

A report on the views of Children and Young People with Special Educational Needs and Disabilities in Northamptonshire





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Summary

The views and opinions of children and young people (CYP) with special educational needs and disabilities (SEND)¹ are often overlooked and most common engagement methods are not designed to engage this group or facilitate their feedback. Often the views of their parents or carers are sought rather than those of the CYP. Engaging directly with CYP with SEND can be a challenge, but a little creativity can deliver amazing results². Moreover, CYP with SEND experience significant health and social inequalities³ and the more their voice is heard the more this can be addressed.

Since September 2015, Healthwatch Northamptonshire (HWN) has engaged with CYP with SEND using a variety of activities and methods. Through attending events run by partner organisations and by delivering assemblies and Personal Social Health Education (PSHE) lessons in schools we spoke to 230 CYP with SEND, either face to face (74) or via their completion of a survey (156).

We were able to hear the views of children as young as two years old (with the help of their parents at the SENDsation day) and get their opinions on health care services. This report brings together the key findings and makes recommendations for how HWN and other organisations can work together and engage with CYP with SEND.

¹ Special educational needs and disabilities (SEND) can affect a child or young person's ability to learn. They can affect their:

- behaviour or ability to socialise, e.g. they struggle to make friends
- reading and writing, e.g. because they have dyslexia
- ability to understand things
- concentration levels, e.g. because they have ADHD
- physical ability

www.gov.uk/children-with-special-educational-needs/overview, accessed 12/07/2016

² Engaging with children with SEN, www.teachearlyyears.com/a-unique-child/view/engaging-with-children-with-sen, accessed 12/07/2016

³ Emerson, E. & Baines, S. (2010). Health inequalities and people with learning disabilities in the UK: 2010. www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf, accessed 12/07/2016



Key findings

- The majority of the 74 CYP that HWN engaged with at the SENDsation day reported having had a good experience with their doctor, dentist or at the hospital.
- 85% of the 156 CYP with SEND who answered our survey felt that there was nothing about their health and wellbeing that worried them.
- 56% of CYP with SEND who answered our survey said they had been bullied, including children as young as 11. 16% said they had bullied others.
- More females reported having been bullied than males.
- 22% of CYP with SEND who answered our survey reported that they had self-harmed, including children as young as 12.
- 85% of CYP with SEND who answered our survey felt that there wasn't anything about their health and wellbeing that worried them at the time. Weight was the most common concern amongst those that were worried.
- Using innovative methods it is possible to engage with CYP with SEND.

Recommendations

Healthwatch Northamptonshire recommends the following based on these findings:

1. HWN and partner organisations should work together to find out more about the health and wellbeing issues affecting CYP with SEND and how CYP and families can be better supported to improve their health and wellbeing.
2. There may be a need for further work and resources to support CYP with SEND who are being or have been bullied.
3. HWN could work with local organisations to promote existing local resources and information available relating to SEND and different health and wellbeing services.
4. Schools should be considered as good locations for accessing CYP with SEND to gather their views, for promoting awareness of health and wellbeing issues for CYP with SEND, and for providing support.



Method

The following methods were used to engage with CYP aged between 2 and 22 with SEND and to obtain their feedback on health and wellbeing:

- At the Summer SENDsation family fun day CYP were asked to draw their handprints on a table cloth and to tell us about their most recent experience with a hospital, doctor or dentist. Promotional beachballs, water bottles, bags and wristbands were given out to encourage people to engage with the activity. Younger children were helped by their parents to give feedback.
- A further short survey for young people with SEND was developed focussing on health and emotional wellbeing (Appendix 1). A mixture of multiple choice and simple open questions were used and the survey was kept to one side of A4 for ease of completion. In order to keep the survey brief and simple it was decided to focus on general health and wellbeing rather than include all issues that could relate to CYP with SEND.
- Confidentiality was assured to everyone who spoke to us. No one is referred by name or specifically identified throughout this report.

Between September 2015 and April 2016 HWN staff and trained volunteers (with completed enhanced Disclosure and Barring checks) attended the following events:

- **Summer SENDsation day, 13 September 2015:**

- A free family fun day for CYP with SEN/Disabilities run by Northants Parent Forum Group (NPFPG) and Northamptonshire's Local Offer held at Northampton College (Booth Lane Campus).
- 74 children gave their opinions of their most recent visit to the hospital, dentist, or doctor.



- **'Moving on Up' conference, March 2016:**

- HWN was part of the 'Moving on Up' conference organised by the Information and Advice Service for SEND (IASS), held at Northampton Saints Rugby Football Club (RFC).
- The event was aimed at young people with SEND to prepare them for independence and adulthood.
- 46 young people with SEND from six schools in Northamptonshire completed the health and wellbeing survey.



- **Visits to schools for CYP with SEND, January-March 2016:**
 - HWN delivered a PSHE lesson about HWN, Young Healthwatch and ways for young people to get involved at The Gateway School (a school for CYP with SEND). 21 CYP completed the survey after this lesson
 - 76 CYP with SEND from Northgate School (another school for CYP with SEND) and The Bee Hive (a work based learning environment and education provision run by Northgate School) also completed the survey.
 - A further 13 surveys were received by post from other schools with CYP with SEND.
- Overall 156 surveys were completed.

Findings

SENDSation Day - opinions of hospitals, doctors and dentists

The event was organised for CYP with SEND and their families. It aimed to involve them in a range of activities as well as providing information for families to give them an overview of what is available locally and how to work together to help young people.

