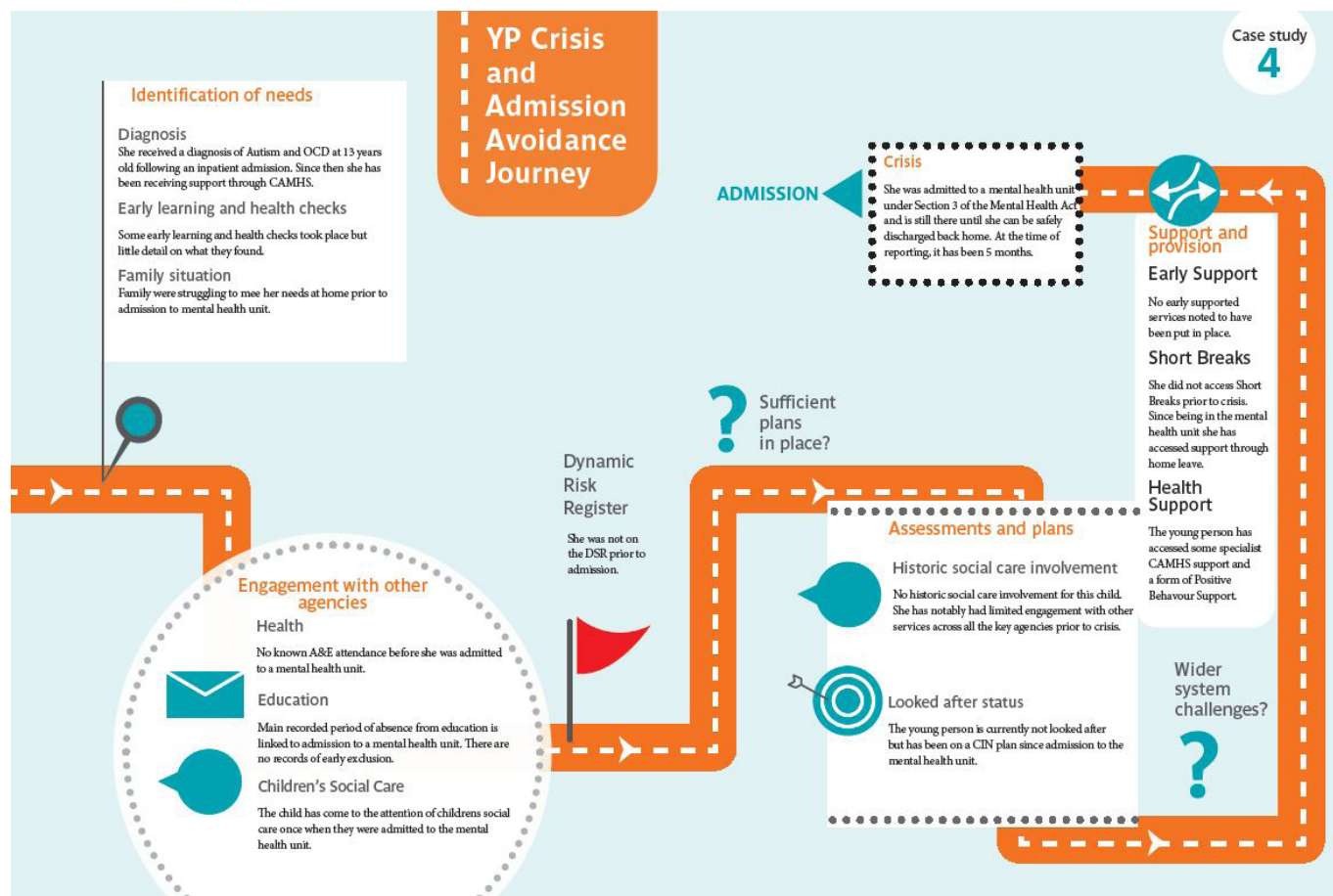
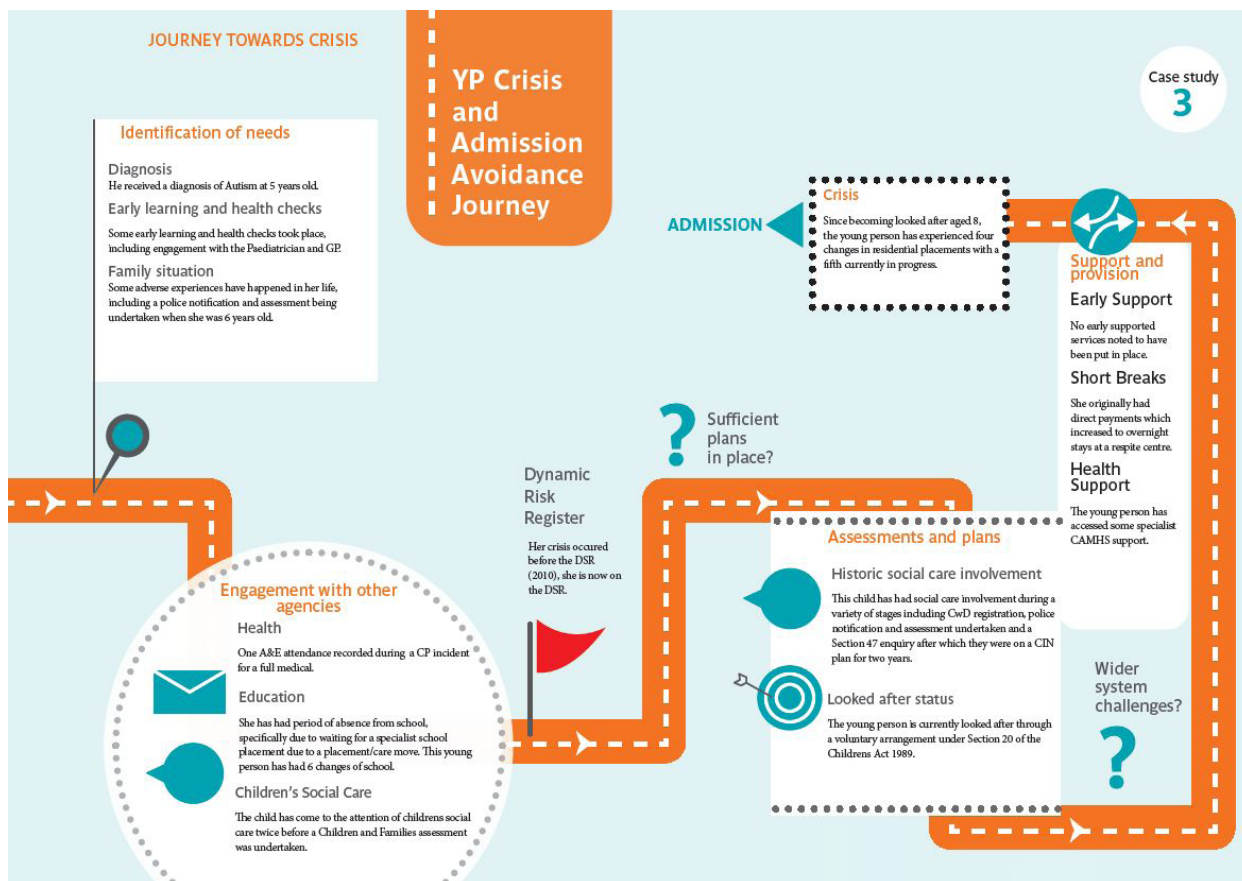
Experience of inpatient/admissions avoidance

