



CHILDREN'S AND YOUNG PEOPLE'S TRUST BOARD

COMMITTEE ROOM 1, COUNTY HALL, MATLOCK, DE4 3AG

Thursday 10th December 2015, 4.30pm – 6.30pm

AGENDA

1.	Apologies for Absence	
2.	Declarations of Interest	
3.	To confirm the minutes of the meeting held on 10th September 2015 and matters arising	
4.	To confirm the minutes of the Core Business Group meetings held on 22nd October and 12th November 2015 and matters arising	
5.	Derbyshire Youth Council <ul style="list-style-type: none"> How can the Trust Board support the Youth Council in delivering its Manifesto priorities: Follow up on action points from 10th September Board Meeting 	DYC Members
6.	Joined up commissioning <ul style="list-style-type: none"> Main discussion item: Joined up commissioning in the context of Re-thinking the Early Help Offer (to be presented on the day) 	Linda Dale Mel Meggs

PAPERS FOR AGREEMENT

7.	Future in Mind Transformation Plan <ul style="list-style-type: none"> Update on progress. Healthwatch CAMHS Reports – North and South Derbyshire 	Linda Dale Karen Ritchie
8.	Children's Trust Workforce Strategy Sub-Group <ul style="list-style-type: none"> The Board will be asked to confirm the priorities for this group and review attendance 	Ian Johnson
9.	Healthwatch – Autism Report <ul style="list-style-type: none"> The Board will be asked to note the findings in this report and the action that will be taken by the Children's Autism Co-ordinating Group 	Karen Ritchie
10.	SEND – Update report	Alex Howlett

	<ul style="list-style-type: none"> The Board will be asked to note the work underway and offer any feedback, comments or advice 	Programme Manager, SEND Reforms
11.	School Readiness <ul style="list-style-type: none"> The Board will be asked to endorse the 10 keys to unlocking school readiness and commit to further joint working to make these recommendations in the report a reality 	Sue Ricketts Senior Adviser for School Improvement

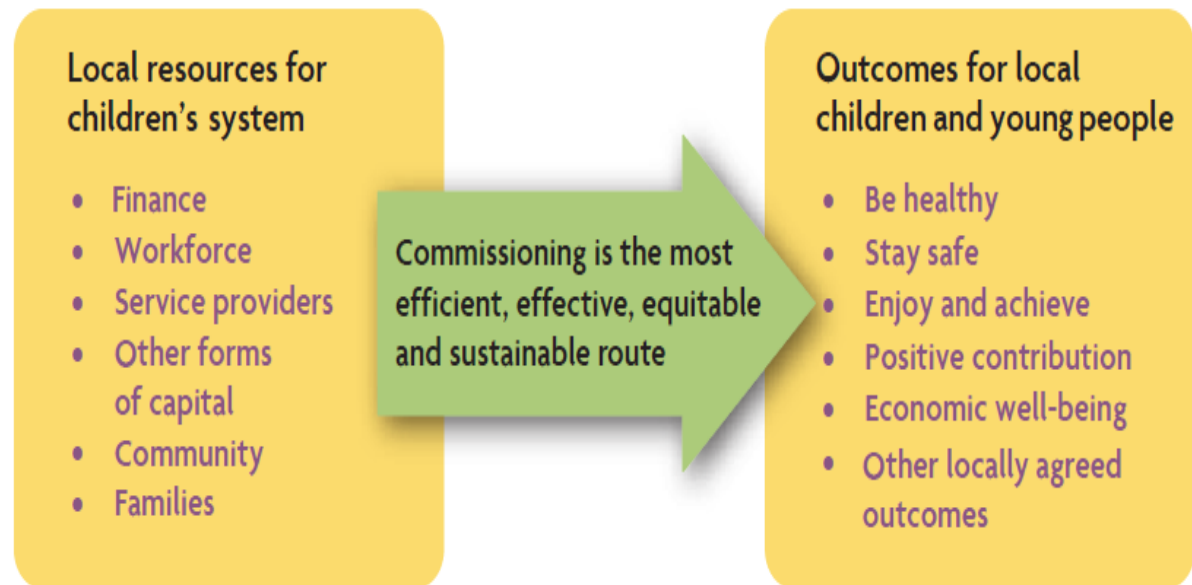
12.	Safeguarding Board update	Christine Cassell
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PAPERS FOR INFORMATION*(It is not planned to discuss any of the following papers at the meeting. If any Board member wishes to discuss a paper for information, please can they notify the Chair 48 hours in advance of the meeting)*

13.	Performance Monitoring Report	Linda Dale
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Joined Up Commissioning

‘Commissioning is the process for deciding how to use the total resource available for families in order to improve outcomes in the most efficient, effective, equitable and sustainable way.’



Principles adopted by Children's Trust in 2011:

- **Local Strategic Fit** with the direction and needs evidenced in JSNA & Children's and Young People's Plan
- **Outcomes** – prioritise investment in prevention and interventions which can demonstrate an improvement in outcomes
- **Evidence of Effectiveness** –prioritise investment in interventions and services with a sound evidence base.
- **Inequalities** –prioritise interventions which address the needs of groups with poorer than average outcomes.
- **Cost Effectiveness** –prioritise investment in interventions that can demonstrate the best possible outcomes relative to cost
- **User Experience of Services** – aim to provide the best possible user experience of services and will engage service users at every stage

Joint Commissioning Group

- Established summer 2015
- County & City LA Children's Services & Public Health Children's Commissioning Leads
- CCG children's commissioning leads
- Key joint priorities:
 - Future in Mind Transformation Plan
 - Children with complex needs – 3-year section 75 agreement, commissioning of hospices
 - SEND

Re-thinking the Early Help Offer

What does Early Help look like now?

- Defined early help offer for those at risk of not achieving good outcomes (includes safeguarding but not exclusively)
- 33 Multi Agency Teams: organised into 6 Localities. Including 22 Youth Centres, 50 Children Centres
- Formed around school boundaries
- Funding investment of £20,000,000 in total
- 14,465 referrals for early help
- 8,408 early help assessments since April 2015

Rising Demand for Services – The Last 3 Years

	2012/13	2013/14	2014/15	Current	Trend
Initial Contacts	22993	23800	26353	29948	↑
Referrals - Social Care	11993	12556	9713	9726	↑
Referrals - Early Help	-	-	11028	14465	↑
Single Assessments Completed	-	-	5838	6420	↑
Early Help Assessments Completed	-	-	6837	8408	↑
Children in Care	664	628	603	626	↓
Children on a Plan	694	644	642	634	↓
Children in Need	3465	3210	3448	3338	↔
Number of ICPC's held	851	935	913	930	↑
Number of potential CSE referrals		268	275	462	↑

The Future: £5-6m reduction in MAT budgets by 2017-18 (39 - 46%)

	Number of MATs	15/16	Reduction in Budget	17/18
Derbyshire	25	12,942,650	5,000,000	7,942,650
Amber Valley	4	1,958,438	756,583	1,201,855
Bolsover & NE	6	3,130,686	1,209,446	1,921,240
Chesterfield	4	2,274,073	878,519	1,395,554
Erewash	4	1,967,420	760,053	1,207,367
High Peak	4	2,026,171	782,750	1,243,421
South Derbyshire	3	1,585,862	612,650	973,212

At reduced funding levels:

- Only Child in Need (section 17) or Child Protection (Section 47) thresholds
- No joint working at an area/school cluster/whole-school level to address issues of concern
- No Early Help Assessments for children with “emerging needs”

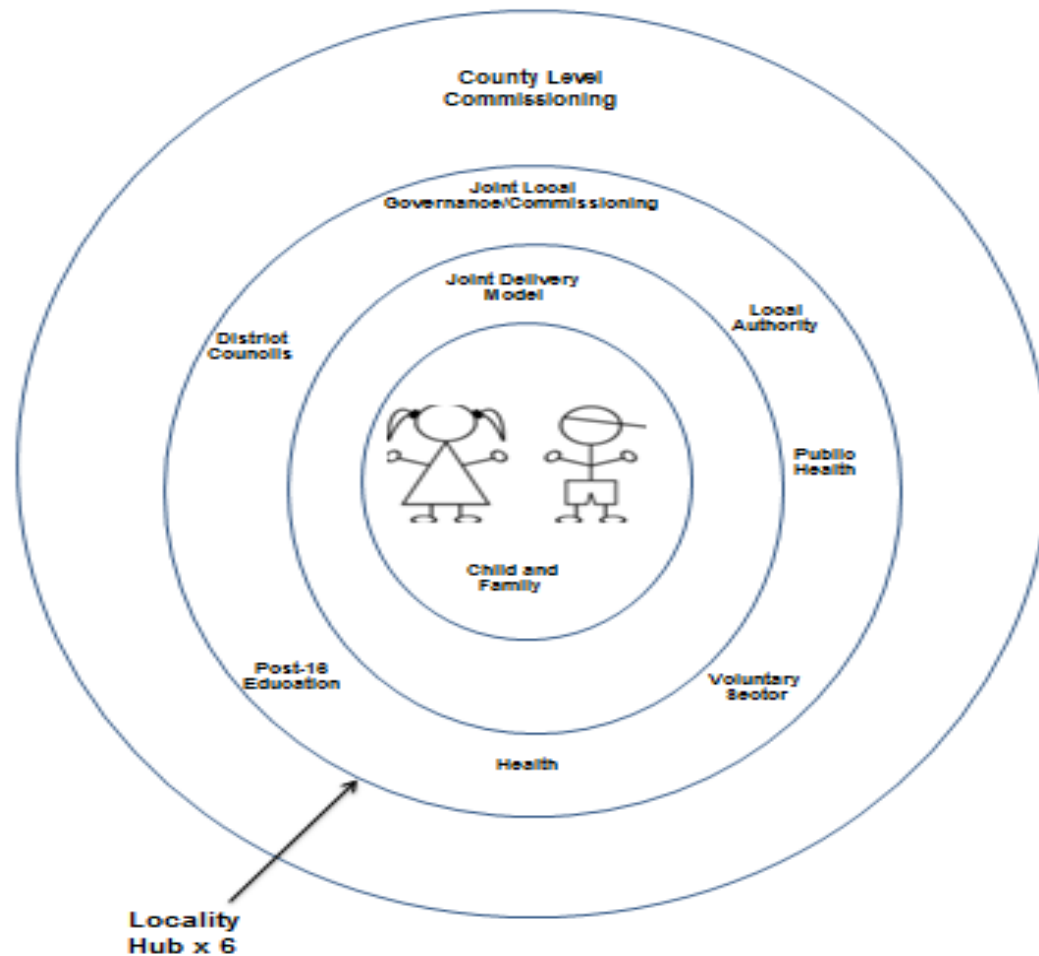
The Proposal

- **Voluntary re-pooling of £5m school funding allocations and £8m Derbyshire County Council funding for local Early Help Services**
- **Locality based co- design of services based on agreed outcomes/performance framework**
- **Budget for each Locality controlled by a “Commissioning Hub”**

5 Prototype areas developing models for co-commissioning and service delivery:

- **Whittington Green: Aligning school based family support with MATs**
- **Kirk Hallam: Co-ordinating across MATs and schools; focusing on school readiness**
- **Hope Valley: Strengthening governance**
- **South Derbyshire: Joint governance, partnership working with health and voluntary sector**
- **Heanor Gate: Early stage, focus on joint working**

Radical Rethink of the Early Help Offer (REHO) – Proposed Co-Commissioning Model



1 Commissioning Hub in each Locality (6 Localities):

- 1 representative from each school cluster
- Children's Services - Head of Service (Locality)
- Public Health
- Voluntary sector
- NHS Clinical Commissioning Group
- 1 x Commissioning Manager
- Locally decided partners

- **Commissioning Hub = formal governance group**
- **Formal agreement in place setting out responsibilities and arrangements**
- **Joint accountability to all contributing partners**

5 Prototype areas exploring the model:

- **Whittington Green: Aligning school-based family support with MATs**
- **Kirk Hallam: Co-ordinating MAT and school support. Focusing on school-readiness**
- **Hope Valley: Governance and accountability**
- **South Derbyshire: Joint governance. Partnership working with health and voluntary sector**
- **Heanor Gate: Early stage, focus on joint working.**

Group Discussion:

What are the strengths and opportunities of a locality based commissioning model for Early Help Services?

What are the risks?

How does the proposal align with partners' thinking about future commissioning models and approaches?

How do Children's Trust partners want to be involved?

Are there other budgets or funding streams which could be aligned within a Locality Commissioning model?

What should the relationship be between Locality Commissioning Hubs and Locality Partnerships?

Children's Trust Board Meeting – 10th September 2015

DYC ISA.D Flipchart Activity

Living Wage

<u>Issue</u>	<u>Sector</u>	<u>Action (responsibility)</u>	<u>Deadline (when by?)</u>
Make Your Mark Campaign	All	Promote the campaign and ensure all partners are aware of it	3 rd October 2015

Online Safety

<u>Issue</u>	<u>Sector</u>	<u>Action (responsibility)</u>	<u>Deadline (when by?)</u>
PSHE Consultants to support with development of resources	Kathryn Boulton CAYA	To connect Libby and PSHE consultant so can work together	By the end of September
Headteachers and governors	Kathryn Boulton CAYA	To enable access to HT + Governor forums to share messages and Libby's resource	As required
Competition for secondary schools on e-safety – need to join up with the youth council	Amanda Clarke Julie Oldknow CAYA	Youth council to be involved in judging and making use of campaign	December
Post 16 resource used – Cruel Kindness	Guy Hodgkinson – Derby College	To share resource details	
Free online resources			
Parenting support will include on-line safety + resources from Youth Council	CAYA – Ian Johnson	Review partnership programme in schools Resources out there already – review what we can use in different schools	By 20 th October 2015

Headteachers and governors	CAYA Kathryn Boulton	To enable access to HT + Governor forums to share messages	As required
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Mental Health

<u>Issue</u>	<u>Sector</u>	<u>Action (responsibility)</u>	<u>Deadline (when by?)</u>
Derbyshire VCI Consortium – Bid	Derbyshire VCI/DYC	Tackling the stigma/looking at what is already provided/how can we make changes	
Future in Mind – Transformation Plan	Health	Looking at eating disorders support/transparency in services/continuing CAHMS – is this always the right way to go/Having a crisis support line – something relevant instead of A&E/Anti-stigma campaign in schools	Mid October
Elaine Michel	Public Health	What elements are already in place? – meeting /All ages mental health/Suicide prevention – links to safeguarding/Supporting families – bond better with child/Transition from young person to adult – making this process more slick	

Work Experience

- Work experience placements and apprenticeships are a priority

- We need to ensure quality of experience – find out where the gaps are?

FUTURE IN MIND

Background

1. Future in Mind is a new CCG funding allocation aimed at improving the emotional health and well-being of children and young people. CCGs were required to produce a plan to release their full funding allocations.
2. The four Derbyshire CCGs, Derby City Council and Derbyshire County Council collaborated to produce a joint Plan, which was submitted on 16th October. The Plan was approved on 26th October.
3. Tameside and Glossop CCG submitted a separate Plan, which covers the Glossopdale community. This is fully consistent with the Derbyshire Plan. The Tameside and Glossop Plan is also expected to be approved.

Summary of Plan

4. Development of the Plan has been led by feedback from children, people and their families. Key elements of what they tell us are highlighted in Section 2 of the Plan.
5. The shared vision is that, by 2020:

'Children and young people are able to achieve positive emotional health by having access to high quality, local provision, appropriate to their need, as well as a range of support enabling self-help, recovery and wellbeing.'
6. The Plan is underpinned by a whole systems approach. Each part of the system has an integral part to play, and links between education, health and social care are imperative if the vision is to be achieved. The intention is to improve outcomes by intervening earlier, prevent needs from escalating and reduce demand for high-cost support.
7. The Plan will:
 - Invest in additional staff and training to deliver a single, outcomes-focused service specification for eating disorders which will meet national access and waiting time standards.

- Invest across the ‘whole-system’ including primary care, schools and voluntary sector to build resilience, enable self-care and provide access to early help, reducing the need for high-cost support including inpatient/Tier 4 beds.
- Extend the use of evidence based approaches such as the Children and Young People’s Improving Access to Psychological Therapies programme (CYP IAPT) within the Multi-Agency Teams (MATs), and increase CAMHS support to the MATs.
- Build up investment in ‘rapid response’ to ensure access to CAMHS 24/7, with more home-based treatment to reduce the need for inpatient beds.
- Increase therapeutic support for children in care, and invest in training to improve access to therapeutic interventions for children and young people who experience sexual abuse/child sexual exploitation.

8. Some objectives and approaches are specific to either the North or South Units of Planning, reflecting their different starting points and arrangements to enable the shared vision to be realised and building on previous experience.

9. In the North, an initial key priority for the specialist CAMHS will be to work towards becoming ‘CYP IAPT ready’, in order to join a collaborative. This will involve the use of routine outcome monitoring, improving IT systems and data collection methods.

10. In the South, there will be additional investment in evidence-based parenting programmes. As a principle year one will be used to pilot different evidence based integrated delivery models to test ‘proof of concept’. This is consistent with the wider CCG children’s transformation programme and will inform learning to roll out future developments.

11. For more detail on the action plans for 2015-16 and beyond see section 4 of the Plan.

Future in Mind Funding Allocations

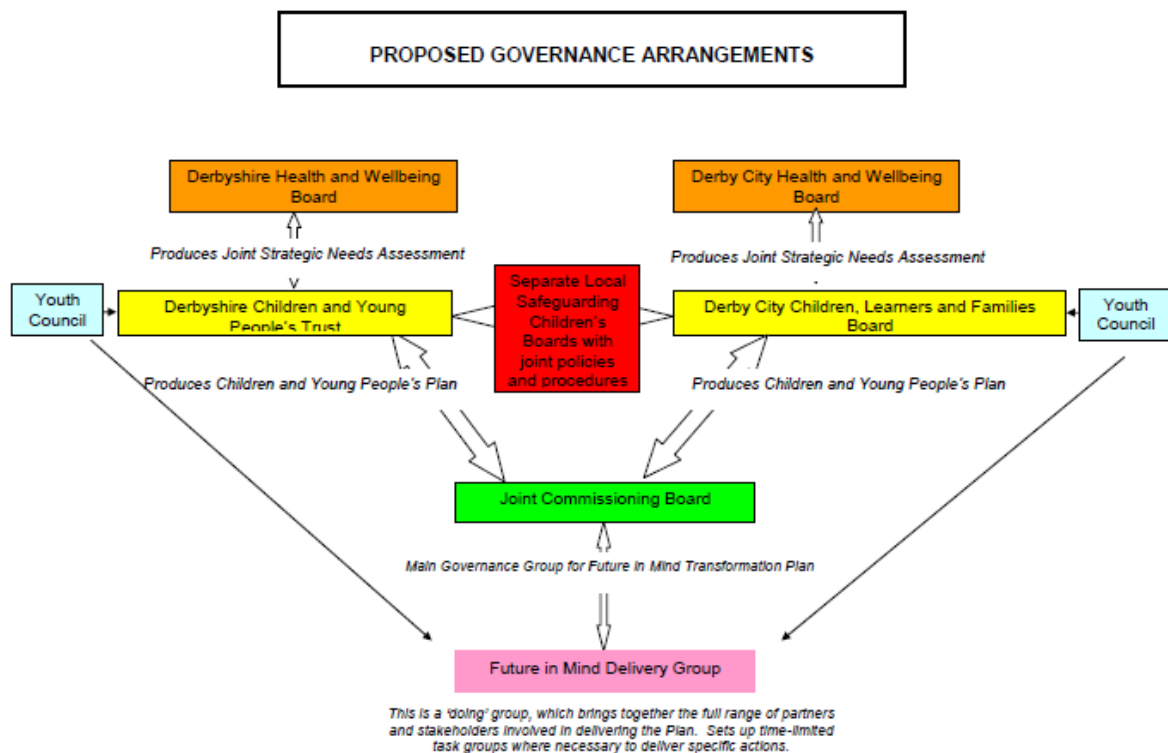
12. The additional funding which is available for the Plan is detailed below:

CCG Name	Initial allocation for eating disorders	Additional funding available following assurance of Transformational Plan
	£	£
Erewash CCG	55,042	137,776
Hardwick CCG	60,397	151,179
North Derbyshire CCG	157,846	395,105
Southern Derbyshire CCG	293,875	735,598

Governance Arrangements

13. The existing Integrated Behaviour Partnership Group will become the Future in Mind Transformation Plan Delivery Group. This will be a 'doing' group of key partners and stakeholders who will co-ordinate and deliver action to implement the Plan. The membership will be expanded so that it includes a wider range of partners and stakeholders.

14. This programme is part of the Joined up Care Transformation programmes in the north and south units of planning. The Future in Mind Delivery Group will report progress information to the transformation programmes. The overall programme will be strategically monitored and reviewed quarterly by the Joint Children and Young peoples' Commissioning Board which sits across the four CCGs and two Local Authorities. The proposed governance arrangements are illustrated in the diagram below:



15. The four Derbyshire CCGs are individually accountable for the commissioning of children and young people's mental health services at local level and will also be individually accountable for the Future in Mind funding allocations and how these are used to improve local services. This work will be coordinated via the Joint Commissioning Board to ensure there is parity and alignment of strategy and provision.