The children and young people were asked to draw around their hand and tell us what they thought about their last/most recent visit to their dentist, doctor or hospital.

Children as young as two years old were keen to engage with the activity, found it fun, and gave us their opinions.



We received responses from 74 CYP who gave seemingly candid and varying opinions. Throughout the day HWN was able to talk with the children and families whilst they were drawing and found that they all enjoyed the activity.



What did you think about your last visit to the hospital?

32 (43%) CYP answered this question, with the majority saying their last visit to a hospital was 'good'.

From speaking to the CYP, it seemed that the main reason they gave a rating of 'good' was having had an experience of caring staff or a positive health outcome.

Good experience examples:

"They looked after me when I was sick and fixed my heart and kidneys"

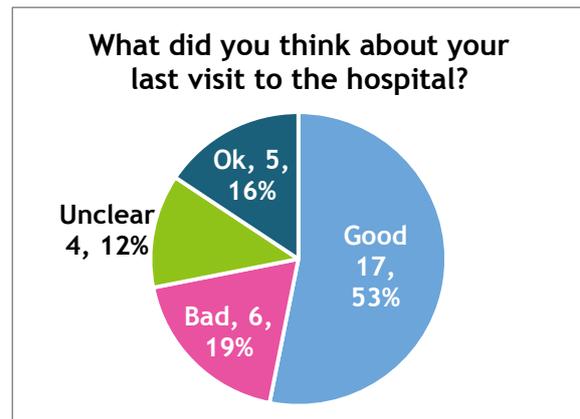
"I got my appendix out and they helped the pain go away but it hurt but they were very good to me"

"The hospital it was painful. They were good to me"

"Hospital good, staff really nice, operation will be good"

"NGH Café good, ladies in WRVS shop, opticians, Children's outpatients"

"A&E great"



Poor experience examples:

"A&E takes ages"

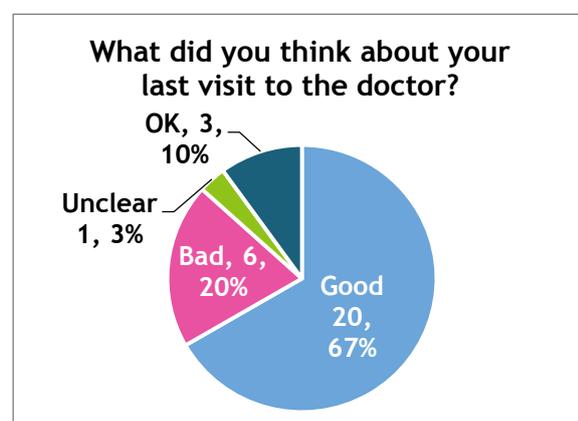
"Hospital could be better"

"Hospital bad and broke leg"

What did you think about your last visit to the doctor?

30 (41%) CYP answered this question, with the majority saying their last visit to doctor was 'good'.

Most of the further comments received were not specific. Again experiences appeared to be based on whether the CYP liked the doctor and what the health outcome was.





Good experience examples:

“Ordering prescription very good”

“Doctor brilliant!”

“Doctor good, long wait two hours”

Poor experience examples:

“My visit to the doctors was not very nice, I will have a surgery”

“Nervous, no appointment”

“Doctor boring, three hours”

What did you think about your last visit to the dentist?

35 (47%) CYP answered this question, with the majority saying their last visit to the dentist was ‘good’

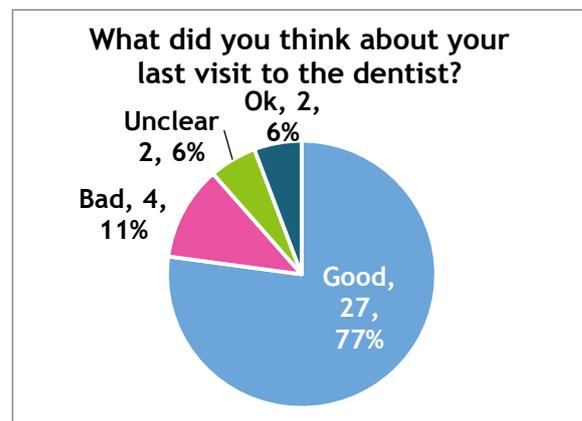
Again, there were few specific comments.

Good experience examples:

“Dentist good, fell asleep”

“Good dentist trip”

“Dentist = ‘amazeballs’”



Poor experience examples:

“Dentist was so bad, we went to Herefordshire”

“Dentist = so bad :(”

Most of CYP at the event reported having a good experience with their doctor, dentist or at the hospital, although there were some negative comments. Many of the bad experiences were a result of having had an uncomfortable experience or undesired treatment rather than disliking the staff.



IASS Conference and school wellbeing survey

The Information and Advice Service for SEND (IASS) 'Moving on Up' conference was aimed at young people in school years 9 and 10 with SEND (most were aged 13-15 although there were some older students in attendance). The aim of the conference was to prepare them for independence and the process towards adulthood.

At the event, 46 young people aged 13-22 (average age 14.3) with SEND completed the wellbeing survey. The students were from the 6 schools in attendance:

- Corby Business Academy
- Abbeyfield School, Northampton
- Billing Brook School, Northampton
- Greenfields School and Sports College, Northampton
- Malcolm Arnold Academy, Northampton
- Northampton Academy



A further 76 CYP from Northgate School Arts College and The Bee Hive completed the survey during PSHE lessons about HWN, Young Healthwatch and the survey, delivered by HWN staff.

