

healthwatch
Northamptonshire



A REPORT ON THE VIEWS AND EXPERIENCE OF CHILDREN, YOUNG PEOPLE AND FAMILIES OF HEALTH AND SOCIAL CARE - JANUARY 2014



Healthwatch Northamptonshire is the new, independent consumer champion for people who use, or could use, health and social care. Established in April 2013, our aim is to gather the views and experience of patients, service users, carers and the wider public. We will report these views and experiences to health and social care decision makers to influence and improve the quality of care. Our vision is to make a positive difference to the quality of care and improve health and wellbeing in the County.

If you would like more information about this report; the work of Healthwatch Northamptonshire and how to get involved please email enquiries@healthwatchnorthamptonshire.co.uk reference: Children and Young People or ring us on 01604 893636.

Contents

Summary of findings:	3
Methods of engagement with children, young people and families – gathering our evidence: ..	6
Views, experiences and questions by themes, with recommendations for change:	6
Mental health:	7
Autism Spectrum Disorder:	7
Other Community Health Services:	8
Coordination of support for disabled children and their families:	8
Case study	10
Access to assessments, support and care	11
Pathways	12
Accessibility of services	12
Child and young people friendly services	13
Partnership with service users	13
Education Health and Care plans	14
Summary of questions arising	14
Recommendations for change:	15
Annex 1: Survey	16

Summary of findings:

The two local clinical commissioning groups (Nene and Corby) plan to improve children’s community health services. Clinical Commissioning Groups buy (or commission) the majority of health services for the local population. The commissioning groups will re-commission child and adolescent mental health and emotional well-being services; services for children with complex care needs and services for children with special education needs and disability. New services will be in place from 1 October 2014.

Healthwatch Northamptonshire wants to ensure that the views of children, young people and families were gathered and heard through the re-commissioning exercise and that these views positively influence any changes that could occur as a result. We have gathered views and experiences through a survey; discussion groups; attending meetings and talking individually to children, young people and families as well as health and social care professionals. We have done this to add to the engagement activity also being undertaken by the clinical commissioning groups. This report will be circulated to the Nene and Corby Clinical Commissioning Group Children and Young People’s Community Health Services Re-Commissioning Clinical Board. We intend to add to our knowledge of the views and experiences, by continuing to engage with children, young people and families.

The key themes we heard during the consultation were:

- Many children and young people don’t get the right support at the right time. Several young people and parents described the “struggles” or “fights” they have had to get services. Many people talked about the high level of need they have to demonstrate in order to get any support. The impact this has on the lives and wellbeing of children, young people and families is significant, at times overwhelming, and makes it difficult to plan for independence and is life-limiting in the long term. A list of factors were highlighted by people who gave us their views:
 - Lack of continuity of care between different services
 - Lack of continuity in the transition to adult services
 - Lack of professional time or perceived commitment, interest and sensitivity on the part of professionals
 - Gate-keepers/criteria which block or limit access to services
 - Services being inaccessible weak partnership working with the voluntary sector
 - Difficulty accessing the right services for children with complex behavioural issues
 - Lack of information on support available - not knowing where to go to get support was a recurrent theme
 - Inadequate social support to prevent crisis or deterioration
 - Long waiting times for services during which time the child/young person’s health and wellbeing can decline
 - Lack of meaningful involvement in service design.