Communications and Engagement

16. One of the first tasks of the Delivery Group will be to prepare a communications plan, so that all key partners and stakeholders are aware of the transformation plan and have an opportunity to contribute.

17. A range of workshops and learning events are also planned, which will enable learning and sharing across both Units of Planning. This will address the action to hold a workshop in the refreshed Health and Wellbeing Strategy for 2015-17.

Child and Adolescent Mental Health Services (CAMHS)

Experiences of using CAMHS in North Derbyshire, as told by young people, parents, carers and professionals.

Helen Hart
July 2015

CONTENTS

	Page
1. Acknowledgement	3
2. Disclaimer	3
3. Background	3
4. Rationale for the Report	5
5. Methodology	5
6. Information & Signposting	6
7. Summary of Findings	6
8. Findings	6
9. Recommendations	11
10. Response from Service Providers and Commissioners	11

1. Acknowledgement

Many thanks to the CAMHS team for their support and for making our staff feel welcome. We would also like to thank the participants who gave up their time to talk to us.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all young people, parent, carers and professionals who have experience of CAMHS, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that young people, parents, carers and professionals have conveyed to Healthwatch Derbyshire. The data should be used in conjunction with, and to compliment, other sources of data that are available.

3. Background

3.1 Healthwatch Derbyshire

Healthwatch Derbyshire is the local consumer champion for health and social care. The Healthwatch network is made of up of local Healthwatch across 148 local authority areas and Healthwatch England, the national body.

Healthwatch has a common purpose - to ensure the voices of people who use services are listened to and responded to. The network shares a brand, has common values and comes together to work on priority areas and campaigns.

Local Healthwatch work to provide unique insight into people's experiences of health and social care issues in their local area; Healthwatch Derbyshire is the eyes and ears on the ground finding out what matters to our local community.

3.2 Child and Adolescent Mental Health Services (CAMHS)

There is currently a national focus on CAMHS led by the Children and Young People's Mental Health and Wellbeing Taskforce which was established in September 2014 to consider:

- Ways to make it easier for children, young people, parents and carers to access help and support when needed; and
- How to improve the way children and young people's mental health services are organised, commissioned and provided.

The Taskforce produced a report in March 2015 'Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing. This report includes recommendation for both transformation changes, to begin as soon as possible, and a number of longer-term aspirations to be achieved by 2020, to allow for work to be aligned with the NHS Five Year Forward View.

The report highlights a number of key drivers for this change, which are as follows:

- One in ten children require support or treatment for mental health problems.
- 75% of adult mental health problems (excluding dementia) develop by the age of 18.
- In an average class of 30 schoolchildren, three pupils will suffer from a diagnosable mental health disorder.
- A treatment gap exists where only 25%-30% of those with a diagnosable mental health condition accessed support.
- Demand is increased for services, especially for young women with emotional problems and young people presenting with self-harm.
- Early intervention and prevention in childhood can avoid expensive and longer term interventions in adulthood. For example, children with early conduct disorder are 10 times more costly to the public sector by the age of 28 than other children.
- There is a cost benefit to society of tackling mental health issues early in life. These benefits are achieved through the reduction in use of public services due to better mental health and by increased earnings associated with the impact of improved mental health on educational attainment.
- In some areas there is a poor provision of out-of-hours, crisis point and psychiatry services and some local authorities do not have a Care Quality Commission (CQC) recorded place of safety.
- The Taskforce noted a lack of clear leadership and accountability arrangements for children's mental health issues across agencies, including Clinical Commissioning Groups (CCGs) and local authorities, creating the potential for individuals to 'fall through the net.'

The report focuses on 5 key themes, and makes a range of recommendations to improve the structure, delivery and transformation of services.

1. Promoting resilience, prevention and early intervention.
2. Improving access to effective support - a care system without tiers.
3. Care for the most vulnerable.
4. Accountability and transparency.
5. Developing the workforce.

Locally:

- Services are reporting an increasing concern about self-harm. CAMHS report a sharp increase in around 10% in referrals. Self-harm and eating disorders feature prominently in this increase.
- In 2013-14 the rate of hospital admissions of 10-24 years olds in Derbyshire due to self-harm was 377.5 per 100,000, above the 2012-13 national average.
- The number of Derbyshire young people who require Tier 4 (in-patient) CAMHS placements remain low in comparison with other areas, however numbers have increased sharply over the past 3 years (up from 5 in 2011/12 to 30 in 2013/14). Trends in Derbyshire are in line with an increase in Tier 4 placements nationally.

Local response to 'Future in Mind': The Derbyshire CCGs, Derbyshire County Council and Derby City Council are working together to plan a response. A transformation plan will be

required imminently to release additional funding to address developments/improvement to CAMHS.

4. Rationale for the Report

In addition to an awareness of the national and local focus on CAMHS, Healthwatch Derbyshire had received a cluster of comments from users of CAMHS, which were of mixed sentiment. This led Healthwatch Derbyshire to choose CAMHS as a work priority from January - March 2015. The aim was to explore these experiences in more detail, to find out what was working well, and what could be improved.

It is the hope that this report will provide service providers and commissioners with some useful insight into how service users experience CAMHS, support service development plans and provide suggestions for improvement.

5. Methodology

From January - March 2015, our 4 Engagement Officers spent their time out and about in the community, at groups and in CAMHS clinics listening to what people had to say about CAMHS.

This report covers the comments made in 29 interviews. Many of these interviews were conducted at CAMHS clinics, which gave the benefit of being able to talk to participants about their experiences at the point of service delivery. Some participants also spoke about experiences of using other services not provided by CAMHS. Although this was not the focus of this piece of work, these experiences are included in this report for completeness.

Our Engagement Officers developed a series of discussion prompts to use when talking to young people, parents, carers or professionals about their experiences of CAMHS. These prompts were very broad and covered experiences during referral and access to the service, what it was like to use the service, the quality of care they received and if they felt it was helping. These prompts were used informally to help steer the conversation when necessary but staff used a flexible approach with this as a prompt sheet rather than a formal interview style. This is because although questionnaires or structured interviews would have given more measurable data, this could have been a barrier to engagement.

The 29 interviews conducted were a mixture of young people using CAMHS services, parents, carers, and professionals.

All responses have been themed and are outlined in the findings section of this report.

The reasons for referral (where known) included:

- Anxiety
- Panic Attacks
- Self-Harming
- Depression
- Suicidal
- Attachment Disorder
- ADHD

6. Information and Signposting

In addition to ensuring that the voices of service users, patients and the public are heard by decision makers within health and social care, we also provide an information and signposting service to the public about accessing health and social care services.

During this piece of work Engagement Officers signposted many participants to a combination of groups, including Think Carer, Derbyshire Carers, Derbyshire County Council for a Carer Assessment, Parenting Additional Needs, Chesterfield Community Farm and Everyone Hurts.

7. Summary of Findings

There are patterns in these experiences that would suggest that some parts of the experience works well, whilst others do not work as well.

The clearest example of this relates to the relatively high number of negatives, compared to positives, regarding referrals and diagnosis. Sometimes participants spoke about a real challenge to get into the service in the right place, at the right time - although there were positives in this regard too. All comments regarding diagnosis were negative.

Conversely, there were many positive comments regarding quality of staff, the quality of the service and the seemingly positive impact for those using CAMHS, with only a few examples of negative experiences.

In short, the information suggests that the main difficulties lie in getting into CAMHS and going through the referral and diagnosis process. Once participants were 'in' the CAMHS service, they were generally very positive about the experience.

8. Findings

8.1 Referrals

There were a range of experiences around the referral to CAMHS.

To some the referral was a quick and responsive process, whilst for others it was a more protracted experience.

It was also highlighted that there were some problems for foster children.

Positive

- 'Referral was done via a GP who was excellent and had recognised a problem.'
- One family had seen their own GP and within 5 days had heard from CAMHS.

- 'GP referred my child very quickly to CAMHS, we only had to wait 1 month for an appointment.'
- 'School Nurse did an emergency referral - we only had to wait 4 days for an appointment.'

Negative

- 'We had to see our GP more than once to get a referral in to CAMHS.'
- 'GP referred us to CAMHS as an emergency referral but we waited 5 months for an appointment.'
- It was 3 appointments with the GP before a referral took place as the young person, aged 13 years, was diagnosed as 'naughty'. It wasn't until a violent incident that it was taken seriously and led to a referral, which then took 2 months from the date of the incident.
- Young person, aged 12, had been referred by school doctor in June 2014, first appointment at CAMHS was January 2015. Still no diagnosis. The mother referred to 'battling since he was 2½ years' and it is now apparent that the child may have Asperger's.
- 'Re-referral not possible if discharged ... you have to go through same process again.'
- One family experienced a major crisis before they got in to CAMHS, 'It took months.' They felt that had they got in sooner the crisis may not have happened. Their child was admitted as an in-patient.
- An account was given of problems regarding foster children, in that they cannot be referred by Social Services to CAMHS unless they are in a stable, long term placement. The problem reported is that if the child does have mental health issues then it is likely they are 'moved on', therefore will not have a stable home, and in this case can only be helped by the GP.
- One professional said that referral can be very hard. They said that in many cases they found that CAMHS 'bounced cases back to MATS due to behaviour' when it clearly wasn't. 'You feel every referral has to be justified and every single detail included otherwise it comes back as behavioural.' They added, 'I have had to pull teeth to get them here today and it has taken 6 months to get a first appointment.'

Mixed

- 'The school doctor referred to CAMHS, but it took two attempts. The first referral had been made by a GP who had listened, but nothing happened despite a 6 month wait.'
- 'Our GP originally referred us to see a Psychologist for 6 weeks of CBT and then my child was discharged. Things got worse and we were put on a waiting list for 1 year to see a Psychologist again, we had to go back to the GP to try and speed things up.'
- 'GP referred my child really quickly because of self-harming concerns. I only had to raise it once and the GP acted on it. I had to wait 3 months for an appointment, the GP didn't advise me on any coping strategies in the meantime.'

8.2 Diagnosis Delays

The interviews highlighted that there were real problems with delays in diagnosis.

All experiences described were negative.

This links with the section above, which also contains accounts of diagnosis delay.

- Despite parent mentioning to nursery staff about child's social and emotional behaviour, it was dismissed by staff saying that it was 'due to level of maturity.' By the time the young person reached school age, things were still the same.
- 'No formal diagnosis - we are still waiting for CAMHS.'
- 'In state of limbo until diagnosis confirmed which takes too long ...'
- One mother referred to being passed from pillar to post ..., 'From Education Psychologist, to Visual Impairment, to Speech and Language to Occupational Therapy to Child Development. You name it, we've been there and still waiting diagnosis.'
- One parent had five different CAMHS workers. The first one said the child had anger problems, the second denied it could be Asperger's despite all the traits being displayed. 'I have been going 8 years to CAMHS and they still won't label my child.'

8.3 Appointments

Appointments were sometimes found to be an issue in terms of length of time before appointments began, frequency, duration of appointments and cancellations.

Generally appointments seem to be made to suit working arrangements/school etc.

Several clients and/or carers spoke about what the appointments had given them, and spoke of some improvement in feelings.

Positive

- One young person said the appointments had given them a chance to talk about their illness, and had CBT treatment.
- When appointments were made, the distance to travel was considered and CAMHS said they would hold appointments at premises near to the child's school.
- Appointments in one case had been quick and subsequently followed by a second appointment, some three weeks after which the family thought was good. The appointments were made at convenient times to suit child and parent; there had been no cancelled sessions. Sessions had proved very helpful and child now feels better and making progress.

Negative

- In one case, it was two months before they saw a Consultant Paediatrician who asked 'why has it taken so long?'

- Parent had to cancel appointment due to the fact that child was threatening suicide, and got very little support. The child was discharged from CAMHS in November and now has to go through CAMHS referral again.
- It was felt that appointments every 6 weeks is just not enough.
- A concern regarding only one hour for appointments. One family said they felt they were 'watching the clock' and had thought about finishing the sessions as so traumatic.
- Following the appointment, CAMHS did a follow-up phone call by which time child was displaying aggressive behaviour towards a parent. CAMHS displayed surprise that this should happen as thought they had 'built a rapport.'

Mixed

- Appointment was arranged without any consultation with parent, but the parent was 'just relieved to get an appointment.' Was seen on this date by Paediatrician who referred to Psychologist and said there would be a 10 month wait. Patient also referred to Dietician and Speech Therapy.

8.4 Quality of Staff

Mixed views were heard regarding relationships with professionals, although the majority of accounts were positive.

Many of those interviewed felt that the sessions were highly beneficial.

There is a noticeable peak in the number of positive comments regarding quality of staff compared to other topics.

Positive

- One family were very happy with the CAMHS service. They were attending a 10-week parenting course in terms of coping strategies and Autism awareness so that they could understand their child and the condition. The same family said the staff were all excellent and friendly, including the reception and clinicians.
- 'I really couldn't fault CAMHS.'
- One family said they found CAMHS to be 'friendly, quite comfortable and felt it was confidential.'
- MATS team were very supportive. One family said they act as a 'go-between.'
- 'My child has been attending weekly sessions for CBT, I am able to attend sessions every other week.'
- '... very happy with the sessions at LD CAMHS, they observe well in an appropriate environment and the clinicians engaged well ...'
- 'My child has had 4 sessions, we haven't had continuity with staff but we haven't had to repeat anything, the clinicians are really good at communicating. I think the sessions are really helping. We always go into the appointments on time.'
- 'I feel that the sessions are beneficial; the clinicians give me a lot of advice. The receptionist at CAMHS always seems to be really busy, people seem to arrive at the same time and come out of the clinics at the same time, and she always seems to cope very well though with a smile on her face.'

Negative

- Young person had to be admitted as in-patient in Leicestershire. This was miles away for parent to visit. Communication was not good, for example, parent could be told at 10am that there was to be a meeting at 2pm without any consideration for work or distance to travel.
- '... the CAMHS worker was leaving and she informed us that she would refer us onto a Level 3 worker who could diagnose ASD but we then got a letter a week after saying that we were discharged ...'

Mixed

- 'No cancellations, my child has had continuity with the same clinician throughout. I do think they are helpful but my child doesn't find them helpful because I think they just want a quick fix.'
- 'The main receptionist is very friendly but others are rude and abrupt. You have to press the buzzer when you arrive and the receptionist seems rude.'

8.5 Information/Support

Parents and carers spoke about variable support, and a lack of clarity and information about what does exist.

Out of hours support was also raised as a real problem.

Positive

- Some positive experiences were highlighted with groups that had offered support: Parent Partnership x 2, MAT worker x 3, Parents with additional needs x 3, 'Derbyshire Carers Association (DCA) have helped me to apply for a DLA claim' Two additional families had been given information about support/self-help groups/carers information.
- 'We were signposted to an Autism Awareness course which was very useful.'

Negative

- A child had tried to commit suicide and still the mother had no support.
- One carer rang Call Derbyshire to ask for help but, '... they didn't want to know.'
- 'There isn't any community support for my child.'
- 'No direct support from DCA.' Three people said that they had just been sent leaflets. 'Can't access DCA as groups run in day.'
- 'They are out of school for 6 weeks as the school cannot cope but as a parent I don't know where to turn.'
- One parent of a 16 year old child is not told anything about her child's visits to CAMHS.
- One carer said that if her child is having a 'breakdown' then they do not know where to turn too ... told 'take him to A&E' which doesn't feel appropriate.
- Two participants commented that there is no carer support for parents with children with mental health conditions.

Mixed

- Paediatrician did give parent a couple of websites re Autism but as not formally diagnosed parent did not think too helpful. Parent was also informed it might be Asperger's and it might be possible to get the Autism Outreach Team in but not possible until formal diagnosis.
- GP talked about my child accessing some groups but they were in Sheffield, but wouldn't access support groups anyway...
- Little support from CAMHS for Mum when child diagnosed ... GP gave details regarding support groups.

9. Recommendations

Based on the information provided, Healthwatch Derbyshire would recommend that service providers consider the following:

- The referral system and the difficulties highlight getting referred to CAMHS.
- The adequacy of the support and information offered to young people, parents and carers, both before, during and after CAMHS.
- The unique situation of children in foster care.
- The implications of placing young people in out of county beds.
- The frequency and duration of appointments and the involvement of young people, parents and carers in the choices that are made.
- The implications of delayed diagnosis on both the young person, and the parent or carer.

10. Response from Service Providers and Commissioners

Public Health Response

Derbyshire County Council Public Health welcomes the Healthwatch reports for CAMHS services in both the North and South of Derbyshire County. It is valuable to see the positive, negative and mixed experiences articulated by young people, parents, carers and professionals who have first-hand experience of the respective services which can and should be used to inform service design.

We recognise the strengths and limitations of the report content and will ask the Derbyshire Integrated City and County Children's Commissioning Group to consider the findings to enable any learning to be translated into transformational and commissioning plans. Whilst Public Health does not commission CAMHS services, we do recognise the role Public Health has in improving children and young people's emotional health and wellbeing through prevention and early intervention via our commissioned programmes for 0-19s and parenting support. In addition we are working in collaboration with colleagues in the Clinical Commissioning Group and Children and Young Adults department to deliver both the Future in Mind transformation plan and the Children's Emotional Health and Wellbeing priority of the Health and Wellbeing Board. We understand the need to build on

the information provided within the reports and will explore with colleagues the potential for undertaking additional work such as an equity audit to better understand the needs of young people and the profile of clients waiting for and accessing CAMHS.

Yours faithfully

A handwritten signature in black ink that reads 'Elaine Michel'.

Elaine Michel

Director of Public Health, Derbyshire County Council

Chesterfield Royal Hospital NHS Foundation Trust Response

Thank you for sharing the report which we've read with great interest. It's encouraging to hear the positive views expressed and we are keen to consider how we might learn from the more negative comments and to use them to inform service developments. It is difficult to comment on individual statements without know more about the context and details of the particular case however, we do note that a number of statements appear to refer to issues regarding agencies other than CAMHS, including Educational Psychology, Visual Impairment, Speech and Language Therapy, Occupational Therapy, Child Development, Paediatricians, Tier 4 inpatient, Nursery School, Call Derbyshire and GPs.

This reminds us of how dependant we are on working as part of a network of services and that while we might not always be able to influence other service's practice, it is important for us to keep working at maintaining effective working relationships. For example, the practice and process of referral to CAMHS inevitably involves other agencies but we are currently undertaking clarification of our referral criteria to aid referrers in their decision making.

We are undergoing a transformation programme over the next few years which will address many of the areas mentioned in the report and recommendations. These will involve the whole process of assessment, treatment and discharge and have collaborative decision making and service user involvement at its centre.

We feel we've improved our diagnostic processes over the last few years and we are currently developing joint CAMHS and paediatric pathways for ASD and ADHD which will further enhance the experience of assessment and diagnosis for young people and their families. Of course there will always be some occasions when it is difficult or impossible to provide the kind of diagnostic certainty which some service users might desire.

We are mindful of the particular needs of children in Foster Care and we would want to be clear that we do not require young people to be in "stable, long term placements" before we can consider their need for mental health intervention.

We are very aware that the lack of Tier 4 mental health provision within Derbyshire necessitates the use of placements elsewhere. We endeavour to reduce the need for such

placements where possible, to maintain effective contact during placement and to facilitate early discharge where appropriate. We hope that our ability to achieve these aims may be strengthened through the implementation of the Derbyshire CAMHS transformation plans and the release of the associated funds.

Derbyshire CCGs Response

The Healthwatch Derbyshire Report, which provided 2 reports, one for the North where services are provided by Chesterfield Royal Hospital, and one for the South where services are provided by Derbyshire Healthcare Foundation NHS Trust.

The CCGs welcome the report and its content. Both positive feedback and areas for development are appreciated. The comments made by clients in the report are similar to those made through local consultation. It is reassuring to receive positive feedback about service quality.

Commissioners in the South hold a monthly contract management meeting with the CAMHS provider to performance manage the contract and enable on going service development. We have already discussed the recommendations of this report with the provider and have asked the provider how they will respond.

In the North there is a bimonthly CAMHS specific quality improvement and performance group consisting of both providers and commissioners and the North report will be discussed there.

The recommendations are timely and will be used to inform our forthcoming local five year Future in Mind Transformation Plan to improve outcomes in mental health and wellbeing. The additional government investment that comes with Future in Mind provides a unique and exciting opportunity for major service development across all services.

In response to the Report's recommendations

The referral system and the difficulties highlighted in getting referred to CAMHS.

South: At the time of Healthwatch engagement, there were 2 referral systems to CAMHS in Southern Derbyshire, traditional referral routes in South County and a multiagency Single Point Access (SPOA) piloted in Derby City. Following a recent successful evaluation of SPOA, commissioners have agreed its expansion across South Derbyshire. It is anticipated this will bring a significant improvement in the coordination and management of referrals so that 'the right referral goes to the right service' and need is met as soon as possible.