21 responses were received from The Gateway School and a further 13 from other individuals with SEND received by post.

In total 156 surveys were completed.

Demographics

To understand the make-up of the respondents we asked them to tell us their age, their gender, where they lived and whether they were affected by any of a list of conditions. The full breakdown of the result can be found in Appendix 2.

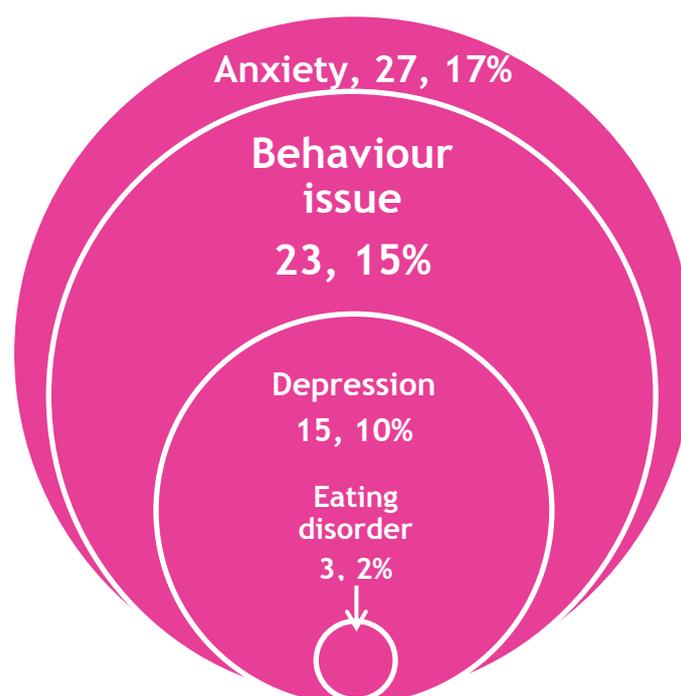
- The respondents ranged in age from 11 to 22 years old. 14 was the most common age (25%) as this was the age of most participants at the IASS conference. The average age was 15.2. Two thirds (66%) of the respondents told us they were male and nearly one third (31%) told us they were female. Two respondents (1%) told us they were 'other' and three (2%) preferred not to say.
- Two thirds (66%) were from Northampton as most of the students attending the IASS conference and receiving PSHE lessons were from Northampton.
- 88 (56%) of the respondents said they had a learning disability, 64 (41%) said they had Attention Deficit Hyperactivity Disorder (ADHD) or an Autism Spectrum Disorder (ASD), nine (6%) had a physical disability, 13 (8%) had sight impairment or loss, and 8 (5%) had hearing impairment or loss. 27 (22%) did not select any and 18 (12%) did not know if they had any of the listed conditions.



Mental health and behavioural conditions

We were interested to know if any of the CYP considered themselves to be affected by a mental health or behavioural condition and asked them to tell us if they had any conditions or issues from a list (see Appendix 1).

- 27 (17%) said they had anxiety, 23 (15%) said they had a behaviour issue, 15 (10%) said they had depression and three (2%) said they had an eating disorder. Five (3%) said they had something else, including one mentioning each of anger problems, shakes and dyslexia. 29 (19%) did not select any and 36 (23%) did not know if they had any of the listed conditions.

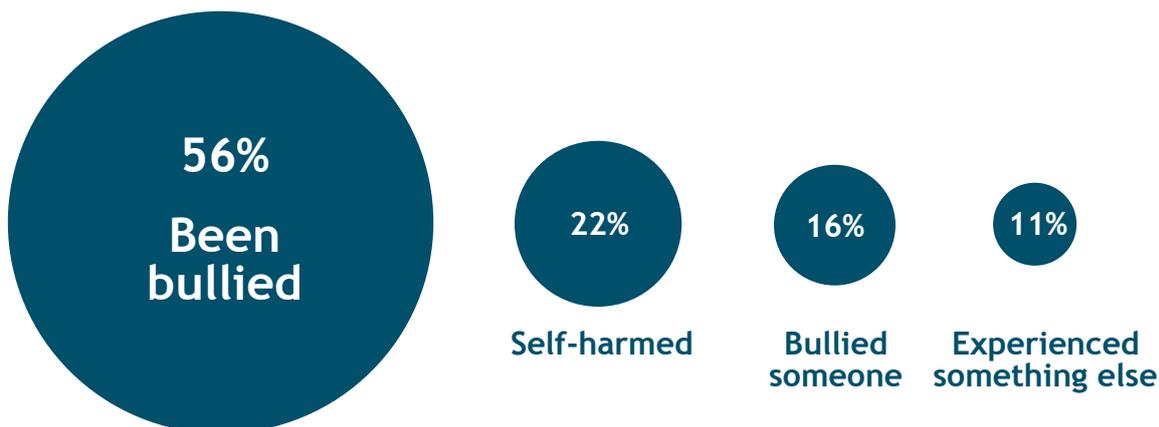


Mental wellbeing

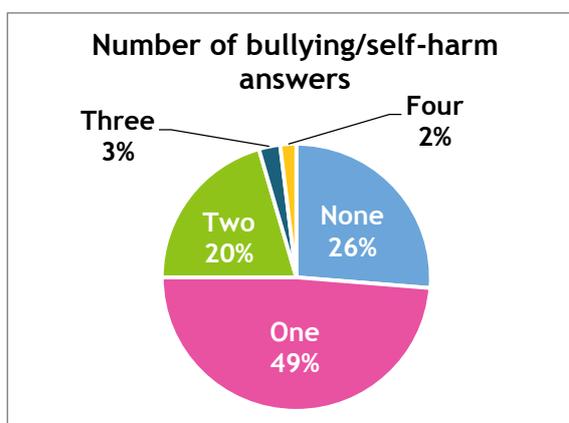
To find out about issues that may be affecting the emotional wellbeing of the CYP we asked them one general question about any concerns they had about their health and wellbeing and one specific question about their experiences of bullying and self-harm.