- Was there a discharge plan? (Y/N/I don't know)
- Was the discharge plan followed up on? (Y/N/I don't know)
- Were they on the Dynamic Support Register? (Y/N/I don't know)
- If so, what happened as a result?
- Were there any Care Education and Treatment Reviews (CETR) or Local Authority Emergency Protocol (LAEP) in advance of, or after admission? (Y/N/I don't know)
- Was there a risk management plan? (Y/N/I don't know)

Appendix 3 – Children's Journey Maps

Visual representations of all 12 individual journey, plus a summary visual.





JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
5

Identification of needs

Diagnosis

He received a diagnosis of Autism at 11 years old after being on the waiting list for 6 months.

Early learning and health checks

Early learning and health checks took place but he was reported to be meeting developmental milestones so no other agencies involved at this point.

Family situation

History of parental mental health issues, with Adults Services involved in relation to these issues (including boarding).

Engagement with other agencies

Health

No recorded A&E attendances or health engagements prior to crisis.

Education

This young person had several fixed period exclusions and was ultimately permanently excluded. First exclusion took place age 11 shortly after secondary school transfer. Following permanent exclusion he was placed in an Alternative Provision but became an Emotionally Based School Refuser.

Children's Social Care

The child was referred to social care at the point of crisis. There had been no early help involvement prior to this.

Dynamic Risk Register

Yes, eventually, once the home situation broke down but not at the point of diagnosis.

ADMISSION

? Sufficient plans in place?

Crisis

He was admitted to a residential provision but has since moved to a local mainstream school. This was in response to an improvement in his capacity to manage his disability and function with support within a school setting.

Support and provision

Early Support

No early supported services noted to have been put in place. Some SEN support was put in place in primary school following diagnosis.