North: The service in the North has also piloted a single point of access following the times the Healthwatch report covered. There are differences in infrastructure within the 2 different providers which have been apparent through the evaluation. The CCGs are committed to working towards the NHS 5 Year Forward View, part of which focused around integrating services. Review of the ADHD and ASD pathways specifically are underway which will result in more positive service user experiences.

The adequacy of the support and information offered to young people, parents and carers, both before, during and after CAMHS.

South: It is positive to know that the range of methods of working with families makes a difference. Providing information in an appropriate form is a core NHS requirement. It is an area we are working with our providers to improve access to services and support through a range of methods, e.g. phone apps, social media. The comments highlight the need for a range of clear sensitive information that is responsive to differing needs.

North: It is clear that many of those young people and families participating in the report feel satisfied with the service they have received. Commissioners will ensure there are processes in place for resolving issues between children/young people/families and professionals as soon as they are identified. This section mentions an aspect outside of the control of CAMHS and CCG commissioners regarding a Tier 4 placement in Leicestershire. It is not a reflection of the quality of staff in North Derbyshire. These services are commissioned by NHS England. Issues around transition between workers when young people go into adult services or their CAMHS worker leaves will be picked up with the service as these negative comments are reflected nationally.

Information and support for parents/carers/siblings and friends is vital and the comments from the report will give us a basis for improvement. Ensuring parents and carers in particular are supported and alongside the young person and become experts in care is something we want to ensure going forward.

The frequency and duration of appointments and the involvement of young people, parents and carers in the choices that are made. Appointment timings are reviewed to allow improved access to appointments out of school/work hours.

South: The good practice highlighted in the report reflects the benefit of flexible appointments. These are available in some part of South Derbyshire but not all. It is acknowledged that access to services particularly after school hours and a choice of options should be improved. We are working with all service providers as part of the NHS 5 year forward plan to extend access to services 7 days a week. The CCG is has recently invested an additional resource to extend the CAMHS liaison/rapid response from 5 to 7 days a week for children and young people in crisis. This service will be fully operational by January 2016.

North: The difference between waiting times and people's experience of this is something the CCGs are working on with the service. The service themselves also recognise this. There were positive aspects of flexibility and we would wish to see these as the 'norm'. It is positive the service is individualising according to need wherever possible. Further investment will be required to ensure 7 day services and an appropriate crisis response. This will be a priority for the money allocated as part of the 5 year transformation plan.

The implications of delayed diagnosis on both the young person, and the parent or carer.

South: The comments raised by parents highlight the importance of help early. Sometimes diagnoses are complex and may take some months to make. They may also require information from other specialists and observations of children in different settings. Our

priority based on local evidence and engagement with service users and is that services should be needs rather than diagnostic led so that support is available until a specialist assessment can be made. A multi-agency early help assessment could identify other agencies that can provide early help support in school or at home.

We acknowledge the challenge of long waiting lists and are working closely with service providers to reduce these. We are monitoring this closely and also looking at other ways of managing the increasing demand for CAMHs differently. For example we are supporting our provider to train school and community workers to deliver short evidence based interventions as part of the expansion of the CYP Improving Access to Psychological Therapy (CYP IAPT) training. This will enable staff to treat low level anxiety and depression in community settings and reduce the need for CAMHS.

North: Issues in relation to diagnosis are often complex. The report mentions issues with services outside of CAMHS. It is not clear within the report if someone has not received the diagnosis that they/parents/carers want, are on a pathway that will deliver this diagnosis and there is unnecessary delay, or whether or not the young person/parents/carers are in dispute with the service about a diagnosis. Additionally, as a mental health commissioning team we are trying to move to system whereby diagnosis is secondary to need. In some situations diagnosis can prove helpful in terms of allowing understanding of an individual, but it is not a solution. The comment around being passed between professionals is one we are aware of and work on the ASD and ADHD pathways specifically will address this through integration and coordination.

It is anticipated through our Future in Mind plan and the additional investment we will continue to work closely with local service users and providers to innovate and improve outcomes.

Child and Adolescent Mental Health Services (CAMHS)

Experiences of using CAMHS in Southern Derbyshire, told by young people, parents, carers and professionals.

Helen Hart

July 2015

CONTENTS

	Page
1. Acknowledgement	3
2. Disclaimer	3
3. Background	3
4. Rationale for the Report	5
5. Methodology	5
6. Information & Signposting	5
7. Summary of Findings	5
8. Findings	6
9. Recommendations	11
10. Response from Service Providers and Commissioners	11

1. Acknowledgement

Many thanks to the CAMHS team for their support and for making our staff feel welcome. We would also like to thank the participants who gave up their time to talk to us.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all young people, parent, carers and professionals who have experience of CAMHS, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that young people, parents, carers and professionals have conveyed to Healthwatch Derbyshire. The data should be used in conjunction with, and to compliment, other sources of data that are available.

3. Background

3.1 Healthwatch Derbyshire

Healthwatch Derbyshire is the local consumer champion for health and social care. The Healthwatch network is made of up of local Healthwatch across 148 local authority areas and Healthwatch England, the national body.

Healthwatch has a common purpose - to ensure the voices of people who use services are listened to and responded to. The network shares a brand, has common values and comes together to work on priority areas and campaigns.

Local Healthwatch work to provide unique insight into people's experiences of health and social care issues in their local area; Healthwatch Derbyshire is the eyes and ears on the ground finding out what matters to our local community.

3.2 Child and Adolescent Mental Health Services (CAMHS)

There is currently a national focus on CAMHS led by the Children and Young People's Mental Health and Wellbeing Taskforce which was established in September 2014 to consider:

- Ways to make it easier for children, young people, parents and carers to access help and support when needed; and
- How to improve the way children and young people's mental health services are organised, commissioned and provided.

The Taskforce produced a report in March 2015 'Future in mind: Promoting, protecting and improving our children and young people's mental health and wellbeing. This report includes recommendation for both transformation changes, to begin as soon as possible, and a number of longer-term aspirations to be achieved by 2020, to allow for work to be aligned with the NHS Five Year Forward View.

The report highlights a number of key drivers for this change, which are as follows:

- One in ten children require support or treatment for mental health problems.
- 75% of adult mental health problems (excl. dementia) develop by the age of 18.
- In an average class of 30 schoolchildren, three pupils will suffer from a diagnosable mental health disorder.
- A treatment gap exists where only 25%-30% of those with a diagnosable mental health condition accessed support.
- Demand is increased for services, especially for young women with emotional problems and young people presenting with self-harm.
- Early intervention and prevention in childhood can avoid expensive and longer term interventions in adulthood. For example, children with early conduct disorder are 10 times more costly to the public sector by the age of 28 than other children.
- There is a cost benefit to society of tackling mental health issues early in life. These benefits are achieved through the reduction in use of public services due to better mental health and by increased earnings associated with the impact of improved mental health on educational attainment.
- In some areas there is a poor provision of out-of-hours, crisis point and psychiatry services and some local authorities do not have a Care Quality Commission (CQC) recorded place of safety.
- The Taskforce noted a lack of clear leadership and accountability arrangements for children's mental health issues across agencies, including Clinical Commissioning Groups (CCGs) and local authorities, creating the potential for individuals to 'fall through the net'.

The report focuses on 5 key themes, and makes a range of recommendations to improve the structure, delivery and transformation of services.

1. Promoting resilience, prevention and early intervention.
2. Improving access to effective support - a care system without tiers.
3. Care for the most vulnerable.
4. Accountability and transparency.
5. Developing the workforce.

Locally:

- Services are reporting an increasing concern about self-harm. CAMHS report a sharp increase in around 10% in referrals. Self-harm and eating disorders feature prominently in this increase.
- In 2013-14 the rate of hospital admissions of 10-24 years olds in Derbyshire due to self-harm was 377.5 per 100,000, above the 2012-13 national average.
- The number of Derbyshire young people who require Tier 4 (in-patient) CAMHS placements remain low in comparison with other areas, however numbers have increased sharply over the past 3 years (up from 5 in 2011/12 to 30 in 2013/14). Trends in Derbyshire are in line with an increase in Tier 4 placements nationally.

Local response to 'Future in Mind': The Derbyshire CCGs, Derbyshire County Council and Derby City Council are working together to plan a response. A transformation plan will be required imminently to release additional funding to address developments/improvement to CAMHS.

4. Rationale for the Report

In addition to an awareness of the national and local focus on CAMHS, Healthwatch Derbyshire had received a cluster of comments from users of CAMHS, which were of mixed sentiment. This led Healthwatch Derbyshire to choose CAMHS as a work priority from January - March 2015. The aim was to explore these experiences in more detail, to find out what was working well, and what could be improved.

It is the hope that this report will provide service providers and commissioners with some useful insight into how service users experience CAMHS, support service development plans and provide suggestions for improvement.

5. Methodology

From January - March 2015, our 4 Engagement Officers spent their time out and about in the community, at groups and in CAMHS clinics listening to what people had to say about CAMHS.

This report covers the comments made in 17 interviews. Many of these interviews were conducted at CAMHS clinics, which gave the benefit of being able to talk to participants about their experiences at the point of service delivery. Some participants also spoke about experiences of using other services not provided by CAMHS. Although this was not the focus of this piece of work, these experiences are included in this report for completeness.

Our Engagement Officers developed a series of discussion prompts to use when talking to young people, parents, carers or professionals about their experiences of CAMHS. These prompts were very broad and covered experiences during referral and access to the service, what it was like to use the service, the quality of care they received, and if they felt it was helping. These prompts were used informally to help steer the conversation when necessary but staff used a flexible approach with this as a prompt sheet rather than a formal interview style. This is because although questionnaires or structured interviews would have given more measurable data, this could have been a barrier to engagement.

The 17 interviews conducted were a mixture of young people using CAMHS services, parents, carers, and professionals.

All responses have been themed and are outlined in the findings section of this report.

6. Information and Signposting

In addition to ensuring that the voices of service users, patients and the public are heard by decision makers within health and social care, we also provide an information and signposting service to the public about accessing health and social care services. During this piece of work Engagement Officers signposted many participants to a combination of groups.

7. Summary of Findings

There are patterns in these experiences that would suggest that some parts of the experience works well, whilst others do not work as well.

The clearest example of this relates to the relatively high number of negatives compared to positives regarding referrals and diagnosis. Sometimes participants spoke about a real challenge to get into the service in the right place, at the right time - although there were positives in this regard too. All comments regarding diagnosis were negative.

Conversely, there were many positive comments regarding quality of staff, the quality of the service and the seemingly positive impact for those using CAMHS, with only a few examples of negative experiences.

In short, the information suggests that the main difficulties lie in getting into CAMHS and going through the referral and diagnosis process. Once participants were 'in' the CAMHS service, they were generally very positive about the experience.

8. Findings

8.1 Referrals

There were a range of experiences around the referral to CAMHS.

To some the referral was a quick and responsive process, whilst for others it was a more protracted experience.

Positive

- 'Learning Disability CAMHS came to school, the referral was done within a matter of weeks.'
- 'I was down and self-harming for 1 ½ - 2 years. I saw the nurse who helped me to calm down, and explained about CAMHS and what it was.'
- Was referred to CAMHS by GP 3 years ago. It took 4 weeks to get an appointment with CAMHS. GP really listened. Was fantastic. Young person was feeling unwell for about 2 months before the going to the GP.
- '... got an appointment with CAMHS worker within one week of initial assessment which took place at Royal Derby Hospital.'
- 'Got an appointment with CAMHS worker within 10 weeks of GP visit.'
- 'I went to my GP, they were wonderful, they listened to us and referred us straightaway ... They sent a letter within a week.'

Negative

- 'I went to a GP who referred to a Paediatrician, who then referred to CAMHS. The GP didn't seem to be aware of CAMHS and about the referral process.'
- 'On 12 month waiting list for a Clinical Psychologist' but the young person needs help now.
- 'I thought no one was listening to me and my child, and they needed help. Why did it have to get so that they were suicidal before something happened?'
- 'GP was hopeless and made life difficult after several months, so tried through Paediatrician and MAT team. We were told it would take 4-6 weeks and it took a further 7 months. I do not understand why can't you self-refer.'

- Parent felt that the school did not deal with the whole situation very well. She got a call from the school nurse to say she had made a referral to CAMHS. This was the first that the parent had heard that anything was wrong. Felt their input or say had not been sought. The school seems to have a default process to refer into the CAMHS.

Mixed

- ' ... second time at CAMHS. This second experience is better as school doctors and CAMHS have worked quicker and are more understanding. Took 2 months to get a referral, the first time it took over a year.

8.2 Diagnosis Delays

The interviews highlighted that there were real problems with delays in diagnosis.

This links with the section above, which also contains accounts of diagnosis delay.

Negative

- 'It took one year; the child was severely traumatised - punching and kicking. We were told it was going to take weeks but it took several months.'
- 'Had hit crisis point by the time CAMHS got involved. Did go to the GP, but wasn't helpful.'
- Parent commented that the way the diagnosis was given was 'disgusting' and continued, 'Was sent a report with a letter. At the bottom of the letter is said that we don't need to see you again. No time was given to go through the report or diagnosis. No support followed once the diagnosis was given.' Parent said that she asked and begged for support but it was not forthcoming.

Mixed

- 'It should have been a 2 week wait but ended up being 3-4 weeks. The first referral from the GP was delayed, credit to school nurse who did the second referral. This is when the process did start.'

8.3 Appointments

There were a number of negative comments about appointments taking place during school/work time which can create problems for young people and parent/carers. However, there were a few comments indicating valued flexibility.

Positive

- 'Appointments are every 4 weeks which is sufficient.'

- 'I feel like the appointments will help, they are open. Told "have meetings and see how you go." I am developing relationship, and am happy with how things are going.'
- 'Once, the member of staff came to the home because I couldn't get to the location. Also opened up at 6pm once. Frequency of appointments is just right - very accommodating.'
- 'Current worker will block out 6 weeks of appointments. This is good because it helps to plan diary.'
- '... was allowed appointments after school so people would not know, and also so parent would not have to leave work ...'
- 'We had 5 weekly sessions, and then some fortnightly, and then a couple monthly. At discharge the decision was the young person's choice not the worker, which allowed them to take control. We can return if needed without a new referral within 6 months.'
- 'Each session is about an hour, we are not rushed ...'
- 'I feel that staff listen most of the time to our child's concerns ... I like that my child can go in alone or with us depending on their needs and wishes.'

Negative

- 'For the first appointment we received the letter notifying us of it on the day of the appointment, this was not enough notice. I had to ring to explain why we had not gone and had to rearrange, which made the referral process even longer. Since then, communication has improved. I wish we could book our appointments in advance.'
- 'You can often hear the receptionist talking to parents etc on the phone. You can hear names, nature of the condition and name of school. You could potentially know who it is.'
- Parent said they had to constantly call to re-arrange appointments for after school. Parents want after school appointments due to vital school year not to miss lessons. Psychiatrist appointments are not after school either. Latest appointment is at 2.30pm. 'So feel like we have to fit into the service.'
- 'Appointments should not be during school time.'
- Both members of staff left. A counsellor told the young person they would refer them to a nurse at the beginning of the summer holidays, but they didn't hear anything so just had to manage.
- 'Once was stood outside for 20 minutes before staff let me in to the building. Seems like there is a high turnover of staff.'
- 'Would prefer sessions evening or weekends so do not have to miss school or work.'
- 'There was a big gap between old and new staff member being allocated.' Mum had to chase up and beg for someone to see child.
- 'All appointments are between 9-5pm so we try and get the last appointment at 3.30pm so only miss one lesson at school. We would prefer appointments so that do not have to miss school and work for the parents. The young person does not want school friends to know, so it is getting harder to explain where they are going when leaving early. This causes additional anxiety.'

- 'They didn't explain staff job titles, what they do and what they mean.'
- 'Had a change therapist midway through. I found that to be annoying and I was cross. I was told 1-2 weeks prior to the member of staff leaving, that she was leaving.' Young person feels like they are going round and round in circles.
- 'I run my own business and though the times were inconvenient I needed to attend for the sake of all of us. I have lost out financially, business wise because of this.'
- 'It would be useful if you could email them between sessions for advice or information, especially if a month until the next session. You will then have something concrete to help you ...'
- 'All sessions are in school time which is hard when trying to hide the appointments from school.'

Mixed

- 'We were offered 12 sessions, which were good and thorough. Appointments are held in the day time which doesn't always work for working parents.'
- 'First appointment took place at school, I was glad it was at school. The rest of the appointments were convenient, happy with the appointments. Not offered a number of sessions, but told will "see how it goes" and was happy with that. CAMHS cancelled some appointments due to staff reasons, and no appointments were offered to replace the cancelled ones.'
- 'The frequency depended on the counsellor, who would say "how often would you like to see me?" Reception doesn't seem to have access to the staff diaries, once I waited 40 minutes for a counsellor and no one had access their diary to know where he/she was. It is not easy to work around the appointments because mum works full-time.'

8.4 Quality of Staff

Mixed views were heard regarding relationships with professionals, although the majority of accounts were positive.

Many of those interviewed felt that the sessions were highly beneficial.

There were several comments about how busy and stretched the service felt.

Positive

- 'My counsellor is easy to talk to, they listen ... They are interested in what is being said ... Feel that the treatment is working. Feel confident and trust they will sort things. Can tell them things I can't tell other people.'
- 'Staff found to be polite, welcoming and well mannered.'
- 'After a few months I feel that things are improving. My child does not need to worry that they are different. The worker addresses that we are all different and not something to be concerned about. I see a real difference in my child. At the minute they do not see the changes but other people around them do and the worker says that it will come with time.'

- 'Someone to talk to about stuff I am not able to talk to anyone else about.'
- After the initial assessment, the young person and family were given a mobile number for a worker to contact as needed between sessions ... 'It was great knowing that we could text and the staff member would get back to us - the reassurance was invaluable.'
- 'Each session was about an hour but could be longer if needed, we never felt rushed.'
- 'Overall the sessions solved problems such as to talk things over with us or to text us if hard to put into words. The young person learnt life skills and we learnt better parenting skills'
- 'Fantastic, I don't know how we would have got through without it. Five stars.'
- 'I have good relations with all the CAMHS team ... They text me regularly.'
- 'A weight has been lifted and I can see light at the end of the tunnel - someone is willing to listen.'

Negative

- 'Sometimes it seems disorganised ... for example staff would forget to bring equipment. It feels like there is an element of them "winging it".'
- Young person felt that sometimes staff member came across like "she doesn't care." Has a sense that she is not listening, and feels rushed out of the door. The staff member likes to talk lots so the young person feels that she isn't given opportunities to talk.
- 'I didn't feel they consider the young person's whole situation.'
- 'Not good at getting back to the parents with information. A sense of being rushed off their feet.'
- 'The whole team are incredibly stretched.'
- 'Would like a more structured treatment plan to help see what working towards and to identify achievements.'

8.5 Information/Support

The parent course is spoken about favourably in a number of comments. There are a number of suggestions in this section about improvements that could be made.

Positive

- 'I also attend parent classes. These have helped tremendously.'
- 'I attend a CBT Group ... I attend the group after school. I like group therapy because it helps to take the pressure off to answer. You can't fill a silence in a one-to-one, whereas a group can.'

Negative

- Parent called CAMHS yesterday out of hours. No one has called back. There doesn't seem to be a sense of urgency to help families. The family is at crisis point.

- 'Would to have liked the parent course to be part of the process - Parent course is optional.'
- 'Need someone to advocate on the parent's behalf. Parent is often stressed and exhausted'.
- 'No information about self-help groups or online information.' Once told about an anxiety group, but suffer with anxiety, so didn't go.
- 'You could do with a 'welcome pack' along with first referral letter of what to expect. This would help the parent and young person to ease into the service.'
- 'Could also do with leaflets and picture boards to show who is who, what their job roles are and what the role means'.

Mixed

- 'The parent course is reasonably good - a refresher would validate what we are doing.'

9. Recommendations

Based on the information provided, Healthwatch Derbyshire would recommend that service providers consider the following:

- The referral system and the difficulties highlighted in getting referred to CAMHS.
- The adequacy of the support and information offered to young people, parents and carers, both before, during and after CAMHS.
- The frequency and duration of appointments and the involvement of young people, parents and carers in the choices that are made.
- Appointment timings are reviewed to allow improved access to appointments out of school/work hours.
- The implications of delayed diagnosis on both the young person, and the parent or carer.

10. Response from Service Providers and commissioners

Response from Public Health

Derbyshire County Council Public Health welcomes the Healthwatch reports for CAMHS services in both the North and South of Derbyshire County. It is valuable to see the positive, negative and mixed experiences articulated by young people, parents, carers and professionals who have first-hand experience of the respective services which can and should be used to inform service design.

We recognise the strengths and limitations of the report content and will ask the Derbyshire Integrated City and County Children's Commissioning Group to consider the findings to enable any learning to be translated into transformational and commissioning plans. Whilst Public Health does not commission CAMHS services, we do recognise the role Public Health has in improving children and young people's emotional health and wellbeing through prevention and early intervention via our commissioned programmes for

0-19s and parenting support. In addition we are working in collaboration with colleagues in the Clinical Commissioning Group and Children and Young Adults department to deliver both the Future in Mind transformation plan and the Children's Emotional Health and Wellbeing priority of the Health and Wellbeing Board. We understand the need to build on the information provided within the reports and will explore with colleagues the potential for undertaking additional work such as an equity audit to better understand the needs of young people and the profile of clients waiting for and accessing CAMHS.