Bullying and self-harm

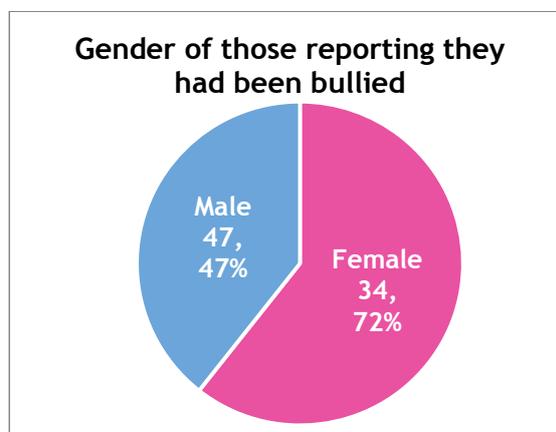
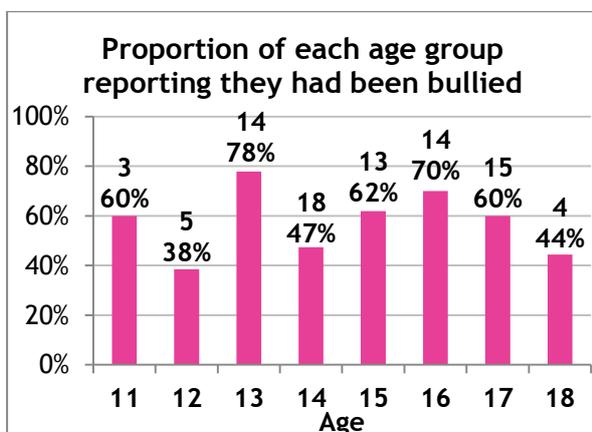
- Over half the CYP (87, 56%) said they had been bullied and 25 (16%) said they had bullied someone else. 35 (22%) said they had harmed themselves on purpose. 17 (11%) said that they had 'experienced something else that they felt wasn't good'.



- 115 CYP (74%) circled at least one of the options given. Seven (5%) circled three or four of the answers and 32 (20%) circled two.
- 19 CYP (12%) said they had been bullied and had self-harmed. The proportion of those who had self-harmed was similar for those that had been bullied (22%) and those that had not (23%) so there is no apparent relationship between bullying and self-harm in this group.

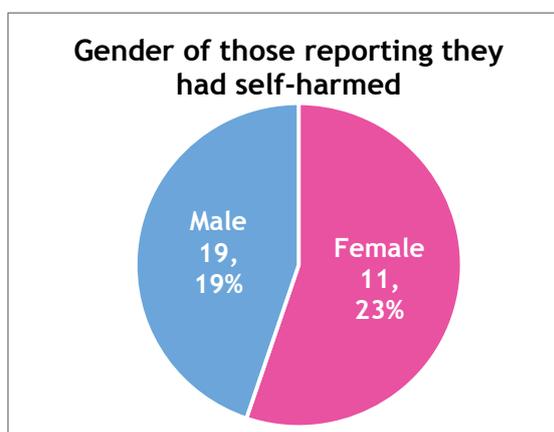
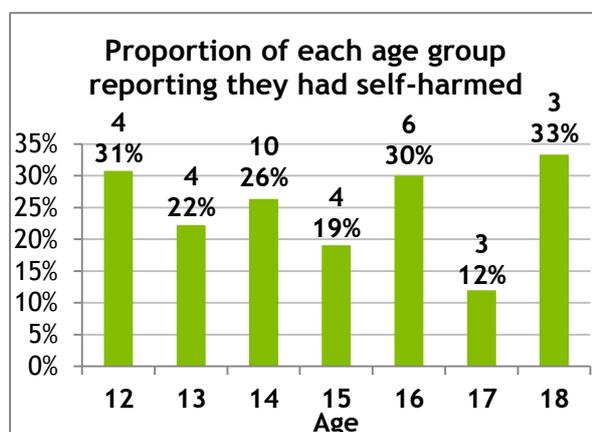


- Having been bullied was reported by all age groups, including the youngest age groups - three of the five 11 year olds (60%) and five of the 13 12 year old (38%).
- Proportionally, more females (74%) than males (47%) reported they had been bullied.





- Self-harm was reported by all age groups. A worryingly high proportion of 12 year old (four of 13, 31%) reported they had self-harmed, although the numbers are small.
- A similar proportion of females (23%) and males (19%) reported they had self-harmed.



