



NHS Long Term Plan

Focus Group: Special Education Needs & Disabilities

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NHS Long Term Plan Local Engagement

Focus Group - Parent Carer Forum

Report Update

The following report has been shared at the South Tees Health and Wellbeing Executive and Live Well Board. As a result of this we have produced a second version taking into account feedback from relevant members which have been highlighted in pink throughout the report.

Background to research

Following the proposal of the NHS Long-term Plan (LTP), the Healthwatch network were funded by NHS England and NHS Improvement to engage with communities across the country to establish how the LTP should be implemented locally.

Engagement involved gathering views through the NHS Long Term Plan surveys and focus groups and this information has since been shared with local NHS to help develop plans appropriate for the area.

Healthwatch South Tees (the operating name for Healthwatch Middlesbrough and Healthwatch Redcar and Cleveland) held focus groups in line with their agreed priority demographic areas for 2019-2020 with the overarching theme of long-term health conditions:

- BAME (Black, Asian and Minority Ethnics)
- Older people
- Young People

Geographically, engagement work focused in the Redcar & Cleveland area on the experiences of children and young people with autism and learning disability. HWST chose this area following wide ranging community intelligence that identified significant issues for young people (18 - 25) with hidden disabilities with the common overarching increase in poor mental health. We consulted with parents/carers and a small number of young people, offering a whole family perspective of SEND and care. The conversations we were required to have with focus groups were compiled by the NHS in relation to their Long-Term Plan developments which were disseminated by Healthwatch England. The focus groups

were identified by Healthwatch South Tees to support the current workplan priorities. The consultation activities explored experiences of assessment and diagnosis, ongoing care, and prevention.

Local Engagement

Healthwatch established links with two different community groups that engage with parents and carers of SEND children and young people, and invited them to attend focus groups:

- Redcar & Cleveland Parent/Carer Forum - Group of parents and carers who work in partnership with local authority and South Tees CCG to make a difference for children and young people with SEND and autism (Redcar and Cleveland Parent Carer Forum, 2019).
- Community Stepping Stones - Not-for-profit organisation supporting individuals with learning disabilities to increase their skills and knowledge for future independence (Community Stepping Stones, 2019).

We also engaged with some young people whose lives had been impacted personally by their disability through consultation at Botton Social Farm (a service for Redcar and Cleveland young people with Autism and Learning Disabilities).

The topics of the focus groups centred around experiences of health and care, as specified by Healthwatch England, and made reference to the Integrated Care System (ICS) priority of *improving the emotional wellbeing and mental health of infants, children and young people*. This was an opportunity to explore how lived experiences impacted on the lives of children and young people with autism and learning disabilities and their families.

Focus Group Format

The format for the focus group followed the requirements for NHS compilation of information, gathering experiences at three different stages of the healthcare process:

- Assessment, diagnosis and treatment
- Provision of ongoing care and support
- Prevention and/or early intervention

Under each of the above areas we then explored:

- What works well
- What could be improved
- Solutions (or ideas for improvement)

Using a colour coded system, the data was analysed against the different stages and themes. It was then forwarded to all participants of the focus groups for their comments, to ensure accuracy of interpretation. To date, no comments have been received. A first draft of this report was forwarded to both groups and where possible, a member of the team attended the groups to present the information and take any comments.

Challenges to research

The NHS Long Term Plan consultation required a quick turnaround and incorporated the Easter holiday period which impacted on people's availability for engagement.

The framework for collecting and reporting data was quite restrictive, with parts of the dialogue not fitting into just one specific theme. It is therefore important to note that individual experiences do cross boundaries and impinge on the individual's care journey at different times and in different ways.

Health and social care experiences are not isolated parts of people's lives. Where participants have talked about other areas of their lives, e.g. education, their contribution has been considered in terms of the impact that this has on their health and social care and what useful information and conclusions can be derived from this.

Main findings

We stress that the opinions represented in this report are those of the parent/carers we interviewed in the organised focus groups and aren't representative of all parent/carers, nor represent the opinions of Healthwatch South Tees.