- There are concerns about **health transitions for young people** moving from child health services to adult services. The fears are that the trust and competence built between families and paediatricians would be lost. There are fears that there will not be continuity of care and support or the same level of support, as young people become more reliant on social care.
- Many families talked to us about a **lack of co-ordination of services** between health, social care and education to meet the needs of families of children with disabilities who have complex needs.
- There are **concerns about the availability of social work support**. One foster family was waiting to be allocated their third social worker within 12 months. Families talked about the impact on continuity of care due to turnover in staff.
- We heard very widespread concern about the **limited availability of Child and Adolescent Mental Health service**. People said CAMHS (Children and Adolescent Mental Health) services are usually good, but the issue is getting access. Many people said that waiting times for CAMHS are unacceptable. This was a view echoed by nearly all the children and young people who spoke to us about CAMHS. Children and young people said the service wasn’t always consistent. One family reported that they had been advised by CAMHS to call the police if their child with autism displayed particularly challenging behaviour. The family were then offered behaviour management support, which wasn’t effective, while they waited for advice and medication from a CAMHS consultant.
- **Access to counselling services is a big issue**. Children and young people aren’t aware of whom to go to and children and young people with urgent needs talked to us about being turned down or calls not being followed up. **We heard from one young woman who had 12 counsellors in 4 years.**
- There were concerns about the **variations in assessments in child protection** and diagnosis across health and social care organisations. Some families felt that generic social work teams weren’t knowledgeable about the health needs and risks to children with disabilities. For example, a carer was concerned about varying professional responses to bruising on a child with physical and complex needs. Some had raised it as a safeguarding issue, while others said it was expected for a child with complex and physical health needs. Families of children with autism said they had experienced a varied range of processes and diagnosis practices from varied agencies and providers. Some local advocates had concerns that NICE guidelines were not being followed.

- Universal and tiered training to support children and young people with Autism Spectrum Disorder (ASD) is an issue. Representatives and parents gave examples of the need for more awareness within all agencies.
- There is concern about the quality of health and wellbeing within schools. One counselling provider wanted better relationships in order to maintain continuity in school holidays.
- There are questions about who is responsible for advocacy for young people aged 16-18 in both health and social care.
- There are fears that services could be taken away from users due to the need to reapply or the lack of service contracts with private providers.

The survey responses included:

- 36% of people who completed the survey said they found the services they were using to be very helpful, 32% said services were OK, 21% said services were not helpful and 11% didn’t answer
- 43% of people surveyed said they need more support
- 43% of people had found it difficult to get support

Staff were identified as the most appreciated part of services in 43% of responses to the survey. Children, young people and families appreciated:

- Staff who took time to explain things
- Staff who made children and young people feel relaxed
- Organisations who had strict rules about confidentiality
- Staff who engaged children during appointments

During the course of our engagement activity, we also heard some positive views about how services do meet need and the reasons included:

- Good information and signposting
- Good social and emotional support
- “Feeling listened to” and being treated as an individual
- Co-ordinated care and support
- Friendly and hard-working staff.

Methods of engagement with children, young people and families – gathering our evidence:

Since early October, Healthwatch Northamptonshire has:

- attended a range of events to hear the views and experiences of children, young people and families
- talked to health and social care professionals around the County who work with children, young people and families
- surveyed children, young people and families - through a paper survey and via the Healthwatch Northamptonshire website, Twitter and Facebook. 53 surveys have been completed to date. The survey is attached as Appendix 1.
- held focus groups with families and young people at Time 4 Support, Dreams Youth Café and New Ark Foundation
- circulated information about the re-commissioning plans to local communities including schools, early year’s settings, children’s centres and GP surgeries
- shared information with various organisations and agencies that have posted it on their websites and publicised our engagement activities through Facebook, Twitter and other media. These include: East Northamptonshire District Council , Northampton Borough Youth Forum, BBC Radio Northamptonshire, Inspiration FM, Northamptonshire School’s Bulletin, Northamptonshire Parent Forum, Time for Support Parent Group, Northamptonshire early years and children’s centres bulletins, Deaf Connect and Northamptonshire Early Help Fora.

Other evidence:

- Healthwatch Northamptonshire ran a general engagement campaign during September 2013 to talk to local people about Healthwatch and find out views about local services. Views and experiences about services for children, young people and families are included in this report.
- Since June 2013, Healthwatch Northamptonshire has collected information received from people ringing or emailing our enquiries line. Views and experiences about services for children, young people and families are included in this report.

Views, experiences and questions by themes, with recommendations for change:

Feedback covered a range of well-being and service delivery areas. The people we spoke to had many questions about the re-commissioning proposals and wanted to be reassured that the re-design would make services better and that early help would be available in a range of situations.