Short Breaks

He did not access Short Breaks prior to crisis.

Health Support

The young person accessed local CAMHS at the crisis point before Forensic CAMHS assessment was commissioned ultimately.

Wider system challenges?

Assessments and plans

Historic social care involvement

No historic children's social care involvement for this child. Following social care intervention at age 11 he was placed on a CIN plan for approximately 6 months before he was moved to a residential provision.

Looked after status

The young person became looked after via a Care Order and was placed in a residential provision to meet needs.

JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
6

Identification of needs

Diagnosis

She received a diagnosis of Autism aged 9.

Early learning and health checks

Early learning and health checks picked up emotional dysregulation which led to an EHCP and CAMHS involvement.

Family situation

As her behaviours escalated and became harder to manage as she got older her parents struggled to manage her at home leading to residential placement.

Engagement with other agencies

Health

No recorded A&E attendances prior to crisis but some CAMHS engagement noted.

Education

Prior to becoming looked after, she was in a specialist provision which managed her well. However, when she became looked after they needed to seek a residential placement so she had three weeks with no provision whilst this was being arranged.

Children's Social Care

Parents had been in touch with children's social care to request support before crisis and two assessments were completed prior to becoming looked after.

Dynamic Risk Register

It is not known whether this young person was on the DSR.

ADMISSION

? Sufficient plans in place?

Crisis

She was placed in a residential placement following becoming looked after which is maintaining her well.

Support and provision

Early Support

Some early support noted following first statutory EHCP aged 9.

Short Breaks

She accessed short breaks through respite activity and overnights, which increased overtime.

Health Support

The young person has accessed occupational, speech and language and sensory therapy since her diagnosis.

Wider system challenges?

Assessments and plans

Historic social care involvement

She had some previous social care involvement including an Early Help assessment aged 13 and a Children and Families assessment aged 14, shortly before becoming looked after.

Looked after status

The young person became looked after via a voluntary arrangement under section 20 of the Children Act 1989.

JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
7

Identification of needs

Diagnosis
She received a diagnosis of Autism around age 5.

Early learning and health checks
Early learning and health checks took place but it is not clear what agencies were involved as a result of these.

Family situation
No known issues within the family; they are currently managing her well at home.

Engagement with other agencies

Health
No recorded A&E attendances or other health-led interventions.

Education
No noted absences from school or early exclusions. She is noted to have had a change in school aged 7 but no concerns with corresponding absences.

Children's Social Care
As her needs have escalated she has had two social care assessments. One to assess for short breaks in 2020 and a Children and Families assessment in 2021.

Dynamic Risk Register
This young person is not on the DSR.

ADMISSION

? Sufficient plans in place?

Crisis

She has not reached crisis as she is currently managing with her short breaks and targeted support.

Support and provision

Early Support

She has received early support through an Early Intervention support worker, a specialist school PBS plan and behavioural support through a local service.

Short Breaks

Her current short breaks package is under review but includes a grant towards a play scheme, a weekly play session (with transport) and 3 hours of community care weekly.

Health Support

No specific health interventions noted in EHCP.

Wider system challenges?

Assessments and plans

Historic social care involvement
Following the Children and Family assessment in 2021 she was briefly placed on a CIN plan for 2 months but this has since been stepped down.

Looked after status

This young person is not currently looked after.

JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
8

Identification of needs

Diagnosis
She received a formal diagnosis of Autism age 13. It is not known whether she was on a waiting pathway.

Early learning and health checks
During primary school she was identified as having challenging behaviour and was referred to the local CAMHS team for support.

Family situation
Family was engaged with social care for five years prior to young person becoming looked after due to challenges with managing the young person at home.

Engagement with other agencies

Health
She has one recorded A&E attendance at age 15. She first received CAMHS support aged 11.

Education
She has been excluded once at age 12 due to challenging behaviour and aggression. There are some further absences noted related to deterioration in mental health and wellbeing.

Children's Social Care
She has come to the attention of social care once, since then she has continued to be open and receiving support.

Dynamic Risk Register
Yes, at Amber.

ADMISSION

? Sufficient plans in place?

Crisis

Upon becoming looked after she was placed in a residential placement, since 2018 she has 2/3 placement changes due to the nature of difficulties and finding the appropriate staffing capabilities.

Support and provision

Early Support

Limited early support has been noted for this young person.

Short Breaks

She did not receive any short breaks.

Health Support

She has received some specialist support from CAMHS and medication related to her needs.

Assessments and plans

Historic social care involvement
She first became open to Children's Social Care aged 12 and remained as an open case on CIN and CP plans until she became looked after.