11 of the 17 who circled that they had ‘experienced something else that they felt wasn’t good’ gave us more details:

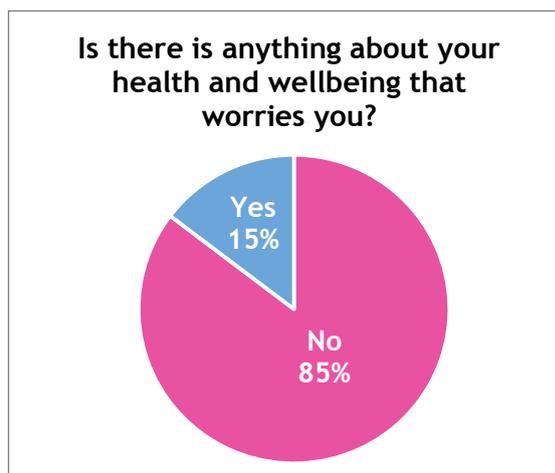
- A feeling of despair and deep sadness. Constant change of mood from overly hyper to extremely depressed in quick succession
- Behaviour
- Being sick
- Death in the family
- Get very angry when people upset me
- I didn’t have a kind mouth and I didn’t like it.
- I had a fit
- Other people being bullied
- Police turned up and said someone was known as a con artist in the area
- Unhappy at primary school
- One of the responses we received involved a safeguarding issue that has been dealt with.

Health and wellbeing concerns

- Most of the CYP did not report any worries about their health and wellbeing. 22 CYP (15%) were worried about something, and 14 of these elaborated on what their worries were:
 - Weight issues were mentioned by five of the 14 (with two specifying being overweight or “fat” and one also mentioning their height).



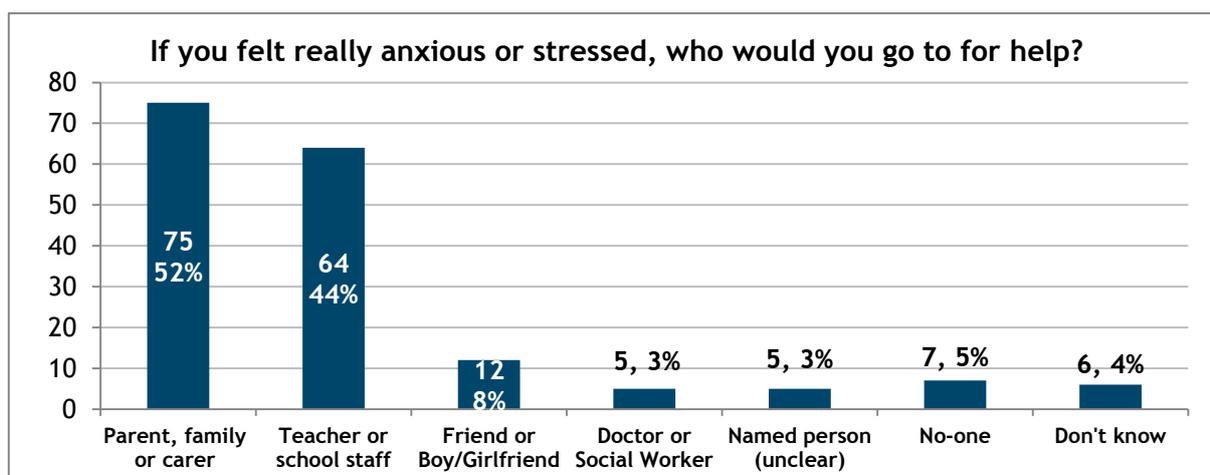
- Two mentioned their minds and one their behaviour. Another mentioned “internet addiction”.
- Two mentioned health issues (headaches and heart problems).
- Two mentioned family issues (being “picked on” by a sibling and not being able to see a parent very often).
- One mentioned being concerned about how they would cope if they “lost” their “best friend” and one mentioned “trying to get hurt”.



Help and information

The final four questions asked the CYP about where they would go for help and advice and whether they thought there was enough information available.

If you felt really anxious or stressed, who would you go to for help?



145 CYP gave 176 suggestions.

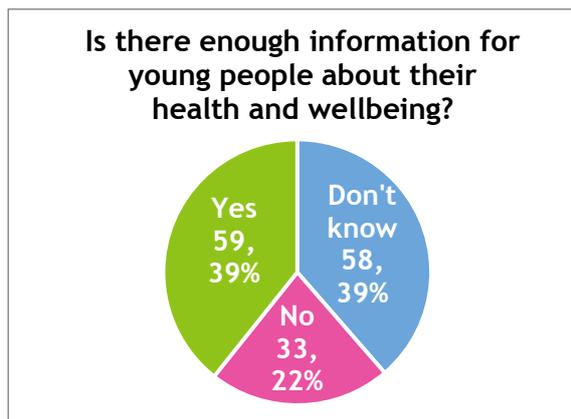
- 59 (41% overall) of those saying they would go to a parent, family member or carer specified a parent.
- 14 (10% overall) of those saying they would go to a teacher or another member of school staff named a particular person.
- Only one said they would go to a social worker (compared to 4 who said doctor).
- One of the seven who said that they would not go to anyone specified that they would help themselves.
- Two CYP gave other answers - any “person they trust” and “Healthwatch”.



Is there enough information for young people about their health and wellbeing?