Mental Health:

Children, young people and families reported:

- long waiting lists
- not enough access to high quality support and preventative services
- mental health services which seems to penalise children & young people for serious symptoms & criteria don’t appear to be wide enough criteria
- children having to go through the teacher to see a school nurse, they didn’t want to have to talk about issues to teachers
- police not signposting child victims to counselling support
- having to seek diagnosis privately
 - “Everywhere I go there is a long waiting list and it’s hard to cope with when I am suffering from depression”
 - “My mum contacted [serious assault counselling service] but they didn’t get back to us” the young person then went without counselling for two years
 - “When I asked to get a different counsellor they sent me to xxxx. I didn’t get a proper counsellor, so I left.”
- fear that the implementation of Common Assessment Framework (CAF) to access services will be a barrier to asking for help as some young people already struggle to come forward, they test with a low level presenting issue, and “won’t consent to it all written down in black and white”
- children with complex needs have had to wait up to three months for a crisis response, during which time school and family life deteriorates
- unfair withdrawal/cessation of services
- children and young people could continue to fall through the net

Recommendations for change: When we asked what decision makers could do to help, responses included:

- Ensure clearly and easily accessible information on mental health support for Looked After Children
- A whole system approach to mental health and wellbeing of children and young people, which can demonstrate that young people won’t fall through the net
- Services equipped to deal with adolescent mental health and challenging behaviour
- Involve service users more.

Autism Spectrum Disorder:

Issues:

- People warn that the most vulnerable families can’t cope with the stress of having to fight so hard to get support.
- Inconsistency in awareness in schools.
- Families were concerned that children with ASD currently fall through the net.

- There was specific concern about inconsistency in school support and management of ASD and that children are expelled from school because of challenging behaviour.
- Parents felt schools give up on children with challenging behaviour & complex needs.
- Clarity was sought on whether schools have a responsibility for children who could as a result, be out of school for up to a whole year.
- Families have to exaggerate needs and concerns to get any service, which works against preparation for independence and life chances. They wanted to know how the new model would stop this.

Recommendations for change

- ensure staff are equipped to meet the needs of children with ASD and know how to identify triggers
- families want to know how the early help model would work for children with ASD
- families want to know what Step up and Step down services would actually be.

Other Community Health Services:

Questions arising: Will there be an Ear Nose and Throat service for children under five?

- Will acute hospital services interact with community health services to ensure children are discharged promptly?

Coordination of support for disabled children and their families:

Issues:

- Not having a care-plan
- Lack of information-sharing between services
- Difficulty accessing information
- Long waiting lists
- Lack of understanding about needs of families including pressures and stresses
- Lack of commitment to help
- When asked what made access to the currently used services difficult responses included:

“Services aren’t all combined, nobody knows about everything. It’s hard to get hold of information” “gate-keepers not wanting you to have anything, you are made to feel guilty for asking” this was a view shared by many families. One professional included: “...general lack of understanding of how to engage voluntary community agency professionals”

Recommendations for change:

- NHS providers, Education Health and Care planning and Social Care Transitions services should work together
- Ensuring stronger links between statutory and voluntary sector agencies

DRAFT

Case study

Tom is 16 and was diagnosed with Autistic Spectrum Disorder (ASD) as a young child. Tom lives with his mum Sam and they are supported by Tom’s grandparents. Sam explained that when Tom began puberty at 12: *“it was as if he just couldn’t contain himself”*. The family tried to get more support as they felt his ASD symptoms were out of control.

18 months ago Tom was excluded from school because of his behaviour. Tom was then referred to CAMHS for support and asked to see an anger management therapist. The family felt this wasn’t working and had to push for an appointment with the CAMHS doctor, which they received after six months. During this time they could not access crisis care and were told by staff to ring the police to respond to Tom’s challenging behaviour. Once Tom was on the medication prescribed his anger management therapy worked well. By the time the medication and support was in place and Tom was able to go back to school, he had been without schooling for a whole year.