Yours faithfully



Elaine Michel

Director of Public Health, Derbyshire County Council

Response from Derbyshire Healthcare NHS Foundation Trust

We welcome this report and both the positive and negative feedback, which will help to inform, develop and improve our CAMHS services going forward. We would like to apologise to those young people and families who have not received the care and treatment they expected. We aspire to put our patients at the centre of everything we do, and we will try our utmost to meet their needs in the future.

As part of our ongoing service transformation process, CAMHS is moving towards a more integrated, interagency approach, with collaborative care pathways and service models. This will involve a more effective use of our resources with the consultants working differently as part of our new ways of working. A more centralised structure is being developed based on specialist care pathways, in order to achieve a more standardised and consistent approach, with equality of access and more effective evidence-based interventions and outcomes for our young people.

Taking each of the recommendations in this report in turn:

Referrals

We have introduced a new single point of access process for our city services, as a pilot, which we have just evaluated. (Evaluation report provided to Healthwatch Derbyshire).

The Single Point of Access (SPOA) was created as an approach within Derbyshire Healthcare NHS Foundation Trust in February 2014. It was initially developed by Child and Adolescent Mental Health Services alongside Community Paediatrics and School Health, clinical Psychology, counselling services and Community Paediatrics as an integrated approach to managing referrals through emotional and behavioural pathways.

The SPOA for Derby City children's services is now well established and is currently being rolled out for Derbyshire county services. The benefit of the SPOA is that parents and children can be sure of reaching the right service in the right place and at the right time, reducing the number of duplicate or 'scattergun' referrals. Referrers such as GPs also benefit as the process is more transparent and easier to navigate. The process also enables an efficient step-up and step-down process in the clinical pathway, based on the child's needs.

Other benefits of the SPOA in terms of quality and efficiency included:

- Significant reduction in the number of inappropriate referrals for specialist assessment and intervention.
- The operation of a single entry point for specialist services supporting higher level needs by a care coordination approach to assessment.
- Initial screening and triage to inform whether specialist assessment is indicated.
- Intervention provided and maintained at a lower level by support, advice and consultation to staff in partner agencies.
- Clear and integrated pathways for referral, support and early intervention.
- Working in a preventative way, providing a response within timescales which delivers outcomes and avoids escalation of need.
- An emergency response for families who are in crisis to manage and, at the earliest assessed opportunity, move down to lower level services.
- Effective signposting to the most appropriate service and at the right level.
- Where specialist intervention is required, smooth transition to the most appropriate evidence-based pathway.
- Continuity of service for those needing ongoing care at points of transition.
- Services delivered flexibly in terms of time and location and in ways to maximize user engagement.

Following the evaluation of the City SPOA we are now rolling this out to have a South County SPOA.

Please note that Clinical Psychology services are provided by Derby Teaching Hospitals NHS FT and not by Derbyshire Healthcare NHS FT.

Information

We acknowledge that this is an area of development for our CAMHS services and we have commissioned one of our service user reps, with the support of GIFT - Great Involvement Future Thinking (DoH) - to review and support us to improve the quality of our information and to improve the accessibility of our online information. The 'welcome pack' idea will be included in this and we expect this work to be completed by the end of the year.

CAMHS works toward assessment of individual needs and six-weekly reviews and is based on the principle of a collaborative working relationship with the young person, which

includes working on the goals identified by the young person. Treatment end dates are developed collaboratively when the treatment goals are met and are based on individual needs.

Team leaflets are available in the teams and we will ensure that teams put up photos with their names and roles in line with the 'Hello my name is' campaign.

We have parenting groups for parents where this is identified as part of the treatment plan. We strive to work collaboratively with parents and carers following a Think! Family person centred approach.

Appointments

CAMHS aims to adhere to NICE guidance on evidence-based interventions underpinned by a collaborative working relationship with those the service supports. Through collaborative working, CAMHS aims to develop a partnership relationship with children and young people and parents/carers in all aspects of the assessment and care plan, treatment, and appointments process in order to suit individual needs and generate regular feedback and enable outcome monitoring in the sessions.

The care package can be reviewed to incorporate elements that the young person would find most helpful.

The service has experienced some disruption related to staff going on training as part of the IAPT (improving access to psychological therapies) service transformation, as there were delays in getting back-fill staff. However, many of the staff have now returned having successfully completed training and are now able to offer more effective interventions and consistency in care.

Appointment timings

We acknowledge that there is an inconsistency across the teams with regard to out-of-school-hour appointments. We have some evening clinics and appointments and also offer home visits but we acknowledge that there is not enough. We appreciate the importance of education for the young people in our services and want to work with them to achieve their goals.

We will review opportunities to access the service outside of school hours, including seven-day working. This would, though, be subject to availability of premises out of hours and would potentially have cost implications that we would need to address with commissioners.

Delayed diagnosis

This is not an issue that has arisen in any of our other service monitoring. However we acknowledge the impact and strength of feeling in the comments regarding diagnosis; clearly a delay must be a source of frustration and concern for all those affected.

While it is difficult to investigate incidents of delayed diagnosis without knowing the specific details, we will undertake further work to clarify the extent of this issue.

As the SPOA rolls out across the services in the south of the county, we will have an engagement plan for communication with referrers, including GPs, to ensure they understand the referral process. More timely access to services should reduce the length of time to diagnosis.

Alongside our colleagues in Paediatrician and Therapy Services, we are also involved in developing a neuro-developmental care pathway which we expect will improve the response to referrals and facilitate a more timely assessment.

We envisage this will improve access to assessment, diagnosis and treatment particularly concerning autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).

The implementation of this pathway will introduce a new skill mix and avoid some of the capacity problems that we have experienced over the past few years in relation to the growth in demand.

We have commenced recruitment in to these posts and would hope that this will begin to become operational around autumn 2015. We expect the new pathway to provide a more fluid service with the need for internal referrals and handovers and thus significantly reduce the waiting times that are currently experienced.

Once again, we thank Healthwatch Derbyshire and our patients and carers for this opportunity to learn about our services. We will work closely with Healthwatch Derbyshire to apply the recommendations they have proposed in this report.

Carolyn Gilby
Acting Director of Operations
Derbyshire Healthcare NHS Foundation Trust

Derbyshire CCGs Response

The Healthwatch Derbyshire Report, which provided 2 reports, one for the North where services are provided by Chesterfield Royal Hospital, and one for the South where services are provided by Derbyshire Healthcare Foundation NHS Trust.

The CCGs welcome the report and its content. Both positive feedback and areas for development are appreciated. The comments made by clients in the report are similar to those made through local consultation. It is reassuring to receive positive feedback about service quality.

Commissioners in the South hold a monthly contract management meeting with the CAMHS provider to performance manage the contract and enable on going service development.

We have already discussed the recommendations of this report with the provider and have asked the provider how they will respond.

In the North there is a bimonthly CAMHS specific quality improvement and performance group consisting of both providers and commissioners and the North report will be discussed there.

The recommendations are timely and will be used to inform our forthcoming local five year Future in Mind Transformation Plan to improve outcomes in mental health and well-being. The additional government investment that comes with Future in Mind provides a unique and exciting opportunity for major service development across all services.

In response to the Report's recommendations

The referral system and the difficulties highlighted in getting referred to CAMHS.

South: At the time of Healthwatch engagement, there were 2 referral systems to CAMHS in Southern Derbyshire, traditional referral routes in South County and a multiagency Single Point Access (SPOA) piloted in Derby City. Following a recent successful evaluation of SPOA, commissioners have agreed its expansion across South Derbyshire. It is anticipated this will bring a significant improvement in the coordination and management of referrals so that 'the right referral goes to the right service' and need is met as soon as possible.

North: The service in the North has also piloted a single point of access following the times the Healthwatch report covered. There are differences in infrastructure within the 2 different providers which have been apparent through the evaluation. The CCGs are committed to working towards the NHS 5 Year Forward View, part of which focused around integrating services. Review of the ADHD and ASD pathways specifically are underway which will result in more positive service user experiences.

The adequacy of the support and information offered to young people, parents and carers, both before, during and after CAMHS.

South: It is positive to know that the range of methods of working with families makes a difference. Providing information in an appropriate form is a core NHS requirement. It is an area we are working with our providers to improve access to services and support through a range of methods eg phone apps, social media. The comments highlight the need for a range of clear sensitive information that is responsive to differing needs.

North: It is clear that many of those young people and families participating in the report feel satisfied with the service they have received. Commissioners will ensure there are processes in place for resolving issues between children/young people/families and professionals as soon as they are identified. This section mentions an aspect outside of the control of CAMHS and CCG commissioners regarding a Tier 4 placement in Leicestershire. It is not a reflection of the quality of staff in North Derbyshire. These services are commissioned by NHS England. Issues around transition between workers when young people go into adult services or their CAMHS worker leaves will be picked up with the service as these negative comments are reflected nationally.

Information and support for parents/carers/siblings and friends is vital and the comments from the report will give us a basis for improvement. Ensuring parents and carers in particular are supported and alongside the young person and become experts in care is something we want to ensure going forward.

The frequency and duration of appointments and the involvement of young people, parents and carers in the choices that are made. Appointment timings are reviewed to allow improved access to appointments out of school/work hours.

South: The good practice highlighted in the report reflects the benefit of flexible appointments. These are available in some part of South Derbyshire but not all. It is acknowledged that access to services particularly after school hours and a choice of options should be improved. We are working with all service providers as part of the NHS 5 year forward plan to extend access to services 7 days a week. The CCG is has recently invested an additional resource to extend the CAMHS liaison/rapid response from 5 to 7 days a week for children and young people in crisis. This service will be fully operational by January 2016.

North: The difference between waiting times and people's experience of this is something the CCGs are working on with the service. The service themselves also recognise this. There were positive aspects of flexibility and we would wish to see these as the 'norm'. It is positive the service is individualising according to need wherever possible. Further investment will be required to ensure 7 day services and an appropriate crisis response. This will be a priority for the money allocated as part of the 5 year transformation plan.

The implications of delayed diagnosis on both the young person, and the parent or carer.

South: The comments raised by parents highlight the importance of help early. Sometimes diagnoses are complex and may take some months to make. They may also require information from other specialists and observations of children in different settings. Our priority based on local evidence and engagement with service users and is that services should be needs rather than diagnostic led so that support is available until a specialist assessment can be made. A multi-agency early help assessment could identify other agencies that can provide early help support in school or at home.

We acknowledge the challenge of long waiting lists and are working closely with service providers to reduce these. We are monitoring this closely and also looking at other ways of managing the increasing demand for CAMHS differently. For example, we are supporting our provider to train school and community workers to deliver short evidence based interventions as part of the expansion of the CYP Improving Access to Psychological Therapy (CYP IAPT) training. This will enable staff to treat low level anxiety and depression in community settings and reduce the need for CAMHS.

North: Issues in relation to diagnosis are often complex. The report mentions issues with services outside of CAMHS. It is not clear within the report if someone has not received the diagnosis that they/parents/carers want, are on a pathway that will deliver this diagnosis and there is unnecessary delay, or whether or not the young person/parents/carers are in dispute with the service about a diagnosis. Additionally, as a

mental health commissioning team we are trying to move to a system whereby diagnosis is secondary to need. In some situations diagnosis can prove helpful in terms of allowing understanding of an individual, but it is not a solution. The comment around being passed between professionals is one we are aware of and work on the ASD and ADHD pathways specifically will address this through integration and coordination.

It is anticipated through our Future in Mind plan and the additional investment we will continue to work closely with local service users and providers to innovate and improve outcomes.

AUTISM PATHWAY REPORT

An Exploration of the Parent Carer Experience, of the Multi-Agency Pathway, that identifies and supports children and young people with Autism Spectrum Disorders in Derbyshire.

Tanya Nolan and Jasbir Dosanjh, Engagement Officers
July 2015

CONTENTS

	<u>Page</u>
Prefix	2
1. Acknowledgments	3
2. Disclaimer	3
3. Background	3
4. Purpose of the Report	4
5. Methodology	4
5.1 Recruitment of Participants	5
5.2 Criteria for Recruitment	5
5.3 Participants	5
5.4 The Interviews	6
5.5 Data Analysis	6
6. Summary of Findings	6
7. Findings	9
7.1 Theme 1: Education	10
7.2 Theme 2: Impact on Families	12
7.3 Theme 3: Communication	13
7.4 Theme 4: Waiting Times	14
7.5 Theme 5: General Practitioners (GPs)	15
7.6 Theme 6: Child and Adolescent Mental Health Services (CAMHS)	16
7.7 Theme 7: Diagnosis	17
7.8 Theme 8: Support during Diagnosis	18
7.9 Theme 9: Post Diagnosis Support	20
8. Recommendations	22
9. Responses	23
Appendix I	26
References	29
Feedback Form	30

Prefix

This is a response from a participant who fed back to Healthwatch Derbyshire on reading the report:

“The report is appreciated and I only hope it may bring about a review of how things are carried out and that it will prompt change to much more appropriate services.

Educating people about autism is key. If people can REALLY understand the challenges that a young person on the autistic spectrum faces, the day to day difficulties, and put in place ways to reduce stress and anxieties for the young person (and their families) then the world will move towards being more ASD friendly.

I would just like to add that for us, the most useful thing in the whole process was receiving a detailed Clinical Psychologist’s report which included and explained a breakdown of (named child’s) cognitive functioning, his strengths and difficulties. This enabled me to develop a deeper understanding of (named child), his emotions, his frustrations etc, so that I knew him even better and could support him more appropriately. I was also able to tell him why he was finding somethings challenging, explain that it wasn’t his fault and give him strategies to cope. I could also feed this sort of information through to schools etc. Consequently this has been the most beneficial thing for (named child) too!

Prompt diagnosis is definitely necessary and, more than that, a full and detailed assessment of what that diagnosis actually means for the individual child.”

1. Acknowledgement

Healthwatch Derbyshire (HWD) would like to thank all 26 families who participated in this Service Evaluation. We would like to express our gratitude to the Autism Coordination Group for their support, and also to the providers that helped to publicise the project to support the recruitment of participants.

2. Disclaimer

The comments outlined in this report should be taken in the context that they are not representative of all parent carers who have experienced the Autism Pathway, but nevertheless offer a useful insight. They are the genuine thoughts, feelings and issues that parent carers conveyed to HWD. The data should be used in conjunction with, and to compliment, other sources of data that are available.

3. Background

HWD is the local consumer champion for health and social care. The Healthwatch network is made up of 148 local Healthwatch organisations and Healthwatch England, the national body.

Healthwatch has a common purpose - to ensure the voices of people who use services are listened to and responded to. The network shares a brand, has common values and comes together to work on priority areas and campaigns.

Local Healthwatch work to provide unique insight into people's experiences of health and social care issues in their local area; HWD is the eyes and ears on the ground finding out what matters to our local community.

Autism Spectrum Disorder (ASD)

"Autism is a lifelong developmental disability that effects how a person communicates and relates to other people. It also effects how they make sense of the world around them." (National Autism Society).

ASD is characterised by a triad of impairments in social interaction, imaginative thought and communication, it includes Asperger' Syndrome and childhood autism. No child presents the same traits and there are no medical tests that can diagnose ASD, clinicians have to observe an individual's behaviour and development to make a diagnosis.

An early diagnosis and the provision of support services are considered essential for a child's development, future progress and general quality of life, as is support for parents and carers in providing guidance on how to monitor and cope with a child who has ASD.

It is expected that 700,000 people have ASD in the UK, which is more than 1 in 100. In Derbyshire there is estimated to be 1,915 young people who may have ASD. (National Autism Society, Statistics).

Derbyshire County Council has a Multi-Agency Pathway for identifying and supporting children and young people with ASD for school age children and pre-school children in maintained early years setting that was produced in 2012. A summary of this pathway can be found in Appendix 1.

4. Purpose of the Report

Anecdotal evidence obtained by HWD during general engagement activity suggested that although there was some good practice across the county, other parents were not entirely happy with how certain parts of the referral pathway operated, including delays in diagnosis and lack of support. This resulted in parent carers feeling isolated and reaching crisis point.

The purpose of this Service Evaluation, therefore, was to give parents and carers the opportunity to talk in more detail about their experiences of the Autism Pathway in Derbyshire.

It is important to note that we looked at the experiences of the pathway, not at particular professionals, departments or issues.

As the pathway operates differently in the North and South of Derbyshire, due to how services are organised, we conducted the study countywide, but also compared experiences between the North and South.

The Autism Co-ordination Group was also very supportive of the Service Evaluation and HWD worked in collaboration with Derbyshire County Council and all relevant stakeholders.

5. Methodology

This Service Evaluation gathered qualitative accounts of parent carer's experiences of Derbyshire County Council's Autism Pathway over a 12 month period.

Although qualitative studies such as this one have a smaller sample size than quantitative studies, it is acknowledged that:

- There will come a point where there is no new themes emerging, if the sample size increases it will no longer contribute to new evidence.
- There is no need to provide a sufficient sample size to estimate or determine statistical information.
- The type of information obtained in qualitative research is rich information. There will be many different parts of information in each narrative collected on interview. It would be near on impossible to transcribe a hundred narratives.

(Ritchie, Lewis pg 83).

5.1 Recruitment of Participants

Recruiting participants for this Service Evaluation was done by disseminating posters and flyers throughout the county via the HWD network, voluntary organisations, schools (including specialist schools and children's centres).

Parent carers were asked to get in touch with HWD if they have a child who has recently received an ASD Diagnosis and wished to share their experiences of this process. During this conversation Engagement Officers discussed the Service Evaluation, and went through the selection criteria.

5.2 Criteria for Recruitment

- Inclusion criteria
 - Parent carer of a child or young person aged 3-18 years who has been through the Autism Pathway in the last 12 months and;
 - Parent carer of a child who is in or has been in a Derbyshire school and;
 - Parent carer willing to provide informed consent to participate in the Service Evaluation.
- Exclusion criteria
 - Person diagnosed with ASD less than 3 years old or over 19 years of age.
 - Child or young person with an ASD diagnosis over 1 year ago.
 - Parent carer of a child or young person who has not been through the ASD Pathway.

All participants received HWD information, a participant information sheet and were asked to give their informed consent before interview dates and times were arranged. Parent carers were able to withdraw from the project at any stage if they wanted to.

5.3 Participants

A total of 26 families were interviewed.

- 14 families - 54% North Derbyshire
- 12 families - 46% South Derbyshire

The large majority of participants were mothers, whilst some fathers contributed in sharing their experience of the Autism Pathway. Two participants were Grandmothers.

Two interviews enabled us to speak to the young people about their experience.

Twenty families were interviewed who had boys going through the Autism Pathway with ages ranging from 3½ to 13 years old.

Six families had teenage girls going through the pathway.

Nineteen families had received a diagnosis, 5 were waiting for a diagnosis in North Derbyshire and 2 were deemed inappropriate for a diagnosis by their lead clinician.

5.4 The Interviews

HWD used an inductive approach which meant that the Engagement Officers didn't go into the Service Evaluation with pre-conceived ideas or theories.

Engagement Officers conducted open, un-structured, face to face interviews with parent carers. The interviews were digitally recorded and then transcribed.

Each interview lasted approximately 1.5 - 2 hours.

Parents were asked to talk about their experience in 3 broad areas:-

- Pre-diagnosis
- Diagnosis
- Post Diagnosis

To maintain some consistency, i.e. to ensure that both Engagement Officers were employing the same interviewing technique, the first few interviews were conducted jointly.

If/where participant's answers or relocations of their experiences were vague; the Engagement Officers used prompts where appropriate.

5.5 Data Analysis

This was a qualitative Service Evaluation, involving the interpretation of data.

Each transcription was examined in depth and a core category of themes emerged.

This technique basically involved breaking down the data that was gathered during the interviews into emerging themes (categories), e.g. communication, referrals, waiting times etc. It began soon after the collection of initial data, i.e. the first few interviews. This ensured that the Engagement Officers didn't go in with pre-conceived ideas, they let the data shape their thoughts. When it got to a point where no new themes were emerging, interviewing stopped.

The findings were recorded separately for both North and South Derbyshire.

6. Summary of Findings

Several overarching themes emerged during the Service Evaluation, these were:

- Education
- Impact on families
- Communication
- Waiting times
- General Practitioners
- CAMHS
- Diagnosis
- Support for parent carers during and after diagnosis

There wasn't a substantial difference between the experiences of parent carers in North Derbyshire compared to South Derbyshire.

6.1 Education

- All parent carers recalled experiences of education.
- Parent carers reported that there needs to be an improvement in support and recognition of the signs of Autism in Education.
- Parents felt that their child was not receiving adequate and/or sufficient support to meet their child's needs. This impacted on their child not wanting to go to school, being bullied and socially isolated, or even temporarily suspended due to teachers not being able to handle the child's behaviour.
- Parents also felt that they hadn't been listened to.
- Parents spoke about a reluctance of schools to make referrals to the educational psychologist.
- There were some examples of good proactive help given to parent carers by staff, but this was not consistent.