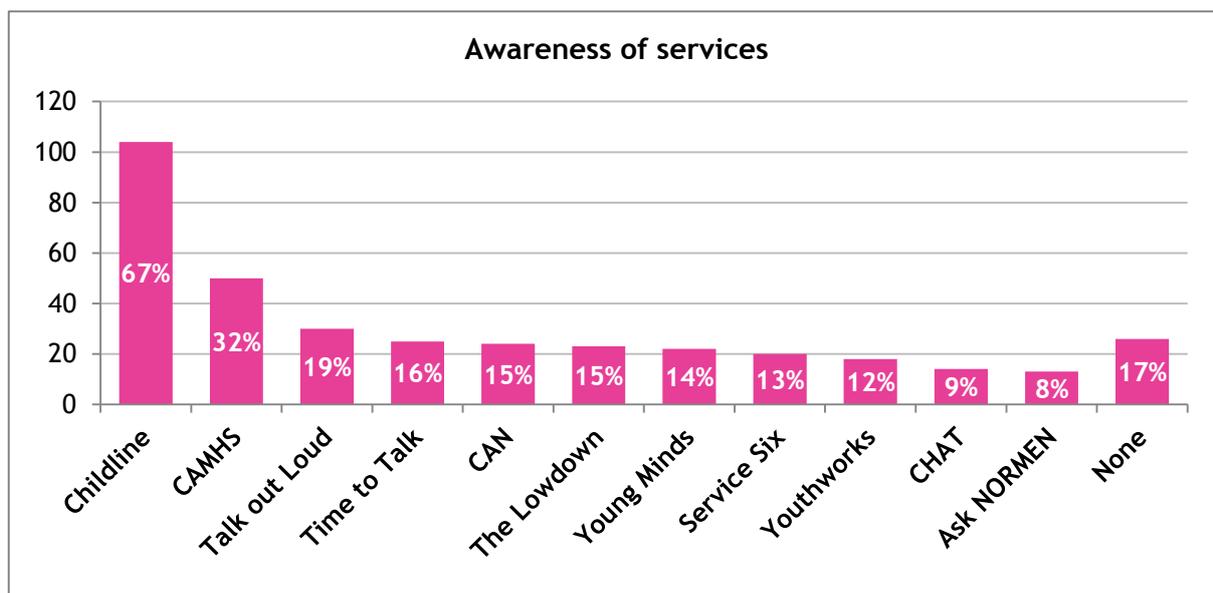
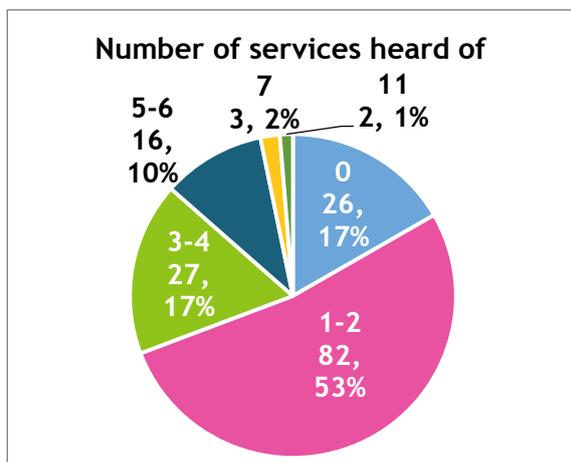
150 CYP answered this question.

- An equal number answered 'yes' and 'don't know' (39% for each, 59 and 58 CYP respectively).
- 22% of the CYP (33) did not think there was enough information.



Which of these have you heard of?

- Most CYP (130, 83%) had heard of at least one of the services. 26 (17%) had not heard of any of them.
- Just over half (82, 53%) had heard or one or two services. Two CYP had heard of all 11 services.
- Childline was by far the most well-known service, two thirds (67%) had heard of it.
- Child and Adolescent Mental Health Services (CAMHS) had been heard of by 32%.
- The other nine services were know by between 8% and 19% (see graph).





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- The results here are similar to a previous survey of young people carried out in February 2015⁴, except there is a higher awareness of CAMHS amongst the CYP with SEND in this survey. This indicates a similar awareness of these services amongst CYP with and without SEND.

What other help/information do you think should be available for young people about health and wellbeing?

81 CYP answered this question, although nearly half of them (39) said they “did not know” what other help or information should be available. Four just agreed that there should be other help/information (answering “yes”) and four thought there was enough help or information already.

The remaining 34 gave various suggestions of methods to use to give help/information and topics to give information on.

Suggested method:

- Five CYP suggested using leaflets (one specified that these should be “sent home”).
- Four suggested using mobile ‘apps’.
- Four suggested having advice phone lines.
- Three thought there should be more information or teaching about health and wellbeing in schools.
- Three suggested using posters or adverts.
- Two suggested having certain advice online (financial and relationship advice).
- Two answered “doctors”.
- One CYP suggested each of the following:
 - having the chance to talk to group of people experiencing the same thing (e.g. eating disorders)
 - having someone to talk to who could help
 - having access to advice and counselling from psychiatrists
 - “helping people”

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www.healthwatchnorthamptonshire.co.uk/sites/default/files/young_persons_wellbeing_report_final_2_0.pdf, accessed 12/07/2016



Suggested topics:

- Two suggested advice on finances.
- Two suggested advice on college applications.
- The following were each suggested by one CYP:
 - depression and eating disorders
 - the negative effects of eating disorders and self-harm
 - bullying
 - CAN and NORMEN
 - disabilities
 - drugs
 - exam stress and pressure
 - relationship advice



Conclusions

Healthwatch Northamptonshire feels very privileged that 156 CYP with SEND took the time and trouble to fill in the survey for us and give us their opinions. There were no spoiled surveys. We feel this was a good number of responses from a group of people often considered 'harder to reach'.