Tom’s family had to search for a school for Tom as the centres he had previously been sent to could not cope with his behaviour. They tried several schools, including those recommended by the Council, but felt that staff were not competent enough to look after children with ASD. They felt that that all schools identified as *“for children with disability”* weren’t always competent and many only catered for children with less challenging needs.

After much searching and visiting schools, Sam finally found a caring and competent school for Tom, which turned out to be a previous respite care provider. As Sam had frequently been called to collect Tom from school and respite care because of his behaviour, Tom ended up using one service for both schooling and respite, this meant Tom could not get any real respite care because he had already been there for normal schooling.

Sam explained that it was exhausting to have to fight for support, constantly wait for meetings and assessments and be turned away from services who were supposed to provide a service. She also explained that she felt lucky to finally have a good service and that without the support of her own parents she wouldn’t have been able to cope.

Sam wants to know why Tom had to wait so long to see the appropriate practitioner, why schools and respite services appear to *“cherry-pick”* the children who will be the least hassle and why so many services are in-equipped, which includes penalising children with exclusion for behaviours which are symptoms of their condition. Sam would like decision-makers to understand the long term impacts of this on Tom’s education and the family’s wellbeing.

“Tom is a child with a condition. He didn’t do anything to deserve ASD; we should be entitled to the same education and quality of life as non-disabled children and families”.

Sam – Tom’s mum

Social Activities and Respite Care

Children, young people and families reported:

- Appreciation of stimulating social activities with interaction and opportunities to learn skills for independence

Concerns:

- Available play activities were more suited to children without complex needs
- Children with challenging behaviour reportedly have their respite care terminated on occasions. This adds to family pressure
- Parents are unhappy with lack of clear professional responsibility for co-ordination of care and limited understanding of physical conditions
- Lack of good quality play schemes for children with disabilities resulting in overcrowding. One parent felt this was causing safety hazards at a Local Authority recommended scheme which they alleged is not being monitored
- Concerns about lack of adherence to NICE guidelines by respite care providers
- “Cherry-picking” by respite services as there is overarching services for “disability” while the needs for ASD are very different to Downs Syndrome and can be challenging.

Recommendations for change:

- Ensure more local activities
- Ensure activities for children with higher levels of need
- Give clear recommendations in specifications about training and standards in provider model to ensure staff have the right attitude skill and capability to support children’s needs.

Access to assessments, support and care

Children, young people and families reported:

- Easy access when arranged by one professional
- Fatigue when having to make a lot of effort to be assessed, and a feeling of wasted time when not eligible
- Perceptions that staff don’t want to give struggling families a service
- No clear pathways for care
- Lack of clear information on help available
“Being pushed from pillar to post”
“It took me a year to get anywhere and I had to go private to get my diagnosis for ASD otherwise it wouldn’t have happened”

Recommendations for change:

- *“Shorter waiting times”*
- *“More knowledgeable and pro-active staff who take action”*
- One service user appreciated a text service.

Pathways

Children, young people and families told us:

- They didn’t like starting all over again when needs changed.
- They expected professionals and agencies to know that needs fluctuate and to plan accordingly.
- They didn’t know where to go to get help and were left without a service when their condition fluctuated.

Questions:

- Will there be a requirement for all providers to ensure staff attend Making Children Safer training, or similar training to enable use of the CAF and to promote interagency working?
- How will the new arrangement ensure a commitment to use of CAF or alternative
- Will the Early Help teams have highly skilled staff to co-ordinate prevention of crisis and exclusion from school?
- Families reported constantly having to wait for meetings and assessments from a range of agencies, including health and education, to meet needs of fluctuating conditions. They wanted to know how the new provisions would address this.

Recommendations for change:

- *“A named person who knows how to provide continuity of care”.*
- Not having to start again.
- Assessments to include meeting children or observing them as it is felt decisions are made without knowing the children concerned.

Accessibility of services

Children, young people, families and representatives told us:

- Location: they preferred convenient local services
- Services *“who only have email addresses”* were difficult to get hold of and took long to get back to service users, including the Early Help Team.

