

Raising awareness of health services and access for children with a learning disability



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What we did

Healthwatch facilitated a series of linked sessions with a group of students at Henry Tynedale School. 8 students attended, representing each class in the upper school.

Henry Tyndale is a Community Special School catering for approximately 140 pupils from age 2-19, who have complex learning difficulties. All pupils have a learning difficulty; many also have an additional need such as a physical disability, a language impairement, or an autism spectrum condition. As such the children and young people, we worked with use more health services than others their age and may have specific needs that make accessing standard services difficult for them.

We aimed to:

- Find out about the experiences children and young people have had and how health and social care services could accommodate children with complex learning difficulties.
- Share the students' recommendations with healthcare providers for their consideration and comment.
- Help students to gain independence and make choices about their health and social care.

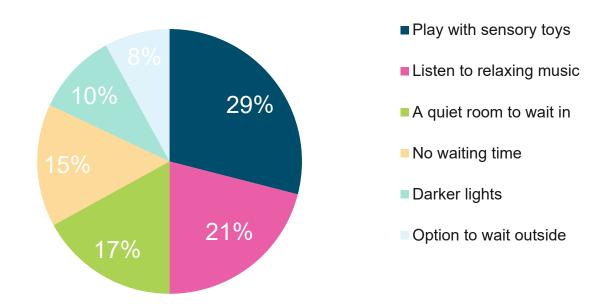
During the first session we discussed 'Who helps to keep us healthy'. The pupils spoke about doctors, dentists, hospitals, school nurses, pharmacy, family and friends. We talked about how they feel when using services using zones of regulation.

As a group the children voted on the services where they felt most in the 'yellow zone'. The emotions in this zone include frustration, worry and loss of some control. The 2 identified were dentists and hospitals.

The 8 students surveyed the rest of the school and asked them 'What would help you feel in the green zone when visiting the dentist or hospital?' Green zone emotions include feeling happy, calm, focused and relaxed.

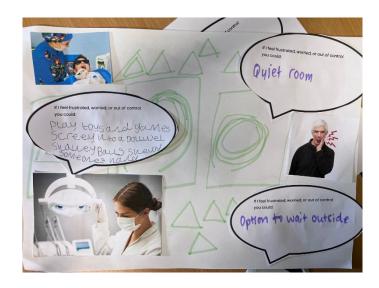
Findings

Self-identified measures to reduce stress and anxiety in healthcare settings.



During the second session we talked about the results of the survey and made some artwork to showcase their preferences.





During our discussions with teaching staff, we looked at hospital passports and how they can support children with learning difficulties who are admitted to hospital or during healthcare appointments. Lots of the difficulties that children have (including their sensory needs) are included on a hospital passport.

Hospital passports

We circulated a survey to parents and carers to find out how many students already had a hospital passport and how useful they felt it would be. We received 71 responses.

Do you know what a hospital passport is?

- Yes 25%
- No 64%
- Not sure 11%

Does the child you care for already have a hospital passport?

- Yes 7%
- No 93%

When we described the purpose and showed an example of a hospital passport 98% of parent-carers thought they would benefit them and their child

I think this is a great idea, as a parent-carer you have to repeat the same information to every health professional that has contact with your child, so having a passport would mean that every piece of relevant information is available to them, as if you or your child is in hospital, it is a time of great distress

or your child is in hospital, it is a time of great distress and things can be forgotten when explaining your child's profile

Parent-carer suggestions for improvement



"It needs to not be paper based as they don't last very well. Staff don't always have time to read them so could it be on the child's digital records?"

"Hospital passports need appropriately trained staff who know how to implement them and look after children with autism correctly. We need more specialist nurses to advocate for children and their families."



For our final session with the students, they produced posters to encourage parents and carers at the school to fill in a hospital passport. These were put up around the school and distributed in the newsletter.





Next steps and recommendations

Next steps

- This report will be shared with the Hampshire Learning Disability Partnership Board, health subgroup.
- We will share the issue of low awareness and uptake of hospital passports with our system partners.
- Healthwatch in partnership with Henry Tynedale School will continue to audit and monitor uptake of hospital passports.
- We will continue to raise awareness of the measures that can be taken to support young people with learning disabilities in health settings.

Recommendations

- Healthcare services including dentists and hospitals to consider accessible waiting arrangements for people with learning disabilities.
- Awareness raising of sensory needs that affect many young people and adults with ASC, learning difficulties and physical disabilities.
 Adapting environments where possible. For example, lowering lighting or offering a box of fidget toys.
- Review of hospital passports and their use in Hampshire.



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