6.2 Impact on Families

- The impact on families was discussed in most interviews. With most parent carers expressing difficulties dealing with the situation, and feeling at crisis point.

6.3 Communication

- There seemed to be a lack of clarity amongst parent carers as to who was the first port of call to trigger a referral to the Autism Pathway.
- For the majority of parents it was stated that there was some form of communication breakdown at some point during the Autism Pathway. Issues in communication ranged from parent carers being unaware they were on the ASD pathway, causing a sense of confusion and frustration of what was going on, to errors and delays in the administration process.
- Parents stated that they had to repeatedly tell their experience to different professionals.

6.4 Waiting Times

- All parent carers stated that they had experienced significant waiting times to see various professionals.
- Some parent carers however understood the pressures that certain departments were under.

6.5 General Practitioners (GPs)

- Some parents felt that GPs were hesitant, or unaware, of who and where to make appropriate referrals to so that parents were quickly and efficiently being directed to the correct part of the system for help.
- Some parents spoke highly of their GP and found them very understanding.

- There was frustration amongst some parents that their GP has said that a referral would be made to a Paediatrician, but when appointments were chased up months down the line no referral had been made.

6.6 Child and Adolescent Mental Health Services (CAMHS)

- Some families also had contact with CAMHS.
- The majority of these experiences were recalled by participants in the North.
- When there had been CAMHS intervention with families, from the interviews it didn't seem to have been explained clearly to parents as to what the link is with the Autism Pathway.

6.7 Diagnosis

- There was an overwhelming sense that all parents wanted to know if their child was autistic because of the impact this would have on their child's future in terms of education, employment, relationships and if they would be able to live independently.
- Parents made positive comments regarding the autism diagnosis appointments.
- There were mixed feelings about the amount of information given. Some would have preferred detailed information where as others were happy with what they were given.
- Those families who received a diagnosis felt they could move forward in getting the right support and intervention for their child. They felt relieved.
- A large number of parents said that their initial instinct was right and wished that the professionals would have taken this on board much earlier in the process.
- Some stated that information was not given to them in plain English, some parents felt that it was meaningless because they didn't understand.

6.8 Support for parent carers during and after diagnosis

During diagnosis:

- Many parent carers said that they were offered some sort of support whilst they were going through the pathway.
- Others said they found great difficulty in getting appropriate support, or knowing where to get it from.
- Some parent carers stated that they were referred for inappropriate support.
- A large number of parents said they were unaware at which point the Autism Pathway had started.
- Parent carers interviewed found the pathway very difficult due to the amount of clinicians, professionals and assessments involved. There was a sense of confusion and lack of understanding as to where they were in the process.
- Parent carers felt they had to find out a lot of information themselves.
- All parents stated that they were the experts with their child and they knew them inside and out. There was a feeling that not all professionals listened to their views and some were quick to say that parents shouldn't want to label their child.
- It was stated that there was a lack of sibling support.

Post diagnosis:

- All the parent carers who had attended the Autism Workshop or an Understanding Autism Course (the details of which course or workshop was attended was not clarified with participant who tended to refer to them both as workshops) spoke very positively of them in North and South Derbyshire.
- Some parents shared their positive experience of getting support from a clinician at a support group.
- Parents commented on how great it was to be able to visit the clinician to get advice on different matters relating to their children on the Autism Spectrum.
- Only one parent carer spoke about being offered a follow up appointment after the diagnosis.
- Some parent carers didn't feel they received support post diagnosis, i.e. they weren't invited to attend the workshop/course, or weren't signposted to support.
- In South Derbyshire participants particularly stated that they had difficulty accessing support services as they weren't local to them. Most of the activity took place in Derby City, Matlock or Chesterfield. To parent carers the term 'local' meant within their district.
- Parents said that they really valued access to parent led support groups, they found that they could learn new coping strategies, meet new friends and share similar stories.

A large majority of experiences related to education which is technically beyond the remit of Healthwatch, however we would be willing to work with agencies to address this area.

Recommendations include:

- Increase awareness in education for teaching staff to recognise the signs of autism and to implement the appropriate support.
- Increase provision in appropriate support/advocacy for parent carers with children and the Autistic Spectrum and co-existing mental health problems.
- Increase provision of information to guide the parents through the pathway, to include the roles of the different professionals, what should happen at each assessment and local/national information.
- Ensure parent carers are aware that follow up appointments are available following diagnosis, when they are available and what their purpose is.
- A single point of contact, where the parent carer could communicate in order to be kept up to date with where they are in the process, and where they can access support to avoid getting to 'crisis point'.

More courses need to be offered to parents whilst they are going through the pathway to help them with coping strategies.

7. Findings

As the transcripts were examined the following themes emerged:-

- Education
- Impact on Family
- Communication
- Waiting Times

- GPs
- CAMHS
- Diagnosis
- Support during the Diagnosis
- Post Diagnosis Support

7.1 Theme 1: Education

All parent carers recalled experiences of education.

The majority of families interviewed across the County explained that there is a lack of autism awareness and training within teaching staff. Parents felt this had a direct impact as to whether staff in education were spotting or exploring the potential signs of autism as a cause of their child's behaviour even when parents were highlighting concerns.

"We didn't spot them and the teacher didn't spot them and the TA didn't spot them because there is not enough autism knowledge in education and I feel that that needs addressing because there is more diagnosis now of autistic children."

"When my child was in Year 5 the teacher said, 'Oh I don't think he is on the autistic spectrum.' I went away thinking maybe we're wrong, maybe we're being over anxious and I don't want to label the child with something ..."

Another parent spoke of the skills of teaching staff:

"Our problem was that the member of staff didn't have the skills. They hadn't got a clue to deal with my child's needs."

Some parents felt that their children were not receiving adequate and/or sufficient support and therefore the establishment was not meeting the needs of the child:

"I have mentioned getting some support from the Autism Outreach team; the school doesn't seem bothered in accessing that support. I don't feel like my child gets enough support because the SENCO only works for a couple of hours each week and she has to see other children."

Parents felt that the lack of support had a direct impact on the child not wanting to go to school:

"I struggled with the primary school, they let my son have unstructured playtime, they labelled him as a naughty child and he had three different teachers in one year. I had to move him because the thought of school in the morning caused him anxiety and made the morning routine very difficult."

Another parent said:

"My child's attendance is low because of the anxiety she faces because of the reluctance to go to school. Her worries start because of bullying, social isolation and the teacher's attitude."

Some parents discussed how they had tried to communicate with educational establishments in relation to their child's behaviour and didn't feel that they had been listened to:

"I highlighted all of concerns relating to my child two weeks before he was supposed to start, I told them all of his behavioural issues and explained how he interacted with other children. Despite my attempts to communicate with the school they couldn't cope with him when he started."

Another parent told us that the school had picked up on signs of autism but no referral was made because they wanted to wait until the child transitioned to secondary school:

"Problems were identified in Year 6 but nothing was done because my daughter was moving up to secondary school, no referrals, no information, nothing."

Parents felt that professionals weren't listening to them and that they were reluctant to refer the child:

"When I said this to the Head, she said, 'He only comes every so often and we've got so many children on our books and, to be honest with you, we're managing the [named child] fine, so I don't think an assessment will be forthcoming But I can ask.' I never heard any more about that and I wasn't pushy enough to say I demand it because I'm sort of quite a humble person ... I don't expect lots of support ... I thought I am the only advocate for my child."

Some children were reported as having meltdowns within the educational environment, being labelled as naughty children they were isolated from other children, activities and, in some instances, they were punished. One parent gave an example of how a member of staff highlighted issues with how other members of staff were treating her child:

"I don't think he's treated very, fairly, I do believe he has some issues, he is singled out as a naughty child and there are certain nursery workers there who are only interested in the children who will behave. If he was the one to put his hand up to partake in an activity, he wouldn't be chosen."

Another example was also highlighted:

"My child was strapped in his pushchair and left in a room on his own, a staff member was supposed to be rocking him asleep but she just left him."

An example was given by a parent explaining how her child was isolated from other children:

"He just wasn't coping well in the classroom situation. The first thing they did was move him away from the other children. They took his desk, put him on his own next to the teacher's desk and right next to a massive radiator ... I had said to them he really struggles with his own temperature regulation ... I said if you are going to put him near the radiator, can you switch it off? So they did but then a couple of days later I came in and it was back on again. His seat was right up against it and he couldn't see any of the other children from where he was ... he wasn't allowed that same interaction ..."

A small number of parents explained that their children had been placed on part-time timetables. Quotes have not been inserted due to possible identification of the families.

A number of children were at the risk of suspension or were permanently excluded. Parents felt that establishments weren't exploring the reasons of what could be causing the behaviour of the children and listening to the parents, this was a contributing factor as to why children were forced to move schools, and why some children were home schooled.

Parents recalled different experiences:

"My child has been moved from one school and excluded from another, both schools did not support him and I had a breakdown in relationships with professionals. My child now has input from the Intervention Pathway Team, I don't have much confidence in them because they don't seem to have much autism awareness. They also use centres that aren't safe."

One parent said, "... I was just beside myself. I thought a primary school aged child being excluded; I'd never heard nothing like it in my life."

Parents spoke about the lack of ownership by the schools regarding referrals and assessments into the educational psychologist:

One parent said, "The school was unhelpful, they did not try to support my child, we never saw an educational psychologist even though we were on the autism pathway."

Another parent said that teaching staff were arguing over who was going to pay for the educational psychology assessment.

A minority of parents had positive experiences with educational establishments. They valued the support from teaching staff and reporting that they helped parents to identify and implement the right strategies and/or make accurate referrals. This resulted in a positive impact on the child's development. It also aided in building relationships with parents.

"... he just sort of says 'oh well, I've been kicked and punched again today' and when I find out about the incidents we go into school and the school deal with it brilliantly ..."

"The pre-school highlighted concerns to me but also recognised that my child was gifted and talented, they made all the appropriate referrals."

"The private nursery has been brilliant from day one, they have gathered evidence right from the start and they have given me lots of support."

"I can't praise the school high enough to be honest; they are amazing they really are."

"[Named school], are absolutely amazing."

We found that experiences of education were consistent throughout the families in North and South Derbyshire.

7.2 Theme 2: Impact on Families

Most of the families interviewed explained the detrimental impact that arranging support for their children had on them. Some families were also trying to deal with other underlying worries as well as the autism.

"There is no support for me as the parent; I have struggled to get down to the secure unit and to understand what has been said."

"[Named child] doesn't always tell me. ... he just accepts some of it 'oh well people hate me, people call me weird, they pick on me that's what happens mum.'"

"When she got frustrated things were getting trashed like whatever came in her hand she just chucked ... four televisions have been smashed, doors, you name it and it was all frustration because she didn't know how to express herself."

"In some ways I think we've got this far because we've pushed."

"I've done a lot of research and I've been reading books, so we've really geared ourselves up, but nobody outside recommended those things to us, we just did it."

"It's horrendous, it's very stressful. We can't go out, it's difficult when you've got three children who are average children and they are doing what kids do but when you've got a child with autism it's so unsafe when you're out."

"My son had enough of going to the assessments; he was frustrated because the clinicians kept asking us why we thought he had autism."

"I thought why isn't somebody listening to me, how loud am I going to have to scream before somebody says, 'oh yes we need to help you' ... getting to tipping point."

"It's definitely put a strain on our relationship." And, "We've got no family, we haven't even got a babysitter that could come and we never go out."

"I want to be seen by a Psychologist because I've had enough of this."

7.3 Theme 3: Communication

There was a general consensus from all the parents that there was some form of communication breakdown at some point during the Autism Pathway.

Issues in communication ranged from families being unaware they were on the ASD Pathway, causing a sense of confusing and frustration of what was going on, to errors and delays in administration processes.

"I missed an appointment because I always book, they'd apparently booked one for 11.30am that is not something I would do. I don't remember ... we got there late, we never had a letter, they didn't send us a confirmation letter or anything so ... we got there and we'd missed the appointment and then it took us another 2 months to get another one. This wasn't very good."

Some parents told us how they repeatedly had to tell their experiences to different professionals:

"I was getting a bit sick of how many times I had to tell this same information over and over again."

"The Speech and Language Therapist referral was not successfully sent by [named establishment] as promised."

"...we were calling a [named professional] for 2 weeks straight every day pretty much, and we were calling on the right days ... we were ringing and we got no answer... we were left in the dark a bit like nothing was happening."

A number of parents were unaware of how they got onto the Autism Pathway:

"I don't actually know who referred me."

Numerous comments were made about the administration of appointments:

"There is no point in having good clinicians and good consultants if the admin is rubbish because the suffering is the same at the other end."

A number of parents said they missed appointments because they didn't receive any correspondence:

"I had been waiting for an appointment for 10 months; I contacted the clinic when I didn't hear anything only to be told that I had missed my appointment months ago. I never had a letter or a telephone call informing me that I had an appointment."

"... they assessed him in school and I didn't know anything about it and they said he was fine. I had a letter to say he was fine and I said, 'excuse me, no he's not fine, you will re-assess him.'"

We found this consistent in both North and South Derbyshire.

7.4 Theme 4: Waiting Times

All families experienced significant waiting times to see various professionals.

Parents felt that the waiting times to see an Education Psychologist, Clinical Psychologist and Paediatrician were significant enough to raise.

A parent said, "... it took over 6 months for an Educational Psychologist to visit the school." The parent recognised that this delay was due to the cross border arrangements.

Another parent said:

"It's ridiculous ... I tell you why it's ridiculous. If you've got a child who's sort of age 14 or 15, 13 weeks of missed school is a whole term. It will mean they are down on their GCSE grades at the best. At the worse it means they have to drop certain GCSEs."

"...we were being told that there was a 12-18 months wait to see [named clinician], which seemed crazy ..."

"The continuity of a person would be good but the biggest problem is the time it all takes. It's such a shame ... if parents are lost or young or whatever you could be desperate, absolutely desperate and takes so long and if there is no support in place in the meantime it's very bleak, it could be a very bleak time. We are lucky we have each other for support."

"I was angry, and you see my son would have still been at day one," and "I was fighting for his rights."

To see a Clinical Psychologist a parent read out a letter which said, *"We have placed [named child] on a waiting list. Unfortunately the waiting list is currently running over 14 months. If this situation becomes urgent we would ask parents to return to the person who's referred them to discuss the situation."* Parent said, *"I think it is a long time to wait."*

"It took from June until September to even get on her waiting list ... there is a waiting list for a waiting list."

Parents told us that the waiting times were long. However they appeared to be slightly longer in South Derbyshire than in North Derbyshire. Some parents understood the reasons behind the waiting times causing frustration with the system.

7.5 Theme 5: General Practitioners (GPs)

Parents felt that some GPs were hesitant or unaware of who and where to make appropriate referrals to so that parents were quickly and efficiently being directed to the correct part of the system for help.

A parent said when they told the GP of what was going on with their child, he/she stated that more help was needed:

"This was another major problem in the system. The doctor didn't know where to refer to. She thought CAMHS."

"The GP was aware of my child due to a previous referral to CAMHS for Obsessive Compulsive Disorder, GP was aware of everything, he wanted to put my child on anti-depressants but this wasn't possible without consent from the Child Psychiatrist. The GP wrote numerous letters without a response which caused a delay in the prescription."

"Our Surgery has been fantastic with the children but I was recently told that my GP wasn't a specialist in this field and if I wasn't going to take the advice from CAMHS then I shouldn't waste their time." The parent carer said that the GP didn't know enough about the Autism Spectrum Disorder.

"I am constantly going back to see my GP with my child, he was reluctant to refer us to CAMHS but he did refer us to the paediatrician. GPs should be able to offer more advice on coping strategies or to signpost you to someone that can."

"The GP didn't think another referral to CAMHS would help us."

"I feel like I am going back and forth with my GP and passed from pillar to post, I feel like I am on a merry-go-round. We have many referrals into CAMHS but then my child doesn't fit the criteria and I have to go back to my GP to initiate a further referral."

A few negative comments were picked up which were around GPs not listening the parents:

"I have seen every GP in the building, there is a lack of continuity which doesn't help the situation."

"It was the doctor who was very patronising, said he's far too young shouldn't be referring him anyway ... it's not about labelling him, it's about getting the right intervention."

"I'm trying to see about having a [named] therapy to try and help him that way, and is there any way we can get any money through the PCT to help him? GP replied, 'No, no there's no funding,' so anyway it was a no-go area, everything I was fighting a losing battle so I just walked out."

Some parents spoke highly of their GP:

"My GP was great with us, I don't have any problem getting appointments, and my child was referred for Global Development Delay. She said that my child obviously needs support and help."

"My GP is great, I have no trouble getting an appointment and they seem to understand what I am going through."

GP is *"... a lovely lady, very caring, she was very supportive, very caring."*

Parent experiences of their GPs were similar in North and South Derbyshire.

7.6 Theme 6: Child and Adolescent Mental Health Services

Some families also had contact with CAMHS, the majority of these were based in the North of the County. They described their experiences below:

"CAMHS were slow, it took my child three overdoses before they would offer any help, my child was already known to CAMHS for OCD. My child had been self-harming for some time."

"CAMHS said they would discharge my child because she didn't have a mental health condition, but we didn't have any support from anywhere else. Nothing else was mentioned."

"My child had been under CAMHS for 1.5 years; we didn't see any benefits or see how it had helped. It was just suggested that I attend an ADHD course. They couldn't diagnose with ASD because that was another department's responsibility. I got the impression that both departments kept separate patient records."

"My child had 4 sessions with CAMHS, recommendations had been made to school and I was told that we would get passed onto another worker. I received a letter a week after stating that we had been discharged."

"We are on the waiting list for a year but I don't understand what CAMHS is."

"CAMHS kept saying that my child had an attachment disorder, they don't listen to me as a parent."

One family said, *"We tried to get a referral to CAMHS, they wouldn't take it. Just sent it back and said it wasn't appropriate. Now I know it wasn't appropriate because they didn't have the staff and I get that."* A second referral was made when the child was at secondary school, *"The school nurse there did a further referral to CAMHS ... CAMHS sent it back again."*

One family explained. *"... CAMHS can be a blot on the young person's record depending on which career path they may choose to follow when they are older"*

"We were getting nowhere and she was suicidal and I was having to sleep with her." Parent carer said, *"How can an hour a week make a big difference?"*

On one occasion family had to take child to Out of Hours. The member of staff said, *"Who is your crisis support?"* *"We said, CAMHS are closed, we have none. So she said, 'well the only thing I can do it refer you to A&E.'"*

When one young person began to get better she said, *"CAMHS have done nothing for me."*

"I don't understand what CAMHS is and I don't understand anything about the system."

There doesn't seem to be any clarity from the parent carer's perspective as to how CAMHS fits in with the Autism Pathway.

There were some positive experiences of CAMHS:

"They came out to my house once a week to observe my child which I thought was really good. We got an appointment within weeks and our relationship worked really well. We

got help with issues and I can't praise them enough. We had great communication both by letters and over the phone."

"I thought that the Cognitive Behavioural Therapy was great, I saw a massive improvement with my child."

The majority of the experiences are from families in North Derbyshire.

7.7 Theme 7: Diagnosis

There was an overwhelming sense that all of the parents wanted to know if their child was autistic because of the impact this would have on the child's future in terms of education, employment, relationships and if they would be able to live independently.

Out of the families who received a diagnosis they felt they could move forward in getting the right support and intervention for their child.

"It is one of the hardest times because you don't want there to be anything wrong but you need to know if there is anything so you can access to help."

Parents made positive comments regarding the Autism Diagnosis appointments. There were mixed feeling on the amount of information given. Some would have preferred detailed information where as others were happy with what they were given.

"What does being autistic mean?"

"Diagnosis appointment needs a lot more details, e.g. test/assessment details."

Parents stated they were happy with the accuracy of the reports, although some said that they couldn't understand some aspects of the report because it was too jargonistic in parts.

A couple of parent carers told us how their lead clinician contacted them by telephone to go through the report, the parents were happy with this.

A few families were given information and a clear indication of where their child was on the Autism Spectrum and the others were given no indication. Parents spoke of being able to research specific information about the child on receipt of this information, others found it meaningless.

Other parent carers, with a confirmed diagnosis of autism, didn't mind that this information wasn't shared as they recognised and understood that the autism diagnosis is complicated.

"About his diagnosis, yes we got everything all in there, explained what autism is, that every child is different, there's different sections on the spectrum ... she even put me forward for a course ... which was fantastic."

Parent carers recalled feeling a sense of relief when the diagnosis was given. Comments were made of how the pathway should have been initiated at a much earlier stage in the child's life.

"She saw us all together and with the child outside the room. She said 'we've gathered lots of information' obviously from the whole history that we provided the Speech Therapist, Educational Psychologist and doctor and she, there and then on that day, said,

'It's Asperger's Syndrome.' You could have knocked me over, not from shock because as I say all this had bubbled under for years, just because I really wasn't expecting a diagnosis. I thought here we go again, it's another professional, we're not going to have another 12 months of providing information ... I could have cried because, why could this little poor child not have had this years ago?'