- Opening times of services are not always appropriate - including a child counselling service opened for two mornings a week.
- Children, Young People and Families asked how the new model would be different and ensure early help at every stage.
- Crisis responses are reported to be delayed and in general CAMHS support is reported to be slow, how will the new model meet the demands in Northamptonshire and is there an estimated population per LOT?

Child and young people friendly services

Staff are the most appreciated part of services in 43% of responses to the survey. Children, young people and families appreciated:

- Staff who took time to explain things
- Staff who made children and young people feel relaxed
- Organisations who had strict rules about confidentiality
- Staff who engaged children during appointments.

Concerns:

- Feeling fobbed off by services
- Not being given explanation about health issues
- The feeling of receiving a “quick fix” service
- Services which are unresponsive to bullying
- Lack of understanding about diversity and associated responsibilities, including to families not entitled to benefits in the UK.

Recommendations for change:

- Ensure availability of more knowledgeable and proactive staff and ensure providers adhere to guidelines
- Give clearer guidelines about training and standards
- Work better with partners in the voluntary sector.

Partnership with service users

Children, young people and families reported that:

- They appreciated being listened to
- They appreciated being involved in decisions about their care

Concerns:

- Not being told about changes to services
 - Clinicians who don’t want to listen to patients
- “I can get help, but sometimes not being listened to doesn’t help me get the correct care”*

Recommendations for change:

- Services which genuinely focus on improved health and social care outcomes
- Involve service users in decisions about their care
- *“Assessments should include meeting the child as some decisions are based on paperwork”*
- Gatekeepers should work in partnership with families and listen to what they have to say as they know the needs the best. It could drive down costs and increase knowledge to provide for similar needs.

Education Health and Care plans

Feedback included:

- Referrals to schools need to be based on the individual’s needs
- There needs to be a clearer commitment to focus on outcomes
- Actual health needs to be more prominent in discussions and assessments alongside diagnosis and parents’ perspectives
- Paediatricians should be a prominent part of multi-agency assessment.
- Engagement of all services is required

Recommendations for change:

- Paediatricians to be aware of the requirements for assessment and demonstrate full participation with education and social care staff, through writing of advice and representation at meetings where possible
- Individual schools should not be named by professionals as the suitable placement for a child/young person during the assessment process
- Education, Care and Health assessment meetings need to be attended by Paediatric staff and assessments by paediatric staff should be multi-disciplinary and include the views of children, young people and families
- Education, health and care staff to be encouraged to monitor issues which prevent the above from happening

Summary of questions arising

- How will long waiting lists in community health services be addressed?
- Will there be a whole systems approach to mental health and wellbeing of children and young people?
- How can direct access to counselling for children and young people be arranged without having to go through teachers or miss school?
- How will the general quality of mental health support be improved?
- Police have been reported to be negligible to emotional need of young people. Will there be any commitment to improving the health and

wellbeing awareness of police who encounter children and young people with mental and emotional needs?

- Will there be effective signposting and co-ordination of services for children, young people and families?
- How will consistency be achieved across health providers and social care in assessments, diagnosis and safeguarding?
- Will there be consistency in the approach from hearing services and speech and language therapy for children with challenging behaviour.
- How will “early help” be meaningfully provided for the full range of conditions, particularly ASD?

Recommendations for change:

- **Training:** Ask potential providers to demonstrate how they will ensure their staff will be providing consistent services, which are fit for multi-disciplinary and multi-agency partnerships and working; ask providers to demonstrate their commitment to meeting the needs of challenging children, including those who do not have formal diagnoses.
- **Pathways:** Clear pathways with simple information for children, young people and families about journeys through healthcare. Providers and statutory agencies also need to work with the voluntary and community sector to ensure continuity, consistency and contingency for fluctuating mental health needs.
- **Information and signposting:** A local agreement could also ensure that providers inform signposting agencies when service or access details are updated, in order to ensure continuity for service users. Healthwatch to engage existing and new agencies on accessible, up to date information for all patients and service users about services available. Many respondents said they didn’t know where to go. Signposting should include information on pathways, statutory support services, community and voluntary services.
- **Partnership with service users:** More robust information should be used in contracts which require providers to demonstrate the embedment of partnership. Healthwatch is aware of lack of children, young people and carer representation with some current providers.
- **Coordinated care:** The new Education Health and Care plans present an opportunity for all agencies to work together to promote the child’s educational, medical, psychological and other needs. Health care providers especially should promote inter-agency working to focus on the outcomes of the child, which go beyond diagnosis and consultation.