It is possible to get the views of CYP with SEND if one finds ways to engage with them. We did this using activities at the SENDsation day and by taking a survey to the IASS conference. This project was supported by working with partner organisations and schools, enabling us to attend events and deliver school assemblies and Personal and Social Health Education (PSHE) lessons.

It was encouraging to hear that the majority of CYP that HWN engaged with at the SENDsation day reported having had a good experience with their doctor, dentist or at the hospital. Also, 85% of the CYP with SEND who answered the survey felt that there was nothing about their health and wellbeing that worried them.

More concerning was the number of CYP with SEND who reported having been bullied (56% of survey respondents) and having self-harmed (22%), including children as young as 11 and 12 respectively. Significantly more females reported they had been bullied than males (72% compared to 47%), although only one third of the survey respondents were female⁵. These findings suggest that further research into the experiences of bullying of CYP with SEND would be beneficial, including who they are bullied by and where, what support they receive to prevent it or cope with it, and whether bullying differs between CYP with and without SEND.

In terms of awareness of support services available, it would appear that some of the support groups and services are still in need of better publicity and promotion with this cohort of CYP. This information may be useful for those who work for these services in order to see how well they are known amongst different audiences. Further work may include a review of the information that is available for CYP with SEND and their families, such as that carried out by Healthwatch Slough in 2015⁶

⁵ This is in line with the Department for Education's findings that boys are two and a half times more likely to have statements of SEN at primary schools and nearly three times more likely to have statements at secondary schools compared to girls. (Children with Special Educational Needs 2014: An Analysis". Department for Education. First published September 2014

www.gov.uk/government/uploads/system/uploads/attachment_data/file/350129/SFR31_2014.pdf), accessed 12/07/2016

⁶ <http://healthwatchslough.co.uk/wp-content/uploads/2016/01/HWS-SEND-Report-Jan-2016.pdf>, accessed 12/07/2016



Thanks and acknowledgements

Healthwatch Northamptonshire would like to particularly thank:

- Northants Parent Forum Group (NPF)
- Information, Advice and Support Service (IASS)
- Malcolm Arnold Academy
- Greenfields School and Sports College
- Corby Business Academy
- Abbeyfield School
- Billing Brook School
- Northampton Academy
- Northgate School Arts College
- The Bee Hive
- Gateway School
- All of the others who took part in this survey
- HWN Volunteers for school assemblies





About Healthwatch Northamptonshire

Healthwatch Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

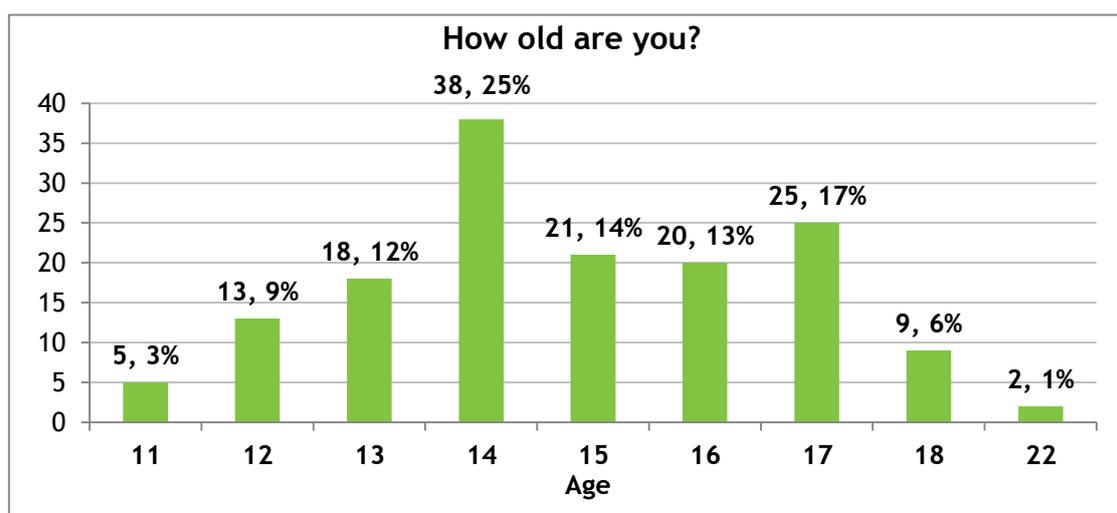
- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.
- Where we do not feel the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of, are being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.



