



healthwatch
Stoke-on-Trent



“While We Were Waiting”

A Story of Special Educational Needs in Stoke-on-Trent

Summary Document

August 2017

The Healthwatch Stoke-on-Trent Mental Health Sub-Group and
Partners.

While We Were Waiting

Healthwatch Stoke-on-Trent exists to make health and social care services better for ordinary people. It believes that the best way to do this is by contributing towards designing local services around their needs and experiences.

Through the latter part of 2016 and early 2017, Healthwatch Stoke-on-Trent devised a project called 'While We Were Waiting'. In partnership with the Stoke Parent Carer Forum the project, aimed to better understand the experiences of people and their families whilst waiting for Child and Adolescent Mental Health Services (CAMHS). The methodology for the project was informed by the voices and opinions gathered as the programme moved forward. The most common of these themes was SEN (Special Educational Needs).

This summary of the report presents themes derived from conversations with various participants including educational staff and parents. These themes are analysed to present findings and recommendations.

To raise awareness of the project a web page was built along with a social media stream, a family event was held at the Mitchel Arts centre, leaflets and posters were distributed across the city and the project was advertised in various newsletters and on the Stoke-on-Trent school intranet. The data received was from;

Focus Group	CAMHS Staff (4), Education Staff (16) (20 attendees total)	Jan 2017
Semi-structured interviews	Parents of children (4) who are service users.	July 2016
Semi-structured interview	Professional working in the field (1)	Jan 2017
Cultural Animation	Session with Borderlines theatre group using Cultural Animation to explore experiences of waiting (13 attendees including 6 parents of service users)	June 2016
Web Page	A web page that received 8 responses to an online call for comments	Winter 2016

What We Found

- In some SEN, a focus upon diagnosis may detract from understanding and delivering for the needs of the child*:

Participants describe how a focus upon diagnosis can lead to missed opportunities to address need. Parents describe there being little support whilst waiting for diagnosis. Meanwhile education staff express frustration because they feel there are things that can be done. However, there can be a lot of pressure upon parents. Things such as simple lack of sleep or financial problems related to caring responsibilities impact. This drives the need for diagnosis further.

- Participants describe communication between education and health services as inconsistent*:

Data protection means staff don't share information as well as they could. This impacts upon coordination of interventions in the child and sometimes makes it difficult for staff to effectively update parents. When agencies do coordinate, participants describe this working well.

- There is great potential to build cooperation between services*:

Education staff expressed a keenness to work with more closely with their colleagues in health. This includes addressing the preventative agenda.

- Services such as school nurses aid the maintenance of relationships*:

Participants describe how relationships succeed through familiarity, once provided by the school nurse. To build relationships and support parents, some schools have been innovative, investing in parenting rooms or delivering wellbeing classes.

- Some education staff describe a lack of confidence in dealing with mental health and wellbeing issues. They would appreciate more access to specialist advice*:

If trained, education staff can also deliver advice to children for their parents. Some staff express a lack of confidence around mental health issues in the report. Parents are flooded with information of mixed quality, so any provision for them, or the empowering of staff to support can only be positive.

* Please see full document

- Parents may have pre-existing unidentified needs such as SEN, mental health or emotional that may contribute to prevalence or outcomes. This is sometimes identified through relationships with schools*:

Participants identified that parents can have their own needs. Indeed, staff describe mental health problems in parents being picked up through a child's referral. Some parents have their own SEN's and may be undiagnosed. Perhaps a holistic view of families rather than the child in isolation would be useful? This may emphasise the importance of relationships.

- The effects of stigmatisation cannot be underestimated in this group. Parents describe being affected by stereotyped ideas*:

Stigmatisation of parents features in the report, as do labels. Despite organisations such as The British Institute of Learning Disability's (BILD) view of labels; "We believe that people labelled as having a learning difficulty are disabled by society"; people are inevitably labelled through a need for diagnosis. In the report, some education staff describe diagnosis seeking for other reasons, for example, for parents to explain the behaviour of a child and not be labelled a bad parent. Parents point out that this is stereotyping and only further stigmatises. One would be reasonable in assuming this thinking would have a negative impact upon the relationship between staff and parents.

- More can be done to improve signposting services*:

Schools offer a good opportunity to signpost to services. The quality of some of the advice available online is questionable.

- There remain questions around the support available to parents and who should deliver it*.

There are currently pockets of good practice in supporting parents but this seems to lack a systemic, consistent approach. Should it fall to schools to address these issues?



* Please see full document

Recommendations

- There is some good practice in Wellbeing and Mental Health support for parents in school and this should be shared.
- There is some good practice in building relationships between schools and families. This should also be shared.
- There should be more promotion of routes into tier two services* for staff and parents.
- SENCO's* suggested having specialist support from CAMHS* for mental health issues (in addition to the NSCHCT referral advice line).
- Work in partnership with parents and families, moving away from a tiered system that encourages parents to evidence need.
- Align with the proactive 'staying well' sentiments of Together We're Better and the Sustainable Transformation Plans¹.
- Explore collaborative approaches to working.
- All staff to be supported in terms of the data protection act.
- Simple Consent Boxes on CAMHS forms so that SENCO workers can be informed when an assessment has taken place.
- SENCO's to be made aware of any strategies that are in place for child where relevant.
- An effort should be undertaken to understand the linkages between Education and Health in light of recent changes to the School Nurse service*.
- More work to be done around the preventative agenda in schools, such as emotional literacy.
- Parents could be systematically made aware of what they can expect in terms of service (the Local Offer).
- Online resources about mental health, coping mechanisms and others to be made available so that SENCO's and public can easily access them via the website.
- Build community capacity to enable parents to engage with schools.
- Ensure consistent channel of communication between parents and staff for the long term.

Healthwatch Stoke believes that by implementing some or all of these recommendations, improvement will be seen to benefit families, professionals and others involved in the service.

¹ <http://www.twbstaffsandstoke.org.uk>

* Please see full document