Annex 1: Survey

Make your Voice Count about Childrens and Young Peoples Services

Thank you for taking the time to complete this survey by Healthwatch Northamptonshire. Your feedback will help us get the community’s view on services for children and young people and where we can make a difference. *Make your voice count!*

1. Please name the services that you use the most and tell us where it is (for example, "Complex homecare support in Northampton")

2. How good do you think this service is?

Not very good

OK

Very good

3. What do you like most about this service?

4. Is there anything you don't like about this service? Please tell us what.

5. What would make this service better?

Make your Voice Count about Childrens and Young Peoples Services

6. Does this service give you the help you need?

Yes
 No
 Sometimes

Please tell us why

7. Do you use any other services?

Yes
 No

8. Have you found it easy or difficult to get the help you need?

Easy
 OK
 Difficult

Please tell us why

9. Is there anything else that you would like to tell us? Please write it here:

Make your Voice Count about Childrens and Young Peoples Services

10. If you would like to hear from us about how you can get more involved in Healthwatch Northamptonshire please give us your details:

My name is:

My email is:

My phone number is:

My postal address is:

11. I'd like to enter a £100 itunes prize draw

Yes

No

12. What is your gender?

Female

Male

13. What age group do you fall into?

<input type="checkbox"/> 10 or under	<input type="checkbox"/> 36 - 45
<input type="checkbox"/> 11 - 16	<input type="checkbox"/> 46 - 55
<input type="checkbox"/> 19 - 25	<input type="checkbox"/> 55 +
<input type="checkbox"/> 26 - 35	

Other (please specify)

Make your Voice Count about Childrens and Young Peoples Services

14. What is your ethnicity?

- | | | |
|--|--|--|
| <input type="radio"/> English | <input type="radio"/> White and Black African | <input type="radio"/> African |
| <input type="radio"/> Welsh | <input type="radio"/> White and Asian | <input type="radio"/> Caribbean |
| <input type="radio"/> Scottish | <input type="radio"/> Any other mixed background | <input type="radio"/> Any other Black/African/Caribbean background |
| <input type="radio"/> Northern Irish | <input type="radio"/> Indian | <input type="radio"/> Arab |
| <input type="radio"/> Irish | <input type="radio"/> Bangladeshi | <input type="radio"/> Any other ethnic group |
| <input type="radio"/> Gypsy or Irish Traveller | <input type="radio"/> Pakistani | <input type="radio"/> Prefer not to say |
| <input type="radio"/> Other white background | <input type="radio"/> Chinese | |
| <input type="radio"/> White and Black Carribbean | <input type="radio"/> Any other Asian background | |

15. Do you have a disability

- Yes
 No
 Prefer not to say

16. If yes, please tick appropriate

- | | |
|---|--|
| <input type="checkbox"/> Mental health | <input type="checkbox"/> Physical disability |
| <input type="checkbox"/> Hearing impairment | <input type="checkbox"/> Learning disability |
| <input type="checkbox"/> Sight impairment | |

Other (please specify)

17. We will always take necessary steps to ensure that your information is protected and treated securely. Any details you give us will be held in accordance with the Data Protection Act 1998 and our data protection policy (part of our overall Information Governance Policy) and code of practice on confidential and personal information.

We will only collect personal information volunteered by you, such as:

- feedback from online forms.
- email addresses.
- preferred means of communication.

All personal information about you will be used in our day to day work and to improve the quality and safety of care. This may include any personal information that you choose to share with us, but we will treat this as confidential and protect it accordingly.

We will never include your personal information in survey reports.

- By ticking this box I consent to my details being used as explained above