Access, assessment and diagnosis

For the parent-carers involved in the focus groups, the social, emotional and physical needs of children with autism, learning disability and associated conditions are not adequately met. Issues included:

- **Parent-professional relationship and understanding behaviour:** Taking a whole family approach to SEND has highlighted experiences of parents and carers; they explained how they didn't feel supported, they didn't feel their concerns about their child's needs were taken seriously, and they felt a culture of 'parent-blaming' exists which can cause parent/carer/family distress and mental health issues. This was particularly linked to education, with many of the parents explaining how they felt that schools and other institutions may not acknowledge and understand behaviour that challenges without a diagnosis. They felt that without an understanding, schools fail to make reasonable adjustments to behavioural policies leading to unfair/inappropriate treatment, low attendance, school avoidance, exclusions, unhappiness, distress, poor mental health, low achievement.
- **Neurodevelopmental assessment and diagnosis pathways:** Parents found the system of pathways very unclear and felt that assessments can take a very long time, during which, a child's and carer's needs are not met and sometimes misinterpreted.
- **Diagnosis:** The parents explained the impact of a diagnosis and how it can change perceptions of a child's presentation and attitudes towards them and their parent's/carers, yet diagnosis may take years and needs have been lifelong. There is also a lack of understanding around female presentation of autism/learning disability leading to under diagnosis of girls.

- **Practitioners:** Parents felt that ongoing illnesses such as bowel, skin and sleep problems etc., are often treated by GPs as single presentations at appointments. HWST agree with the point raised by Cleveland LMC that ‘diagnostic overshadowing’ is not in line with good practice, however the parents’ position was that their children would benefit from a longer-term treatment plan to manage the illness.

Solutions

- Improve parent-professional relationships- Institutions should actively listen, take seriously, recognise and value the information parents present about their child and any concerns they have.
- Neurodevelopmental assessment and diagnosis pathways are currently being developed locally to try and improve the speed of the diagnosis process with assessments happening alongside each other rather than in a chain system. HWST will continue to work with parents and carers to improve information and access to this in terms of ongoing developments and the production of a new strategy, to keep parents informed.
- Early intervention and preliminary diagnosis to trigger personalised support, therapy, and other interventions based on presenting needs, whether there is a diagnosis or not.
- Parents asked for multiple and ongoing presentations of ‘illnesses’ relating to the same condition to be flagged and to trigger an approach by health professionals that will better treat and manage the issues effectively, thereby preventing flare ups and reducing the need for GP appointments.
- Improve diagnosis for girls.

Provision of ongoing care and support

Although there were some individual examples of good health and care provision, there was a general consensus within the focus groups that provision of ongoing care and support following diagnosis is poor and inconsistent, specifically:

- Poor access to specialist treatments, therapies, training and support for parents/carers and children.
- Poor follow up after diagnosis.

- Files are closed once referral has been made to other service. The option of accessing the service in future may be offered but this doesn't always work.
- GP appointment systems and waiting times don't cater for children finding crowded waiting rooms and long waiting times difficult to deal with.
- Health and social care are not good at working with education to support EHCP's (Education, Health and Care Plans).
- Lack of support and opportunities for developing independence / experience of work, including post 16 / transitions leaving many SEND children very isolated and families overwhelmed.

Solutions:

- Improved support plans: pre and post diagnosis care and support plans based on individual needs and NHS and schools working better together to develop EHCPs.
- Suitable adjustments and changes: As highlighted by Cleveland LMC, practices have a duty under the Disability Discrimination Act and are expected to make reasonable adjustments to accommodate their patients with learning disabilities. Parents and carers suggested that GP appointment systems and waiting times need to be changed for children who find crowded waiting rooms and long waiting times difficult to deal with. Practical adjustments would help; flagging individual files to alert to carers, autism and long-term conditions. Practices should therefore be encouraged to listen to suggestions and make appropriate changes. Cleveland LMC have made us aware that local dispensing of prescriptions and a text system for appointment reminders are being rolled out, however care needs to be taken to make parents/carers and young people aware and updated of this move, as this is support that those we engaged with would really benefit from.
- Improve social care by offering a range of options, including direct payments, registered personal assistants and employment support, based on individual interests and needs rather than commissioned short break options.
- Easy access to support, treatments, therapies, according to needs (not set programmes i.e. 6 weeks)
- Find alternatives to discharging ASD/LD children from specialist provision, especially mental health services.