Looked after status

This young person became looked after through a Care Order.

Wider system challenges?

JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
9

Identification of needs

Diagnosis

He received a formal diagnosis of Autism age 5.

Early learning and health checks

Early learning and health checks also identified

Arrhythmogenic Right Ventricular Dysplasia (ARVD) and mild LD.

Other agencies were involved following this.

Family situation

Family have had engagement from many agencies due to the complexity of this young person's needs.

Engagement with other agencies

Health

Between the ages of 15 and 16 this child has had approximately 5 recorded A&E attendances.

Education

He has previously been suspended from school following an incident with members of staff and children. He has periods of absence related to periods in A&E.

Children's Social Care

This young person first came to the attention of children's social care aged 14, at which point a Children and Family assessment was undertaken.

Dynamic Risk Register
Yes, at Red.

ADMISSION

Crisis

Following crisis, the young person was placed in a standalone placement with 24/7 wraparound care and specialist CAMHS input. He is currently in the process of moving to a residential unit.

Support and provision

Early Support

Some early support was put in place following first statutory EHCP aged 5.

Short Breaks

He did access Short Breaks but no details are known. This support was commissioned by health.

Health Support

On top of specialist support from CAMHS and medication related to her needs, he also received some SALT/OT support.

Wider system challenges?
?

Assessments and plans

Historic social care involvement

Following the Children and Families Assessment aged 14, the young person was placed on a CIN plan until he became looked after at 17.

Looked after status

This young person became looked after through a voluntary arrangement under section 20 of the Children Act 1989.

? Sufficient plans in place?

Dynamic Risk Register
Not on the DSR at this time.

ADMISSION

Crisis

The young person has not reached crisis as the comprehensive support packages around him have mitigated risk well. At times these supports have been increased to meet changing needs.

Support and provision

Early Support

He received a part time programme of 17 hours per week at home through the Early Intensive Behaviour Intervention programme.

Short Breaks

He currently receives both day and overnight short breaks, commissioned by health.

Health Support

He receives complex health support including SALT/OT, specialist support from CAMHS, medication and nutrition support.

Wider system challenges?
?

Assessments and plans

Historic social care involvement

The young person had their first assessment age 4 which led to them being placed on a CIN plan under section 17 of the Children Act 1989.

Looked after status

This young person is not currently looked after.

JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
10

Identification of needs

Diagnosis

He received a formal diagnosis of Autism age 3 after being on the waiting pathway for 7 months.

Early learning and health checks

Young person has complex health needs so was seen extensively by professionals across health agencies, which remained involved with the young person.

Family situation

Family have had engagement from many agencies due to the complexity of this young person's needs.

Engagement with other agencies

Health

Only one A&E attendance at age 6 related to ear pain.

Education

There have been no recorded periods of absence from school or any early exclusions. He had his first statutory EHC needs assessment at age 3.

Children's Social Care

Because of the complexity of needs, social care has been involved periodically.

Dynamic Risk Register
Not on the DSR at this time.

? Sufficient plans in place?

ADMISSION

Crisis

The young person has not reached crisis as the comprehensive support packages around him have mitigated risk well. At times these supports have been increased to meet changing needs.

Support and provision

Early Support

He received a part time programme of 17 hours per week at home through the Early Intensive Behaviour Intervention programme.

Short Breaks

He currently receives both day and overnight short breaks, commissioned by health.

Health Support

He receives complex health support including SALT/OT, specialist support from CAMHS, medication and nutrition support.

Wider system challenges?
?

Assessments and plans

Historic social care involvement

The young person had their first assessment age 4 which led to them being placed on a CIN plan under section 17 of the Children Act 1989.

Looked after status

This young person is not currently looked after.

JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
11

Identification of needs

Diagnosis

She received a formal diagnosis before the age of 4. She also has diagnoses of epilepsy and foetal alcohol spectrum disorder.

Early learning and health checks

It is not clear which, early learning and health checks took place or what they led to in terms of services.

Family situation

The young person has had a complex childhood and is currently looked after by her grandparents through a special guardianship order.

Engagement with other agencies

Health

There have been hospital admissions and attendances related to co-diagnosis of epilepsy.

Education

A previous education setting broke down leading to her missing a term of schooling in KS2. She also had a period of absence at secondary transfer as her guardians struggled to make a decision regarding a specialist placement. She was out of school for 9 months whilst this was resolved and received home tuition.

Children's Social Care

The young person has had significant periods of social care involvement throughout her life.

Dynamic Risk Register
Not on the DSR at this time.

ADMISSION

Crisis

Although the young person has not reached crisis, she has experienced several different specialist day placements in response to her grandparents preferences and her changing medical needs.