Appendix 2 - Demographics

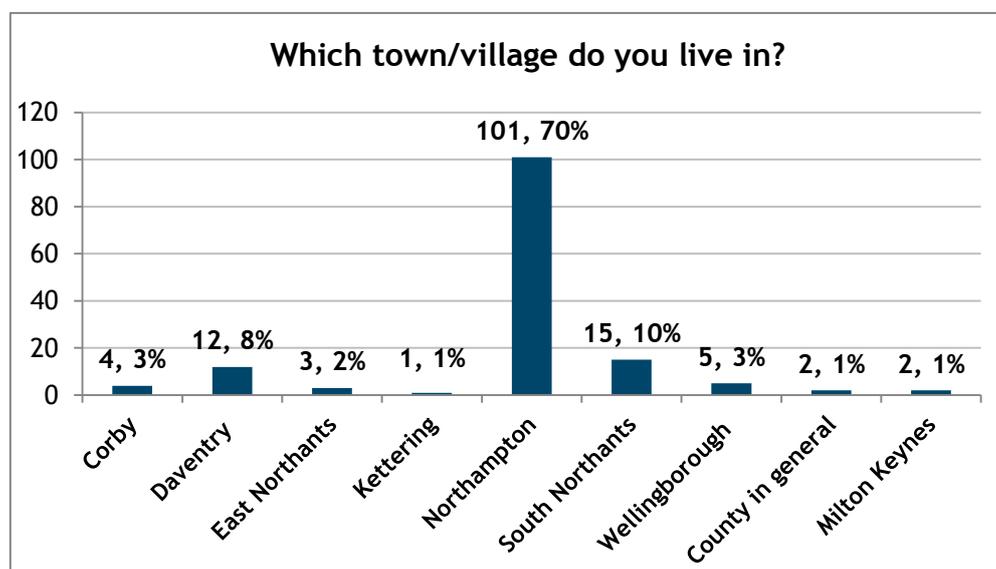
Age

151 CYP answered this question. The respondents ranged in age from 11 to 22 years old. 14 was the most common age (25%) as this was the age of most participants at the IASS conference.



Home town/village

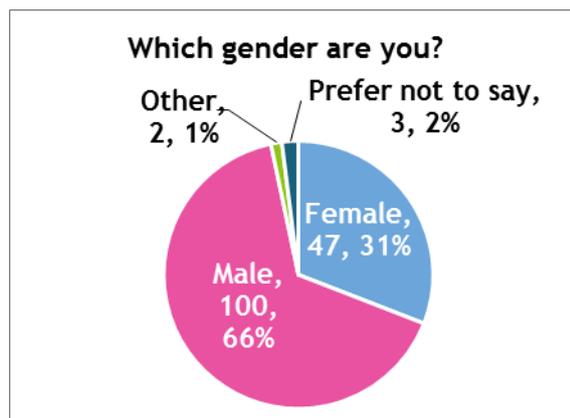
146 CYP answered this question. Surveys were received from across Northamptonshire and have been grouped by locality. Even though HWN tried to obtain a distribution of respondents across the county, two thirds (66%) were from Northampton as most of the students attending the IASS conference and receiving PSHE lessons were from Northampton.





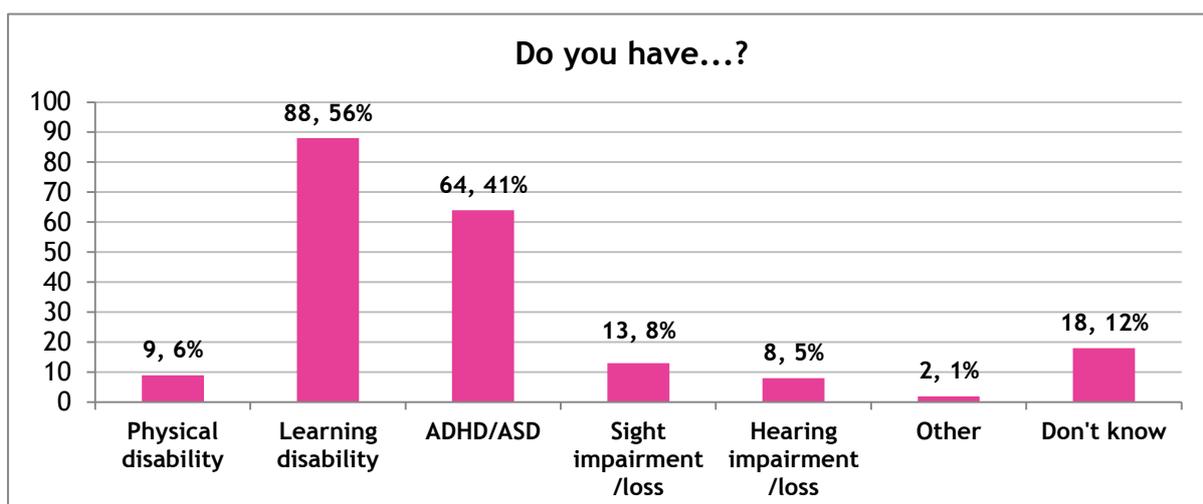
Gender

152 CYP answered this question. Two thirds (100, 66%) of the respondents told us they were male and nearly one third (47, 31%) told us they were female. Two respondents (1%) told us they were 'other' and three (2%) preferred not to say.

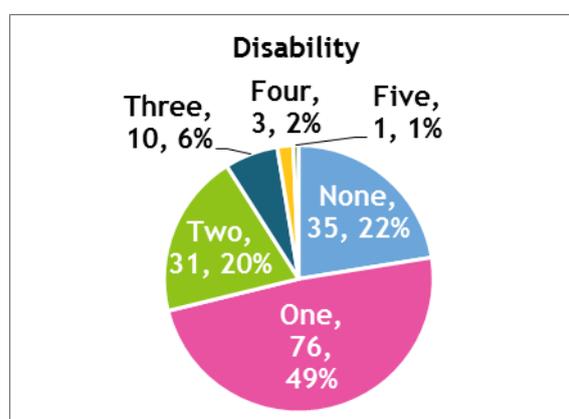


Disability

CYP were asked to select whether they were affected by any disability from a list (Appendix 1). 88 (56%) of the CYP said they had a learning disability and 64 (41%) said they had Attention Deficit Hyperactivity Disorder (ADHD) or an Autism Spectrum Disorder (ASD). One who selected 'other' mentioned epilepsy.



49% of CYP only selected one of the categories, 20% selected two, 6% selected three, 2% selected four, one CYP (1%) selected five and 22% did not select any, although 12% had said they did not know if they had one of the listed conditions.





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