There were a minority of parents who said they disagreed with the outcome of the diagnosis appointment: An Autism Diagnosis was not made. They were not advised what the next steps or options were from that point onwards, e.g. a second opinion could be sought.

A family felt that time was needed to process the fact their child had been diagnosed with ASD. A follow-up appointment would have been helpful to go back and discuss things further.

Most families spoke about the need to learn strategies that they could implement when needed. It was felt that this type of help and support was lacking. For example, wanting help with toilet training.

Parent carers spoke equally positively of how and when the diagnosis was given in North and South Derbyshire. However:

In South Derbyshire families said they were given a pack of information once they received a diagnosis. The families made the following comments about the packs:

"She gave me all these papers and they're all mixed up ... I tried to sort them out."

"The packs were not in an accessible format."

"It took 5 telephone calls for the pack to arrive ... When the pack did arrive there was duplicate information in it ... one printed in portrait and one in landscape ... some other information was good, different websites ... The one thing we didn't find useful was the parent support group telephone number. I rang it up and the lady I spoke to said that the group had not been running for the last two years."

"We've found out now you can claim disability."

7.8 Theme 8: Support during Diagnosis

Many families spoke about being offered some sort of support whilst they were going through the pathway. Others found great difficulty in getting appropriate support, or knowing where to get it from.

"Our problem is that we know that we need support but we don't know what support we need and then the things that we do know we need, people don't seem to be able to help us."

"Still wasn't getting any help and I was pretty much drowning on my own at this point but I was glad they didn't close the case and I hadn't had to fight to keep it open."

"It was stressful going through the pathway, you don't know who to contact for support because you don't know if there is anyone out there. I haven't been given any information about groups. I feel that the whole experience and the lack of support has caused me to develop depression."

From A&E *"... so we just went home and spent the rest of the Easter weekend just on constant suicide watch with no one to turn to. It was awful ..."*

"... you know you've got to make yourself a nuisance basically to get the action that you want from them and I understand there's only two Paediatricians but when you've got all these other people saying yes we are doing this but we are not doing the other and you're expecting something to happen and nothing happens, again you've hit a brick wall, you know you've got to sort it really, really push to get that other appointment."

"Social Services were supposed to offer me support because I was at a crisis point and I felt that I couldn't cope. No one got back in touch with me."

Children's Centre worker, *" ... she was really good."*

MAT worker was found to be very supportive. *"She was our life saver."*

Parents said they have had to find out a lot of information themselves.

Parent carers said they were told to look at websites to find information about local support groups and to try and understand what autism is.

Parent carers spoke about feeling frustrated that they were signposted to attend positive parenting courses, all of the parent carers didn't feel that the course was appropriate for them as they couldn't implement the coping strategies. However one parent found the peer support useful as she was able to learn other family strategies.

Parent carers said they found out about support groups through word of mouth or by the use of social media.

Parent carers that worked full time couldn't access the support groups.

Some parent carers said that they really valued the support they received during the pathway as they were able to talk to parents that were experiencing similar difficulties.

Some parent carers stated that they received support from a carer support service, three of these parent carers said that they were able to help them fill out forms, one parent said that the carers support service couldn't help her fill any forms in.

However they didn't receive any direct support as parent carers with children potentially on the Autism Spectrum, and they thought of them as a signposting service. However, two parent carers were able to access the Carers Break Grant, but parent carers couldn't leave their children.

Some parent carers experienced difficulties with their children who had co-existing mental health conditions, two of which were admitted into secure units. These parents reported that they received no support as parent carers with children with mental health problems and autism.

Some parent carers received support from MAT teams and children centre workers, they all were very grateful for the support. Two parent carers described being discharged when workers thought that they had all the right coping strategies in place.

There was concern expressed at the lack of support that siblings received, stating that they were not identified as young carers even though they provided a lot of support for the child with autism.

7.9 Theme 9: Post Diagnosis Support

All the parents who had attended the Autism Workshop/Understanding Autism Course (the details of which course or workshop that was attended was not clarified with participant who tended to refer to them both as workshops) spoke very positively of them in North and South Derbyshire. Parents greatly appreciated the opportunity to access the workshop/courses as it gave the parent and a family member the chance to understand what autism is and to learn about different coping strategies. Parents mentioned that the workshop/course provided an arena for them to meet other people from parent lead support groups and they developed friendships with other parent carers.

"The autism workshops were amazing; I was put on the waiting list as soon as my child got the diagnosis. It helped my husband to understand autism because he had been sceptical about the whole process as he was under the impression that our child had behavioural issues."

"The clinician referred me to the autism workshops; I really valued the support because I had never come across autism before. It gave me an in-depth understanding."

"Autism course was brilliant."

Some parent carers shared their experiences of getting support from a clinician at a support group; they also mentioned that the clinician even visited parent lead support groups to offer advice on coping strategies and behaviour management. The parents commented on how great it was to be able to visit the clinician to gain advice on different matters relating to their children on the autism spectrum.

One parent carer was offered a follow up appointment after the diagnosis to see how the family was coping. However this was not consistent across all the parent carers interviewed.

Two parent carers were told that their name was on a waiting list but they haven't heard anything since, they did understand that this was because of the high demand due to the success of the workshops.

Parent carers stated that they weren't signposted anywhere when a diagnosis was made and nothing further was offered in terms of support from the professionals. .

"The support is non-existent, we just support each other the best we can."

"If you're diagnosed with autism, the journey with the health service finishes ... effectively because they do not have any autism support."

"Of all the numbers that I've got, I've had to find out myself basically. I thought that even when you're just first talking about it, even before the diagnosis, if you could have somebody say well if you've any concerns there are these numbers they'll get and just people's names what they do, a phone number and an email address and that's all, laminate it and put it into someone's letter. The school should have them, the nursery should have these things just to give somebody because you feel like you're on your own; you really do feel like you're fighting. Or just one local website that's local. I mean we've only just found out about the MAT Team."

"Yes they signposted us to a lot of things. We haven't really taken up with anything. At the time he was really struggling to make friends in secondary school ... and the most

wonderful things have been some of the books that [named clinicians] recommended, for me and to leave around for the child."

One mother said that she was just given a print out about girls and Asperger's, while the other mum said that she wasn't given any information about group or coping strategies.

Not many families had heard about the Local Offer website.

Two parent carers did have extensive knowledge about the Support and Aspiration Agenda.

In South Derbyshire, parents commented that support services, courses, workshops were difficult to access due to not being local to them.

"The problem I am finding is that, at a local level, it's really difficult to find services and information and then, on a national level, when you look on the internet or the National Autistic Society you're bombarded with information that's not in your area."

"We're Southerners and with two other children they are saying they've got this little thing after school, well Matlock's an hour and half away from us ... there doesn't seem to be anything in this area."

"I would like to be notified of things going on in the area that would benefit [named child] or anything."

"... some of things are in Chesterfield and Worksop and not around [named district]."

"There's a lack of information to other families. To sit and talk, to go out, even just get a function room ... there's just that lack of it round here. It's like in Birmingham it is a big thing where there it's like, oh right, we do this but we'll have to keep it a bit more low key sort of thing ..."

"I really needed somebody to come to my house and check in on me."

"We have just found out about charities as well that can/may help."

"You know we are stretched, we haven't got £500.00 to just go and buy a harness. He also needs a buggy which is £400.00. I am hoping that the occupational therapy can help us with some equipment to help us with that."

"There should be leaflets in there with charities that can actually help with specialist equipment, especially if a kid has got sensory issues of meltdowns where they can just go into their room to use some sort of equipment ..."

"He's been diagnosed and nothing has happened since."

All the parents unanimously said that they greatly valued, or would value, peer support:

"I don't want to go somewhere that I don't know, a named person organised a few things late at night and there were about 15 people in a circle. You had a coffee and there was talking about the new system and that was great and that's how I knew a bit about the new thing."

"I've learned so much from my friends because I've got a couple of friends with autism."

"Everything's a battle, you have to fight for every single thing, there is no agency or person in my view unless you find them yourself, there's nobody coming up to you and saying, 'you can ring this number they're going to help you,' you have to find the information yourself and most information is on the internet or its been through another

parent who's at the school saying 'oh you know you can ring this' because they are going through the same thing, sort of like that Net Mums."

"I'm just a mother, working clerical person ... I'm asking for advice with this person who's got autism. I don't know how to deal with it. I want to talk to somebody who deals with it. I haven't spoken to anybody with a person who's got an autistic child who knows how to deal with it, so I don't know."

8. Recommendations

These recommendations for service improvement have all been made by the parent carers themselves during the course of the interviews.

- The worries and concerns of the parents need to be addressed and explored further when their child displays behaviour that parents struggle to rationalise; behaviour being subjective to individual families.
- Time should be taken to actively listen to parent carers about the possibility of autism. (This is after some parents felt that clinician's did not listen to them and made suggestions to the parents about not wanting to label their children).
- Parent carers called for local information, i.e. within a district area. They wanted information and support on:
 - Local and national support organisations such as peer support groups.
 - Local and national support organisations for siblings to access.
 - Local and national organisations that can provide advice on welfare, benefits, charities and grants.
 - Local organisations/groups that can help with form filling.
 - Information that helps parents and the child/young person to prepare for the future such as transition into adult services.
- Parent carers called for agencies and professionals to work in a more co-ordinated way so that parents do not have to repeat information over and over again.
- Parent carers would benefit from the contact details of a named professional through whom they can communicate with the rest of the Autism Team. It was envisaged that this named person would keep the parent carer, child/young person up-to-date with information about waiting times, sequences of assessments, what to expect etc.
- Parent carers wanted a choice about how (if appropriate) they would like the information regarding the pathway to be shared with them and their child during the assessment process. For example, should the child/young person be at the appointments with parents, what would be an appropriate and convenient time to have the appointments?
- Parent carers requested that once a diagnosis had been made, that the information was shared with other relevant professionals and agencies, with parental consent.

- As only one parent carer mentioned the follow up appointment taking place, and other parent carers said that they would have benefitted from a follow up appointment, there seems to be some confusion as to whether they were offered/took place or not. Hence we would recommend that it is made clear to parent carers that follow up appointments are available, when and what they are for. This is because families expressed a need to digest the information given and gather further questions they may have for the professionals. This would also allow exploration of the risk of autism in siblings too.
- It was felt that the provision of specialised support for parent carers should be available across the county, this could involve advocacy services for parent carers. Support for siblings should be increased, siblings may not provide direct personal care but the experience still has an impact on them.
- Many parent carers made requests for a booklet similar to the Child Health Record, to guide them through to pathway to include:
 - A flowchart of the pathway.
 - What to expect.
 - Explanations of clinicians' job roles.
 - Charts to record pertinent points of the family history.
 - Record medication and sleep patterns.
 - A list of coping strategies.
 - Support groups.
 - A tick box to guide them through the assessment processes to help them understand where they are in the pathway.
 - The ability for this to be used as a communication aid between the different professionals.
- Parent carers requested more Autism Workshops, but also other courses that could be offered to parents whilst they were navigating the Autism Pathway to help them with coping strategies and give them someone to talk to about the process.

9. Responses

Response from the Derbyshire Children's Autism Co-ordinating Group

The Derbyshire Children's Autism Co-ordinating Group brings together parents and carers of children and young people with autism with professionals from Education, Social Care, Health and the voluntary sector. The group works to improve support for children and young people with autism.

The Group welcomes this report by Healthwatch Derbyshire. The group welcomes feedback from families about their experience of the current Derbyshire autism "pathway". The findings will inform a review of the current pathway for children, young people and their families to access support. Members of the group will also discuss the findings with their services and teams, to make sure that we learn from families' experiences of services.

Families' experiences of education

Although none of the recommendations in the report relate to Education specifically, the group notes the strength of parent carer feedback about their experiences of Education. The group will consider what more can be done to support schools and other Education providers in recognising the signs of autism and providing support.

Listening to parents, and addressing and exploring their concerns

It is disappointing to receive feedback from parents and carers that this has not always been their experience. The current Derbyshire autism pathway states that:

"Parents and carers must be treated as equal partners at every stage; their concerns must be listened to and they must be treated with respect. It is important that all parents/carers understand the pathway; that they not only understand what strategies and support are being put in place to support their child but can inform and shape those strategies."

All partner agencies will be asked to explore their own practice, and report back to the group on how they are improving parents' and carers' experience of services.

Parent carers called for better local information

A great deal of work has taken place to improve information about services and support. The Derbyshire 'Local Offer' website was launched in September 2014, and brings together a wide range of information about local and national services for children and young people with special educational needs and disabilities, including autism.

The Local Offer is at www.derbyshiresendlocaloffer.org

If families cannot find the information they need, or do not have access to the internet, they can ring Call Derbyshire on 01629 533190 and ask them to help.

The group will review the information on the Local Offer about services for children and young people with autism, to make sure that it is comprehensive and easy to find.

The Local Offer also needs to be publicised to families better. Information is being placed in libraries, GP surgeries, schools, children's centres and other settings. Details are also being sent directly to the parent carers of children and young people with statements of Special Educational Needs/Education Health and Care plans and to the Derbyshire Parent Forums.

Services need to work together in a more co-ordinated way. Families should have access to a named lead professional. Information should be shared with other relevant professionals once a diagnosis is made, with parental consent.

Parents/carers should have choice regarding how information about the pathway is shared with them and their child throughout the assessment process. Follow up appointments should be available following diagnosis

The group accepts these recommendations, many of which are already expected within the existing pathway. Services will review their current practice, and report back to the group on how they will make improvements.

Provision of specialised support for parent carers, including advocacy services

The Derbyshire Information, Advice and Support Service for Special Educational Needs and Disabilities (formerly Derbyshire Parent Partnership Service) is an information, advice and support service which supports parents and carers of children and young people (0-25 years) with special needs or disabilities. The service works closely with statutory and voluntary organisations.

Parent carers can also request to access disagreement resolution services if their child has a special educational need or disability, and they are not satisfied with the education, health or social care provision which is being made.

Support for siblings should be increased

More autism workshops and other courses should be offered to parents to help with coping strategies and give them someone to talk to in the process.

The group accepts that support for siblings is not consistently available, and that it would be desirable to increase support. The group welcomes the very positive feedback from parent carers who have attended workshops or training. Currently some parent carers may not be able to access these sessions, due to the age of their child and/or the service(s) they receive. The group agrees that it would be desirable to increase the provision of workshops and training. These recommendations will need to be considered in the context of the significant budget challenges facing both the Local Authority and NHS.

A booklet similar to the child health record to guide families through the pathway

The group welcomes this suggestion and will explore the possibility of developing a booklet.

Appendix I



Derbyshire Autism Pathways: Information for families

The Derbyshire Children's Trust has agreed how children and young people with autism in Derbyshire should be identified and supported. This information is a summary for parents/carers. The full pathways are on the Derbyshire County Council website at: www.derbyshire.gov.uk/autism

School-age children

If anyone has concerns about a child's development, they should raise them with the child's school - or with the local multi-agency team if the child is not attending school. You can find your local multi-agency team in the Derbyshire Family Information Directory (see Derbyshire County Council website or telephone Call Derbyshire 08456 058 058)

The school or multi-agency team will look at what is causing concern and identify what can be done differently to support the child. The school may be able to get advice and support from specialist services at this stage, for example an Educational Psychologist. The school will normally try out new ways to support the child for a term (around 13 weeks) to see how well these approaches work.

If there are still concerns at the end of the term, and it seems possible that the child may have autism or another developmental disorder, the school/multi-agency team will make a referral to a Community Paediatrician.

At this time, the school/multi-agency team will also identify someone to take the lead in working with the child and his/her family and to co-ordinate any support that may be needed. There may also be an assessment of the child and family's needs, carried out in partnership with the family (a "CAF"). The school will consider whether any extra educational support is needed, following the Special Educational Needs Code of Practice.

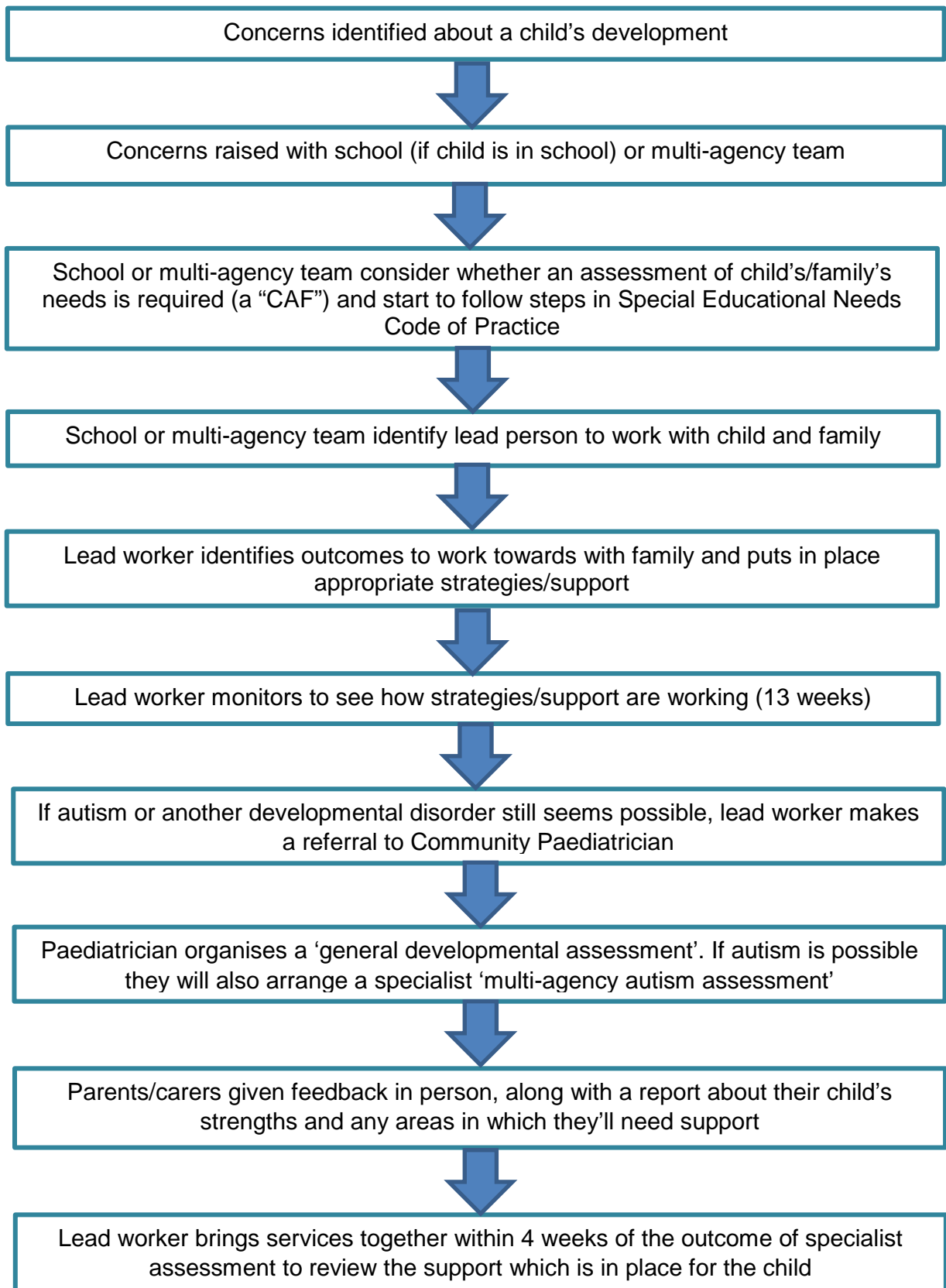
The Paediatrician will organise a developmental assessment. It's unlikely that a diagnosis will be made at this stage. If the Paediatrician thinks that autism or another developmental disorder is possible, they will arrange a more specialist assessment. This will always include professionals from different backgrounds with relevant experience and specialist training.

While the assessments are being carried out, any support which has been identified for the child will continue to be provided by the school and local services.

The outcome of the assessment will be communicated to parents/carers in person, along with a report which sets out their child's strengths and any areas in which they will need extra help. With parents' permission, the report will be shared with the school and with other services supporting their child.

Once the specialist assessment has been completed, the professional who is working most closely with the family will bring services together again (within four weeks) to review and update the plan for supporting the child. The child's plan will always include clear outcomes for the child and family, and will be regularly reviewed.

Flowchart: Pathway for school-age children



Pre-school children

Pre-school children who attend nurseries funded by the Council will be supported in the same way as children who are at school. There are a few small differences for children who attend private day nurseries, childminders and children's centres; and for children who don't attend any early years provision:

Children who don't attend any early years provision: If anyone has concerns about a child's development these should be raised with the local multi-agency team (or children's centre – children's centres are part of the local multi-agency teams). They will consider a CAF and make sure that the child is receiving appropriate support. If there continue to be concerns after 13 weeks, the multi-agency team will make a request to the 'Derbyshire Early Years Panel' for additional educational support and/or referral to a Paediatrician for a developmental assessment.