Support and provision

Early Support

She accessed early learning support and attended a nurture provision in her primary setting.

Short Breaks

She has not accessed short breaks support.

Health Support

She receives complex health support including SALT/OT, specialist support from CAMHS (including music therapy), medication and ongoing family/carer support.

Wider system challenges?

Assessments and plans

Historic social care involvement

Her first engagement with social care was at age 1. She was previously on a CP plan for neglect for 14 months and has been on several CIN plans, the most recent was for 8 months.

Looked after status

This young person is not currently looked after, and is being cared for by her grandparents through an SGO.

? Sufficient plans in place?

JOURNEY TOWARDS CRISIS

YP Crisis and Admission Avoidance Journey

Case study
12

Identification of needs

Diagnosis

He didn't receive a diagnosis of Autism until 13 and ADHD at 15. However, parents noticed traits as early as 2 years old and it isn't clear why there was such a long delay to diagnosis.

Early learning and health checks

His early needs went undetected for a long time during his childhood, however he did have some SALT in reception focused on communication.

Family situation

The young person has been managed at home for most of his life with limited support from other services.

Engagement with other agencies

Health

The young person presented at A&E 3 times between April-August 2021, aged 15.

Education

The young person was excluded from school at age 15 due to an escalation in his mental health presentation. Following this, CAMHS and other health support services were put in place.

Children's Social Care

The young person did not receive support from children's social care until age 15 at the time of his exclusion.

Dynamic Risk Register
Not on the DSR at this time.

ADMISSION

Crisis

This young person experienced a rapid escalation in mental health needs which led him to come to the attention of social care and health. Since then a robust package of support has been implemented to keep him safe at home.

Support and provision

Early Support

Except for some SALT engagement at reception, this young person has received limited early support due to delays in diagnosis.

Short Breaks

He has not accessed short breaks support.

Health Support

Following social care involvement, he has a robust package of support including CAMHS, PBS, personal health budget and medication.

Wider system challenges?

Assessments and plans

Historic social care involvement

This young person has not had historic social care engagement and was only brought to social care's attention at age 15 when we had an escalation in his mental health needs. At this time he was placed on a plan to manage support.

Looked after status

This young person is not currently looked after, and parenting training and 1:1 support at home have been put in place to mitigate against this.

? Sufficient plans in place?

PRIOR TO CRISIS

Identification of needs

Diagnosis

75% received a diagnosis by age 11, with 5 receiving a diagnosis by age of 5. 3 didn't receive a formal diagnosis until adolescence and for at least one young person this was linked to inpatient admission.

Early Learning and Health Checks

The majority of children had some form of needs identified at these checks but only 50% are known to have other agencies involved following these checks.

Children and Young People's Journeys in London

Engagement with other agencies

Health

7 children presented at A&E during their lives, with one young person presenting approximately 5 times between 15 and 16

Education

75% of children had recorded periods of time out of school and four experienced at least one exclusion.

Children's Social Care

The children were known to children's social care, with the majority coming to their attention between one and six times.

Dynamic Risk Register

4 were on the DSR, 3 were not known whether they were or not.

? Sufficient plans in place?

CRISIS

Reviews

All young people who experienced residential placements (8) were seen by a variety of professionals and reviews happened in a timely way.

Changes of provision

All except one young person experienced at least one change of provision.

In one instance this was because complexity of needs reduced, allowing a placement with other young people.

Discharge Plan

For young people in an inpatient setting (4), all except one had a discharge plan that was followed up on.

Half had not been on the DSR.

Assessments and Plans

Historic Social Care Involvement

66% of children profiled had historic engagement with social care and many had been subject to either a CIN or CP plan.

10 out of 12 young people had been on a CIN.

Looked After Status

Following their engagement with children's social care, 6 young people became looked after. Half of these young people became looked after under Section 20 of the Children's Act 1989.

Case study
All

Support and Provision

Early Support

11 out of 12 had received some early support but the extent of interventions ranged greatly.

Short Breaks

Only 5 families were able to access this and predominantly at low levels.

Health Support

Only one young person was experiencing no health support or treatment, with the rest of the sample experiencing 3-4 supports on average.

Wider system challenges?





NATIONAL
CHILDREN'S
BUREAU

United for a better childhood

The National Children's Bureau brings people and organisations together to drive change in society and deliver a better childhood for the UK. We interrogate policy, uncover evidence and develop better ways of supporting children and families.

Let's work together: 020 7843 6000 | info@ncb.org.uk

London: 23 Mentmore Terrace, London, E8 3PN

Belfast: The NICVA Building, 61 Duncairn Gardens, BT15 2GB