- Review short break provision to include benefits to parents and carers.
- Improve post 16 transitions to adult services.

Prevention and/or Early Intervention

Prevention and/or early intervention is fundamentally linked to recognising individual needs. Parents and carers told us that the delay in diagnosis and the length of time spent assessing needs resulted in escalation of children's needs and early intervention would improve the overall health and wellbeing of children, parents and families. The strongest message from the focus groups is:

- Early intervention and prevention across health and care provision, and better working together with education, would significantly improve the mental wellbeing of children, their parent's and carers, preventing crisis intervention.

Solutions

- Early assessment and diagnosis and acknowledgement of needs during assessment processes.
- Improved working together with parents and carers and other agencies including education.
- Better prevention measures for parents and carers, recognising undiagnosed conditions and multiple caring roles.
- Provide timely and relevant information and signposting for parents /carers including things like entitlements to benefits.

Botton Social Farm Consultation

The consultation with the two young people working at Botton Social Farm made it very evident that early diagnosis can have a significant impact on individual happiness and wellbeing. Briefly, the young person with early diagnosis was happy, had a great outlook on life and was clearly achieving her individual ambitions in life. In comparison, the individual who had received late diagnosis (in his teens) had some very unhappy times, describing poor relationships with his family and peers, being frightened and bullied at school. He felt continually judged and misunderstood for his communication and behaviour.

Suggestions and Recommendations to Local NHS

The recommendations in each of the above sections have been submitted to NHS for considerations in implementation of the Long-Term Plan.

A summary of the key messages are as follows:

Improved care and working together with parents and carers, recognising and valuing:

- Their unique, exclusive and distinctive perspective.
- Their wellbeing as fundamental to providing the best care and support of SEND children and young people.

Early diagnosis and ongoing assessment as part of a personalised individual package supporting identification of changing and ongoing needs, dual and comorbid diagnosis.

Improved personalised care, support and treatment packages including:

- Access to specialists.
- Recognition and treatment of long term-health conditions.
- Better social care including a range of options for developing independence away from the family and in the community.
- Improvements in post 16 planning and transitions.

Significant improvement in NHS working with other agencies, particularly education and Education, Health & Care Plans (EHCP'S).

Improved mental health for children and young people with autism / learning disability and those caring for them has been an overarching factor throughout the consultations and focus groups, which reinforces community intelligence that this is a major issue. Discussion groups and subsequent data, suggests that the causal factors are related to the attitudes of others and personal life experiences associated with having hidden disability, exacerbated by late diagnosis and unmet needs. The case studies with two young people supported this hypothesis.

Next Steps

The NHS Long Term Plan consultations have provided Healthwatch Redcar & Cleveland an opportunity to reflect on how this information can be used for local impact. Whilst the focus for improvement during this work has been for NHS consideration, there are several factors that will inform our local priorities:

- Working with and supporting GP Practices to improve the overall experiences of parents / carers; encouraging the identification of carers and making reasonable adjustments for carers and those they care for.
- Supporting GPs to improve practice for patients with autism / learning disability and improved outcomes for associated long term health conditions, with long term treatment and management plans.
- Influencing improvements towards autism / learning disability friendly communities.
- Direct engagement with young people to explore the causal factors of poor mental health in children and young people and their ideas for local solutions. This work will target all young people but ASD/LD can be profiled as part of this.

Healthwatch will apply the learning from the consultation in Redcar & Cleveland across the South Tees area.

Acknowledgements

Redcar & Cleveland Parent / Carer Forum

Community Stepping Stones

Botton Social Farm

All parents/carers and young people involved in focus groups.

We also acknowledge the feedback from Cleveland LMC regarding this report and have highlighted relevant comments throughout.



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