Children who attend a private day nursery, a childminder or a Children's Centre: If anyone has concerns about a child's development, these should be raised with the child's early years provider. The Special Educational Needs Code of Practice will be followed and the provider will consider a CAF. If there continue to be concerns after around 13 weeks the provider will make a request to the 'Derbyshire Early Years Panel' for additional educational support and/or referral to a Paediatrician for a developmental assessment.

Contact: Linda Dale – linda.dale@derbyshire.gov.uk. Tel 01629 532456.

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Your Feedback - Autism Report

Healthwatch Derbyshire is keen to find out how useful this report has been to you, and/or your organisation, in further developing your service. Please provide feedback as below, or via email.

1) I/we found this report to be: Useful / Not Useful

2) Why do you think this?

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.....
.....

3) Since reading this report:

a) We have already made the following changes:

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b) We will be making the following changes:

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Your name:

Organisation:

Email:

Tel No:

Please email to: karen@healthwatchderbyshire.co.uk or post to FREEPOST RTEE-RGYU-EUCK, Healthwatch Derbyshire, Suite 14 Riverside Business Centre, Foundry Lane, Milford, Belper, Derbyshire, DE56 0RN



DERBYSHIRE CHILDREN & YOUNG PEOPLE'S TRUST BOARD

SEND REFORMS UPDATE

10TH DECEMBER 2015

Purpose of the Report

To provide an update to the Children's Trust Board on the SEND Reforms within Derbyshire.

Change of Programme Manager

The Programme Manager for SEND reforms changed on 14th September 2015 from Nicole Chavaudra to Alex Howlett. Alex has previous experience of the reforms from being the Social Care lead officer on the Project Board.

Progress with EHC plans/conversions

In 2014/15 Derbyshire Local Authority converted 274 Statements of Special Educational Need to an Education Health and Care Plan (EHC). In September and October 2015 a further 100 conversions were finalised. At present Derbyshire has remaining 2743 statements to convert or cease April 2018, which constitutes a target of almost exactly 100 per month for the duration of the transition period.

Given the poor progress against the total conversion target in the first year, substantial revisions have been made to the conversion timetable and the guidance to schools. A senior admin officer from the SEND Team has been tasked with focussing on co-ordinating and supervising the conversion process, including detailed monitoring of progress.

EHC Plan writers are now well established in the process for writing the new EHC Plans based on the evidence provided. This means that the writing of new assessments is approaching a point where they are fully on schedule and the backlog of new assessments started in 2014/15 eliminated. In the whole of the 2014/15 academic year 67 new EHC plans were finalised. So far this September and October 2015; 73 new EHC Plans have been finalised.

New assessments will always have priority over conversions due to the statutory 20 week timetable for completing EHC Needs Assessments but it is anticipated that the requests for these will be substantially reducing to a more

manageable flow that can be kept within the 20 week timeframe as a matter of course.

The SEND Administration and Management Team is confident that significant progress will have been made into the overall conversion target by the end of the 2015/16 academic year.

GRIP and ETAEYS

The GRIP (Graduated Response for Individual Pupils) and ETAEYS (Enhanced Temporary Additional Early Years Support) pilot projects are mechanisms for providing additional education funding and support for children and young people with SEN without having to go through the process of an EHC plan. The funding is from the same source as that provided through an EHC, but by avoiding the EHC process this saves the resources that would be used for the assessment process. Additionally the support can be put in very quickly following a relatively straightforward moderating process to ensure consistency and equity of provision. These pilot projects have been approved by Children's Services Senior Management Team to be extended to become a long term Derbyshire SEND Reform initiative subject to Cabinet member approval. Following this the documentation and processes will be reviewed and rolled out to parents/carers, schools, settings and services through in depth training.

The GRIP has been recognised at a recent SEND Tribunal as a way of extending a graduated response to meeting pupils' needs, which is compliant with the SEN Code of Practice and therefore the requirements of the Children and Families Act 2014. The Tribunal confirms that GRIP is good educational practice in intervening early and effectively to meet a child's needs.

GRIP and ETAEYS have received positive feedback from parents/carers and schools/settings, who value early intervention with access to funding and services, without the need to request an EHC needs assessment.

Feedback from families

There has been mixed feedback from families with some reports of excellent practice and a high degree of satisfaction with the GRIP and ETAEYS pilot. However, there are also a lot of issues that Derbyshire Parent Carer Voice (PCV) wants to raise on behalf of parents in relation to the EHC plans.

To take this forward and to get as wide a perspective as possible, Derbyshire PCV have sent out questionnaires to families and also held an event in November for parents to attend and to compile their issues and concerns. Representatives from Derbyshire SEND teams are meeting with Derbyshire PCV on 11th December to discuss further and take this feedback.

As part of the ongoing Quality Assurance and Accountability framework it is planned to repeat these parental participation sessions on a regular basis to ensure we are receiving feedback from families. In addition future Challenge

Days (our internal audit process) will include a parent representative and also feedback from the children and families whose EHC plans are being audited.

Work on Locality SEND Teams / SEND Commissioning Hub

The work of the Integrated Teams Task and Finish Group and SEND Project Board produced a draft new structure with Locality Teams as a suggested way forward. This has been progressed through meeting with Heads of Service of those teams that would be directly affected and also with those stakeholders who would align to the new Locality Teams or be affected by the restructure. These meetings have been undertaken in order to gather views and information on how this structure can be realised operationally and to consider the various options there are in taking this work forward. Scoping work on the restructure has also been undertaken at a Project Board Development session.

The Programme Manager is compiling this information in order to provide a number of options around a restructure that will need to be considered. Final decision on this will be via Cabinet Approval for any affected Local Authority posts and a consultation will then need to take place with all affected staff. The intention is that further work on any restructure will be undertaken jointly with those managers and staff that are experts in their area so that a robust new structure is put in place that will meet all the requirements of the SEND Code of Practice (see below).

As well as Locality Teams, the new structure has a suggested SEND Commissioning Hub. This work has progressed in a similar way to that outlined above and a 'Draft Suggested Outline for the SEND Commissioning Hub' has been produced. This has been shared at The Project Board and Strategic Programme Board. The next stage for this is more detailed discussions with colleagues in the Clinical Commissioning Groups. Any changes to roles / structure affecting Local Authority Staff will go via Cabinet for approval. There will also need to be consideration of how health roles align with the proposed structure and this will be discussed further with CCG colleagues via the SEND Strategic Programme Board and the Joint Commissioning Group.

A Strategy Document that outlines the vision behind these reforms is attached as a Background Paper.

Preparing for inspection

New duties regarding disability and special education needs were contained in the Children and Families Act 2014 and are explained in The Code of Practice (statutory guidance). These duties place responsibility on the local area to identify and meet the needs of disabled children and young people and those who have special educational needs aged 0 -25.

The DfE has requested that Ofsted and the CQC inspect local areas on their effectiveness in fulfilling their new duties and these inspections will commence

from May 2016. As part of Derbyshire's preparation for inspection one of our senior officers, Mark Emly (Assistant Director, Learning Access and Inclusion) who is also an Ofsted inspector, has been seconded to take part in two of the pilot inspections. As a consequence of his participation in these pilot inspections Mark has given presentations to both the SEND Strategic Board and the SEND Project Board to ensure that all partners are up to date with the developing thinking of Ofsted and CQC. In addition members of the SEND Project Board have attended two consultation workshops delivered by Ofsted and CQC on the inspection framework and methodology. The information and PowerPoints from these events have been circulated widely to ensure stakeholders are up to date. There is now a formal consultation on the local area SEND inspections and the SEND Project Board is formulating a response.

A fundamental principal and the starting point for the inspections is that local areas know themselves well and how effectively they identify the needs of young people with disabilities and those with SEN and ensure that their needs are met and their outcomes improve. This means there has to be good process for local area self-evaluation through systematic monitoring and evaluation. To lead on this a Quality Assurance and Accountability Steering Group with representatives from education, health, social care, parents/carers and young people has been set up. The purpose of this group is to develop and establish a monitoring and evaluation and quality assurance framework that captures the necessary evidence to enable a Derbyshire Self-Evaluation Summary (SES) to be produced and reported to both strategic groups and any future inspection team. The SES will outline our strengths and areas for development in relation to needs identification, meeting of needs and improving outcomes. The purpose of this is fundamentally to inform subsequent strategic development and commissioning to improve the provision and offer for young people with a disability and those with SEN, not just a process for Ofsted and CQC.

The steering group will review the existing evidence base and data streams which will inform the self-evaluation. This will identify any gaps in data, both quantitative and qualitative, to support quality assurance and evaluation that will then need to be developed or commissioned. Work has already been commissioned from the transformation unit to develop a comprehensive SEND data set drawn from existing sources such as Tribal, Framework-I, etc. This is currently under development.

The intention is that the systematic monitoring and evaluation, gathering of the supportive evidence and the formulation of the Self-Evaluation Summary will be completed by Spring 2016 ready for any subsequent inspection. There will then be an ongoing process of further development, refinement and reporting.

Background Papers

Attached paper gives the background and vision behind the SEND reforms:

'Strategy for a reformed Special Educational Needs and Disabilities System and Children, Young People and Families in Derbyshire.'

Officer Recommendation

That the Children's Trust Board notes the work being undertaken in this area and provides any feedback, comments or advice that it thinks are pertinent or would be useful to the SEND reforms programme.

SEND Reforms in Derbyshire



**Strategy for a Reformed Special Educational
Needs and Disabilities System and Children,
Young People and Families in Derbyshire
2015-2017**

Contents

1	Purpose of the Strategy	3
2	Context.....	3
2.1	The Children and Families Act 2014.....	3
2.2	Implementation to date.....	3
2.3	Ambitions for phase 2 of the Reforms.....	4
2.4	Consultation.....	4
3	Objectives.....	5
4	Strategy	5
4.1	A single point of access to SEND advice and support will be established	5
4.2	A multi-agency commissioning hub will be created	6
4.3	Inter-disciplinary SEND teams will be established.....	6
4.4	Specialist services will support children to be the best they can	7
4.5	Authentic and meaningful participation.....	8
4.6	Effective communications using information technology	8
4.7	A culture of continuous improvement.....	8
4.8	Workforce development.....	9
4.9	Investment in preventative and early intervention approaches	9
4.10	Personal budgets.....	9
4.11	Preparing for adulthood.....	10
4.12	Commissioning.....	10
4.13	Funding review.....	10
5	Governance.....	11

1 Purpose of the Strategy

Derbyshire is passionately committed to working together to support children and young people with special educational needs and disabilities (SEND) and their carers and families. This strategy reflects our commitment to drive up and sustain quality services, providing challenge and scrutiny to ensure the services we offer are supporting great outcomes for local children and young people. This Strategy sets the framework within which Derbyshire County Council, Derbyshire Clinical Commissioning Groups (CCGs) and other partners will deliver our local ambitions for the SEND reforms. It will describe what we are going to do, and how we are going to do it.

2 Context

2.1 The Children and Families Act 2014

The Children and Families Act 2014 introduced changes for Local Authorities and their partners with regard to how children and young people with special educational needs and disabilities will be assessed and supported. The Act is supported by a revised Code of Practice for Special Educational Needs (SEN), published in August 2014. The principles underpinning this Code of Practice make clear that local authorities must have regard to:

The views, wishes and feelings of the child or young person, and the child's parents;

The importance of the child or young person, and the child's parents, participating as fully as possible in decisions, and being provided with the information and support necessary to enable participation in those decisions;

The need to support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood.

Each local authority was required to be compliant with the requirements of the Act by 1st September 2014, and an Implementation Grant has been provided to Councils by the Department for Education to support the implementation of the Reforms.

2.2 Implementation to date

Phase 1 of the reforms focused on achieving compliance with the requirements of the Children and Families Act and associated Code of Practice for SEN, which includes a focus from 0-25, rather just for children of statutory school age. Phase 1 was led by a multi-agency project board which has delivered the following from September 2014:

- Derbyshire's Local Offer, which describes the types of support available in Derbyshire for children and young people with SEND and their families, from birth to 25 years of age, has been live.

- All requests for assessment of special educational needs now follow the 20 week process for the Education, Health and Care (EHC) Needs Assessment.
- 5 EHC Assessment Facilitators have been appointed to support children young people and families who are referred for an EHC Plan Assessment
- A timetable for conversion of Statements of SEN to EHC Plans, which local authorities must undertake by April 2018, has been published
- A new Personal Budgets officer has been appointed to provide advice
- A threshold document has been developed to inform planning and decision making for SEND cases.

2.3 Ambitions for phase 2 of the Reforms

In June 2014 Cabinet approved investment in a transformation programme to deliver on the ambitions for the SEND reforms in Derbyshire. The Reforms locally seek to deliver:

- A new relationship with children and families – doing with, rather than being done to;
- Reduced bureaucracy;
- More joined up and integrated approaches between services;
- A system that feels different, characterised by person centredness and a focus on outcomes;
- Strategic and integrated commissioning of SEND services.

2.4 Consultation

In July 2014 a public consultation was undertaken to inform the SEND reforms. This has since been complemented by extensive consultation with a range of stakeholders via a multi-agency governance structure for the reforms, and a series of 11 engagement events around the County for children and families, and for multi-agency staff, which involved almost 300 people.

They key themes arising from the consultation are:

- Families wish to access support at the right time, using a graduated response to a child's needs, without the need for a statutory assessment where possible;
- A wish for a less complex, but more multi-agency response to assessment, planning and support;
- For children and families to be at the heart of planning and decision making;
- Families do not want people who have never met their child taking critical decisions about their support;
- Positive views of working in a multi-agency, co-ordinated way in 6 local areas.

3 Objectives

In response to findings from the consultation, and due to organisational drivers, the SEND reforms in Derbyshire has the following objectives:

- High satisfaction from and great experience for children and young people with SEND and their families;
- Improved outcomes for children and young people into adulthood;
- Excellent inspection outcomes;
- More cost effective and streamlined services;
- Responsive and integrated commissioning of SEND services;
- A highly skilled and effective workforce.

4 Strategy

The objectives for this strategy will be delivered through three distinct functions required of SEND services, the details of which will be explored in the following sections:

- Assessment of needs, planning of support and review of progress for individual children's education, health and care needs;
- Provision of specialist support for individual children and young people to deliver identified outcomes;
- Integrated commissioning of education, health and care services to meet the needs of children and young people with SEND.

4.1 A single point of access to SEND advice and support will be established

Starting Point, which is the contact and referral service for requests, advice, support and safeguarding concerns, commenced operations in September 2015. Currently, there is no SEND representation within Starting Point. SEND services will have a presence within the service to provide: expert advice regarding support, including in schools and other settings; consultation with multi-agency professionals; referral to, and support with, the Local Officer; and onward referral to SEND teams if the criteria are met.

'To make the best use of resources, partners should consider how an integrated approach can best support... better access to services' (Code of Practice, 3.7)

4.2 A multi-agency commissioning hub will be created

A new commissioning hub will be created, involving commissioners from education, health and social care, to deliver the following functions:

- Allocation of EHC assessments, or other plans to meet SEND needs, to the appropriate locality SEND team;
- Complex decision making and responsibility for allocating resources;
- Strategic commissioning of services to meet emerging needs of SEN children and young people;
- Quality assurance of SEND services, including compliance with statutory responsibilities;
- Moderation, final sign off and confirmation of EHC Plans.

*'Local authorities and clinical commissioning groups (CCGs) **must** make joint commissioning arrangements for education, health and care provision for children and young people with SEN or disabilities'* (Code of Practice, 3.3)

4.3 Inter-disciplinary SEND teams will be established

Based in 6 localities, aligned to the early help to safeguarding services, the multi-agency SEND teams will be responsible for:

- Integrated assessments and plans for individual children and young people across education, health and care, using a graduated response to meeting needs;
- Regular reviews;
- Person centred approaches;
- Key worker/ lead professional function, supporting families;
- Challenge, training and advice to settings on SEND issues;
- Signposting to the Local Offer, and developing the websites content in response to local knowledge.

The teams will include education and social care officers, and will be aligned to health workers, such as health visitors, school nurses, and therapists, in the locality. Within the teams, professional specialisms in different life stages for children, including early years and transition to adult, will be retained.

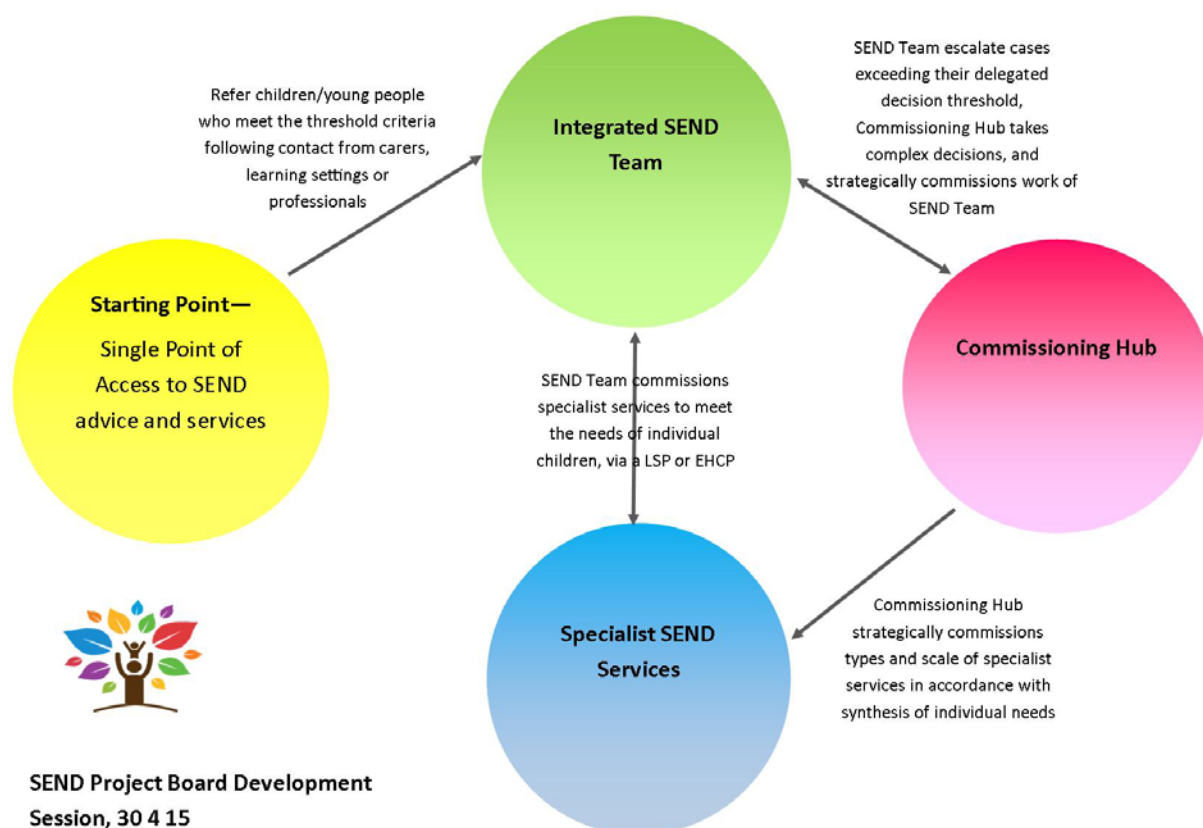
We will 'provide personalised, integrated support that delivers positive outcomes for children and young people, bringing together support across education, health and social care from early childhood through to adult life, and improve planning for transition points such as between early years, school and college, between children's and adult social care services, or between paediatric and adult health services.' (Code of Practice, 3.7)

4.4 Specialist services will support children to be the best they can

Specialist services providing bespoke and evidence based support for children and young people are an important component of the new system. Specialist services will be responsible for: expert advice to support assessment and planning for individual children; delivery of provision in accordance with plans to meet SEND needs of individual children; participation in reviews; provision of specialist training.

‘Services will include specialist support and therapies, such as clinical treatments and delivery of medications, speech and language therapy, assistive technology, personal care (or access to it), Child and Adolescent Mental Health Services (CAMHS) support, occupational therapy, habilitation training, physiotherapy, a range of nursing support, specialist equipment, wheelchairs and continence supplies and also emergency provision. They could include highly specialist services needed by only a small number of children’ (Code of Practice, 3.9)

Fig 1. New service functions



4.5 Authentic and meaningful participation

A participation strategy will identify where and how children, young people and/or families should be strategically engaged in planning and review functions. A system for enabling feedback from service users for each contact, and throughout their involvement with SEND services will be developed.

There will be a link to the regional 'principles for participation' and the use of Easy Read via Mencap and communication in print including costs and licensing will be explored. Technologies which will facilitate participation for young people both those at special schools and within mainstream settings, eg Google Hangout will also be explored.

'Effective participation should lead to a better fit between families' needs and the services provided, higher satisfaction with services, reduced costs (as long-term benefits emerge) and better value for money' (Code of Practice, 1.12).

4.6 Effective communications using information technology

A recording system will be in place to enable all practitioners to record their contacts with families. Parental input into the child's background information will be enabled, as will multi-agency practitioners' ability inform planning online and to develop online plans.

A data reporting system, drawing from the range of recording system used across education, health and social care, including adult care, will be created to secure robust identification of needs, progress and intelligence regarding SEND in Derbyshire.

'Local authorities should ensure they have access to good quality data to inform their decisions' (Code of Practice, 4.28)

4.7 A culture of continuous improvement

SEND services in Derbyshire will continuously manage its performance in meeting and identifying the needs of children and young people with SEND through:

- Data tracking, using the system referenced in 4.6;
- Quality information from feedback, participation and through quality assurance mechanisms including performance clinics and challenge days;
- Identification and use of evidence and research to inform great practice.

'Local areas should maintain up-to-date information on research and guidance about good practice, for example through referring to NICE guidance and Campbell collaboration/Cochrane collaboration' (Code of Practice, 3.3)

4.8 Workforce development

The skills and knowledge of the workforce will be of a sufficiently high standard to deliver excellent services using best practice. To achieve this, the development needs of workers will be identified, and training developed with a focus on person-centred, outcome focused practice will be developed and delivered.

Bespoke packages of training and skill development for critical stakeholders, including schools, parents and wider services, will be created in response to emergent needs identified by the commissioning hub, SEND teams and service leadership.

We will 'build person-centred services that take into account the developmental needs of the young person as well as the need for age- appropriate services.' (Code of Practice, 8.56)

We will 'support the child or young person, and the child's parents, in order to facilitate the development of the child or young person and to help them achieve the best possible educational and other outcomes, preparing them effectively for adulthood' (Code of Practice, 1.1)

4.9 Investment in preventative and early intervention approaches

A pilot using high needs block resources to facilitate a graduated response to meeting the needs of children and young people with SEND, via their learning setting, will be undertaken. This will seek to reduce demand for statutory assessments, and enable learners to thrive in mainstream settings wherever possible, improving their longer term outcomes, and reducing demand for lifelong support.

We will support 'prevention, identification, assessment and early intervention and a joined-up approach'. (Code of Practice, 3.4)

4.10 Personal budgets

Guidance and support for staff and families with a potential interest in personal budgets will be developed, including e-learning, online guidance available via the local offer, films and in person advice from the Personal Budgets Officer.

*'Young people and parents of children who have EHC plans have the right to request a Personal Budget, which may contain elements of education, social care and health funding. Partners **must** set out in their joint commissioning arrangements their arrangements for agreeing Personal Budgets.'*

They should develop and agree a formal approach to making fair and equitable allocations of funding and should set out a local policy for Personal Budgets' (Code of Practice, 3.38)

4.11 Preparing for adulthood

A pathway to support young people in preparing for adulthood will be established. This will ensure that learners will be supported to plan for their adult life from year 9 onwards, using a range of supports from services, including linking to adult care services.

'As young people prepare for adulthood outcomes should reflect their ambitions, which could include higher education, employment, independent living and participation in society' (Code of Practice, 6.79)

4.12 Commissioning

A joint commissioning strategy will be developed to establish the framework for shared planning, funding, review and commissioning of services to meet the needs of children and young people with SEND across education, health and social care.

'Local authorities should involve children, young people and parents (including local Parent Carer Forums and Youth Forums) in the design or commissioning of services providing information, advice and support in order to ensure that those services meet local needs'. (Code of Practice, 2.6)

4.13 Funding review

The support of a technical expert will be secured, to explore how support for individual children and young people might be resourced in the future. The experts will undertake an exploration of the following challenges:

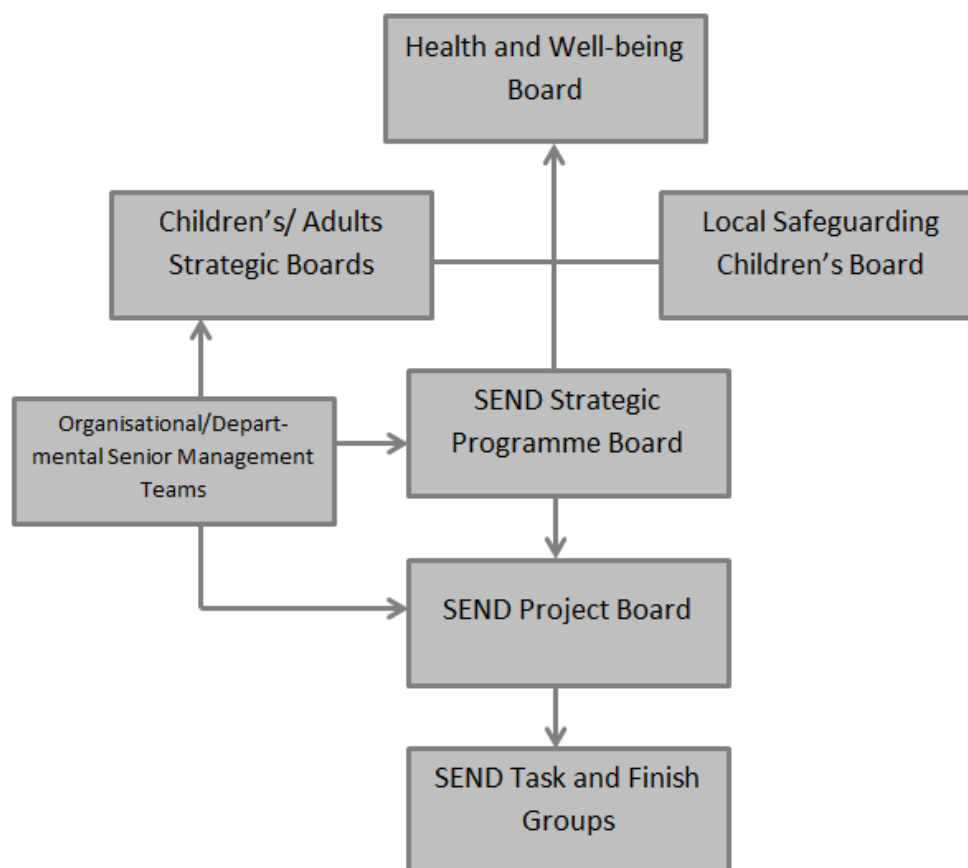
- How might we have fewer statutory assessments by working with our partners, including schools, to mobilise resources to support individual SEN at a local level?
- What changes might be required to the system of funding to achieve this ambition?
- How might we support a change in the culture of associating statutory assessment with accessing resources across the system, towards a culture of early and local intervention?
- What implications might there be for the current configuration of SEN support services if this ambition is to be realised?

Furthermore, they will explore whether current categories of SEN appropriate and effective, and whether the level of resourcing attached to categories fair and proportionate?

5 Governance

A clear structure for accountability will oversee the delivery of this strategy, with overall accountability resting with the Health and Wellbeing Board.

Fig. 2 Governance Structure



The principles are:

- **Leading change** – giving clear direction, engendering trust, engaging stakeholders, appointing the right people at the right time, being clear about uncertainty, solving problems and creating novel solutions, and supporting transition to the new ways of working;
- **Envisioning and communicating a better future** – a clear vision statement that is consistent and communicated, and recognising and rewarding those involved in improvements;
- **Focusing on benefits and threats to them** – all benefits will be aligned to the strategic objectives, a risk register will be kept up to date and well managed, the

benefits of the programme will be understood, and the programme will remain focused;

- **Adding value** – the programme will add value to the sum of the constituent projects and there will be a plan for quick and visible performance improvements;
- **Designing and delivering a coherent capability** – a schedule of activity will ensure the optimum level of change is delivered within minimum adverse impact on operational services, with rigorous management of interdependencies between projects, clear understanding of different responsibilities within the programme, regular reviews, and removing obstacles to change;
- **Learning from experience** – a reflective stance will be taken by all members of the programme organisation and this will be facilitated by the retention and maintenance of a log of lessons learned, and use of the Programme Quality Impact Assessment tools (monthly by the Programme team, and every 6 months by the Programme Board);
- **Remaining aligned with corporate strategy** – external influences on the programme will be identified, projects will be carefully monitored and the business case will be regularly reviewed.



DERBYSHIRE CHILDREN & YOUNG PEOPLE'S TRUST BOARD

10th December 2015

The Children's Trust Board is invited to recommend to the Health and Wellbeing Board that it:

- i) Notes the findings of the consultation
- ii) Endorses the **10 keys to unlocking School Readiness** and the recommendations for action
- iii) Commits to further joint working with Derbyshire Children's Services to make these recommendations a reality as agreed within the working group of the Early Years Strategic Group, made up of senior officers from Health, Education and Children's Centres.

Overall Summary

The term 'School Ready' is used extensively by politicians and in the media to mean many different things for many different purposes. There is no clear national definition of what being ready for school actually means. In Derbyshire we felt that we needed to create a definition with those who live and work with 0-5 year olds. **We felt that having a definition of being 'Ready for School' would help parents and professionals to feel confident about developing the right skills and attitudes in young children to set them off on a happy and successful path of learning.** We agreed to define this at the start of the Reception year, when children have their fifth birthday.

The Derbyshire Early Years Strategic group commissioned the Ready for School survey in March 2015 to be conducted in June and July of that year. The survey was available on line for anyone interested in responding and in paper copy for targeted schools and settings and all Children's Centres in the County. Participation was encouraged through an extensive media campaign. The survey was developed by Health

and Education colleagues working together with a wider steering group of professionals acknowledged at the end of this report. It was trialled with a small number of schools, settings and parents prior to full release.

We were delighted by the strength of response to the Ready for School survey, with over 1,800 forms completed by parents and professionals all over Derbyshire.

The purpose of the report was to analyse the results of the survey and present them in a way that is accessible to everybody. **The report will be used by all of us who coordinate services for young children and their families to support planning and development work so that Health, Education and Children's Centres work together with parents and carers to make sure more children than ever arrive in Reception classes happy and ready to learn.**

What was really heartening was that very clear priorities emerged as we analysed the survey responses. We have synthesised these into what we have called **'The 10 keys to unlocking school readiness.'**



READY FOR SCHOOL IN DERBYSHIRE

The 10 keys to unlocking school readiness*

- I can settle happily without my parent/carer
- I can talk to friends and grown-ups about what I need
- I can take turns and share when I am playing
- I can go to the toilet on my own and wash my hands
- I can put on my own coat and shoes and feed myself
- I can tell a grown up if I am happy, sad or cross
- I know that what I do and say can make others happy or unhappy
- I am curious and want to learn and play
- I can stop what I am doing, listen and follow simple instructions
- I enjoy sharing books with grown-ups and talk about them

Executive Summary and Recommendations

Respondents

- 1,840 people responded to the Ready for School survey in June and July 2015.
- Responses were fairly equally split between parents and professionals, across Health (Health Visitors, School Nurses, Community Nursery Nurses, Speech and Language Therapists), Education (schools, settings and childminders) and Children's Centres. 55% of responses came from parents/carers and grandparents and the rest came from professionals who work with children and families.
- There were strong similarities between the views of all groups of respondents.
- Responses came from all localities in Derbyshire but the largest response (40 per 10,000 of the working age population) was from the High Peak and Derbyshire Dales.
- Respondents were all asked to rank four sets of questions from very important to not important. They were also asked to give five top priorities for school readiness and given the opportunity to make further comments.

Summary of findings

1. The survey responses confirmed that all respondents recognise that personal, social and emotional development (being able to share and relate to others and feeling confident) and self-help skills (being able to go to the toilet, dress and feed yourself) are key to being ready to learn and play in school. Communication and language skills also ranked highly in responses recognising how important it is that children can listen and respond to adults and make their needs and feelings known. These aspects form the majority of the **10 keys to unlocking school readiness** identified in the report.
2. Early literacy and mathematics questions in the survey did not attract quite such high rankings. This does not mean that knowing letters and numbers and being able to write are not good things for children to be able to do at the start of Reception class. However these academic skills alone, will not equip a child adequately to be happy and learn well in the school environment; the personal social and emotional, self-help and communication and language skills being securely in place.
3. The importance of curiosity and a desire to learn emerged through the comments and priorities section of the survey (section F-H of main report). This is of course fundamentally important to being a successful learner at all stages in life.

4. A proportion of respondents (16%) felt that the current national single point of admission to Reception in September each year was not flexible enough to meet all children's needs as some children have only just reached the age of 4 years in the month before they start Reception. Some also expressed a desire for a more phased start to school with part time days leading up to full days and weeks.
5. Compulsory school age was seen by some respondents (5%) as being too young in this country. For example, one respondent commented "I feel that children go to school at too young an age in this country. I feel that at 4/5 children's emotional security and well-being are more important than rushing them into academic learning if they're not ready".
6. 14% of responses reflected the importance of Early Years education not becoming too formal too soon. Basic skills of reading and writing and mathematics do need to be taught, but in an appropriately fun way that recognises children's interests and their need for active playful learning throughout the Early Years Foundation Stage (0-5 years) and into Key Stage 1 (5-7 years).

Recommendations:

The following recommendations all have equal importance and will now be built into Derbyshire strategic planning for Health, Education and Children's Centre services:

- **All services will work together to ensure there is a consistent approach to school readiness and that it is a top priority for service development.**
- **Parents will be supported to develop a secure attachment to their infants and young children and to respond appropriately to their needs to promote development.**
- **Families and Early Years settings will be supported through the 'Every Child a Talker' programme so that typically developing children start school in Derbyshire with age appropriate language skills.**
- **Professionals need to agree appropriate shared milestones for toilet training and then parents must be helped to develop toilet training and other self-help skills at an appropriate time for their child.**
- **All schools will work in partnership with Early Years settings to implement best practice transition approaches.**
- **Schools will be supported to operate flexible admissions practice that best meets the needs of every child and family.**
- **All Derbyshire schools and Early Years settings will strive to deliver 0-5 education that is of the highest quality and child-centred so that children are ready for school. Schools will be ready to make learning exciting and developmentally appropriate for young children.**

Information and Analysis

The full report contains detailed analysis of all response's and respondent groups to the School Readiness Survey (July 2015)

Background Papers

The full Derbyshire School Readiness report is available at:

http://www.derbyshire.gov.uk/images/ready%20for%20school%20report_tcm44-272330.pdf

Officer Recommendation

That the Children's Trust Board recommends to the Health and Wellbeing Board that it:

- i) Notes the findings of the consultation
- ii) Endorses the **10 keys to unlocking School Readiness** and the recommendations for action
- iii) Commits to further joint working with Derbyshire Children's Services to make these recommendations a reality as agreed within the working group of the Early Years Strategic Group, made up of senior officers from Health, Education and Children's Centres.



DERBYSHIRE CHILDREN & YOUNG PEOPLE'S TRUST BOARD

10th DECEMBER 2015

Purpose of the Report

1. To provide an update on the Children's Trust Board key indicator set.

Information and Analysis

2. Updates have been included for the following indicators:
 - Number of children in care per 10,000 population
 - Number of children subject to a child protection plan
 - Children who have run away from home/care overnight
 - Number of children in need per 10,000 population
 - Obese children in reception year
 - Obese children in year 6
 - Smoking in pregnancy
 - 16-18 year old NEETs
 - 17 and 18 year olds participating in learning
 - Care leavers in employment, education and training
 - Achievement of 5 or more A*-C grades at GCSE or equivalent including English and Maths
3. The following indicators have moved in the right direction since they were last updated:

- Obese children in reception year (aged 4-5)
In 2014-15, 7.7% of children were obese, a decrease from 8.6% in 2013-14. This is below the national and sub-national average.
- Smoking in pregnancy
15.1% had smoked during pregnancy in 2014-15, a fall from 16.3% the previous year. Derbyshire's performance remains above (worse than) the national and regional averages.
- % achieving 5 or more GCSEs A* - C including English and Maths
In 2015, 54.5% (provisional) achieved 5 or more GCSEs A* - C including

4. Children's Trust partners will want to note and consider the following:

- Children in care
The number of children in care has increased very slightly. In October, there were 629 children in care, compared with 624 at the end of July.
- Children subject to a child protection plan
621 children were subject to a protection plan in October, a very slight increase compared with 593 in July. The numbers tend to fluctuate on a month-by-month basis.
- Children in need
The number of children in need is 4,668, compared with 4,739 in July.
- Participation of care leavers
In October, 48.4% of care leavers aged 19-21 were participating in education, employment or training, compared with 47.6% in 2014-15.
- Children who have run away from home/care overnight:
The rolling 3-year average in October was 348, compared with 318 in July. This indicator had been on a consistent downward trend but has fluctuated over the course of the past year and is now increasing slightly.
- Participation of 16-18 year olds
3.6% of 16-18 year olds were NEET in October, the same as the figure for June. However, participation rates for 17 and 18 year olds in learning have fallen.
- Obese children in year 6
In 2014-15, 17.1% of children in year 6 were obese, the same as in 2013-14. This is below national and sub-national averages.

Officer Recommendation

5. It is recommended that Children's Trust Board members-

- Note the performance data provided
- Identify any further information or analysis that may be required to understand the reasons for these changes

Linda Dale
December 2015

Key Performance Indicators-Update December 2015.

Indicator	Latest actual number	Current Performance	Performance against target	Direction of travel compared with last update	Comparator average	Comparator best
1.Children in care per 10,000 population (Updated monthly)	629	41 per 10K pop (October 2015)	Not Meeting	Worse	Not Available	Not Available
2. Adoptions from care (% leaving care who are adopted). 3 year average figures. (Updated annually – no update – last update 2011-14)	215	25%		Better	14% (Nat) 16% (SN Ave)	25% (Derbyshire)

3. No of children subject to a child protection plan per 10,000 pop (Updated monthly)	621	40 per 10K pop (October 2015)	Achieving	Worse	Not Available	Not Available
4. EHA's instigated by organisation	Reports in process of being developed					
5. Children who have run away from home/care overnight (Updated monthly)	348 (October 2015)	N/A	Not Meeting	Worse	Not Available	Not Available
6. Children in need per 10,000 population (Updated monthly)	4668 (October 2015)	303 per 10K pop		Better	Not Available	Not Available
7. Hospital admissions of children and young people due to self-harm (10-24) per 100,000 pop (Updated annually – no update - last update 2013/14)	818	621 per 100K	Not Met	Worse	412 per 100K (Nat)	119 per 100K
8. % achieving a good level of development in the	5818	68.5%	Not Met	Better	66.3% (Nat)	72.9%

Early Years Foundation Stage (Updated annually – no update – last update 2015/16)					67.5% (SN)	(Kent)
9. Breast feeding initiation rates (Updated annually – no update – last update 2013/14)	5379	72.6%	Not Met	Better	73.9% (Nat) 71.9% (Regional)	73.9%
10. Obese children in reception year (aged 4-5) (Updated annually – updated for 2014-15)	622	7.7%	Achieved	Worse	9.1% (Nat) 9.0% (SN)	7.5% (Nottinghamshire)
11. Obese children in year 6 (aged 10-11) (Updated annually – updated for 2014-15)	1269	17.1%	Achieved	Same	19.1% (Nat) 18.3% (SN)	16.7% (Northamptonshire)
12. Smoking in pregnancy (Updated annually – updated 2014-15)	1129	15.1%	Not Met	Better	11.4% (Nat) 13.7% (Regional)	10.3% (Leicestershire)

14.English and Maths of children benefitting from Pupil Premium	To be developed					
15. Children living in poverty (under 16) (Updated annually – no update – last update 2012)	21860	16.3%		Better	19.2% (Nat) 18.2% (EM)	11.5% (Leicestershire)
16.16-18 year old NEET (Updated monthly. Annual outcome is a 3-month average of Nov, Dec, Jan DFE publication)	1040 (End of year 14/15)	4.0% (14/15) 3.6% (October 2015)	Not Meeting	Same	4.7% (Nat) 4.2% (SN) 4.4% (EM)	1.9% (Nottinghamshire)
17.Percentage of 17 year olds in learning (academic age) (Updated monthly)	7510	85.2% (October 2015)	Not Meeting	Worse	Not Available	Not Available
18.Participation of 18 year olds in learning (academic age) (Updated monthly)	4478	51.7% (October 2015)	Not Meeting	Worse	Not Available	Not Available

19. Care leavers in employment, education and training (at age 19,20,21) (Updated monthly)	44	48.4%	Not Meeting	Better (than 14/15)	45% (Nat 2014) 42% (SN 2014) 45% (EM 2014)	54% (Staffordshire 2014)
20. Achievement of 5 or more A*-C grades at GCSE or equivalent including English and Maths (Updated annually – Results Day update 2015)	4397	54.5% (Provisional)	Not Met	Better	52.8% (Nat) 56.2% (SN)	60.0% (Worcestershire)
21. Under 18 conception rates (per 1000 girls aged 15-17) (Updated quarterly – no updates – last update full-year 2013)	270 (2013 full-year)	19.4 per 1000	Achieved	Improving	24.3 per 1000 (Nat) 24.4 per 1000 (SN) 24.6 per 1000 (regional)	19.4 per 1000
22. Under 18 years alcohol related admissions to hospital (specific) <18 years per 100,000 pop. Pooled over 3 years (Updated annually – latest update 2011/12 - 2013/14)	70	45.4 per 100K		Worse	40.1 per 100K (Nat)	

