



## **10,000 Voices Regional Report**

### **Experience of Paediatric Autism and CAMHS Project**

**January 2017**

## Foreword

We are pleased to present this 10,000 Voices report in relation to the experience of people who use our Child and Adolescent Mental Health Services (CAMHS) and Autism services across all Health and Social Care Trusts (HSCTs) in Northern Ireland.

Service user experience information is highly regarded as a key indicator of quality of care. The 10,000 Voices Initiative, designed to capture service user experience has been implemented across the six HSCTs in Northern Ireland in a number of service areas. It is providing a robust and systematic model through which service users and staff can work in partnership to improve experience of health and social care as well as informing commissioning and regional work.

The Health and Social Care Board (HSCB) have worked in partnership with the Public Health Agency (PHA) through the 10 000 Voices Initiative to capture the experiences of people who use Child and Adolescent Mental Health Services (CAMHS) and Paediatric Autism Services by providing an opportunity for children, young people/parents/carers and staff to “tell their story”.

This was the first time that the 10 000 Voices initiative had been applied to children’s services and has provided an innovative and meaningful insight into the experience of those who access and deliver these two services. It allows us to identify key messages and to develop action plans which will help to address the issues which really matter to the children/young people/parents/carers and staff.

This report presents the findings, analysis and recommendations from the information we received from 456 children/young people/parents /carers/staff from 1 January 2016 to 30 June 2016. Although the numbers of stories received varied across the Trusts, each story represents a unique and individual experience and collectively the stories help us to identify key messages and themes which will be incorporated into the future planning and delivery of CAMHS and Paediatric Autism services.

We are grateful to those who have taken the time to share their experience with us. The rich information provided in the narratives is a valuable source of information as we look to the future planning and provision of CAMHS and Autism services.

*Fionnuala McAndrew, Director of Social Care HSCB*

*Mary Hinds, Director of Nursing and Allied Health Professionals, PHA*

## Executive Summary

Involving patients, carers and their families in how health and social care services are shaped and delivered is an agreed commitment and priority for both the Health & Social Care Board (HSCB) and the Public Health Agency (PHA). In 2013, as a reflection of this commitment the 10,000 Voices Initiative was established and has been implemented in all Health and Social Care Trusts (HSCTs) in Northern Ireland across a number of service areas.

10,000 Voices aims to develop a more person centred approach to improving people's experience of using health and social care by capturing both qualitative and quantitative information, through SenseMaker methodology, with a strong emphasis on the narrative gathered on peoples' lived experiences. It was agreed by the Regional Patient and Client Experience Steering group that capturing the experience of children/young people/parents/carers and staff who use and deliver CAMHS and Autism services would be included in the 2015/2016 work plan for the 10,000 Voices Initiative.

In keeping with the principle of co-production which underpins the 10,000 Voices model, a number of workshops were facilitated for the key stakeholders to design the survey tools and also to assist with the analysis and interpretation of the information. (The survey tools are presented in Appendix 3)

In total **456** people shared their experience in relation to paediatric autism services and CAMHS, this included stories received during the pilot phase as well as stories from children/young people/parents/carers and staff.

The detail in the individual stories, whether positive or negative, provide the basis for identifying areas for change and improvement. It is clear that both services are valued and appreciated to children, young people, parents and carers.

It was particularly noted, for example that all the stories relating to eating disorder services within CAMHS were overwhelmingly positive. In other specialist areas, such as Intellectual Disability CAMHS and the gender identity service, although there were very small numbers responding, these stories also indicated overall positive experiences. However many of the stories received also highlighted challenges and opportunities for reflection for both Autism services and CAMHS.

The key themes that emerged from the overall information received are as follows:

1. The variance between
  - a. demand for services
  - b. service capacity
  - c. skill mix
  - d. waiting times
  - e. access to services
2. The importance of 'personalising' the service, with a focus on recovery and hope for the future.
3. Extending the availability of support provision for parents, children and young people when needed, including contact point for outside of regular working hours, as well as information, signposting and self-help resources.

These themes were discussed in terms of how they impact on the implementation of the current policy priorities for CAMHS and Autism services. The policy priorities are detailed in Appendix 2. The analysis of the themes in relation to policy priorities highlighted the different stages of development of both services. It was the view of participants at the workshops that CAMHS had been addressing these issues over the last number of years and were 'further ahead' of Autism services.

The findings may also be considered against the standards identified in the Mental Health Service Framework (DHSSPS 2011) which are relevant for children services and applicable to CAMHS and Autism Services. While the Sensemaker survey was not an audit of service user experience against the standards, there are aspects of the survey findings indicating that the requirements of the standards are being met. Consequently it is important that service developments and improvements continue to make reference to these and other key standards such as outlined in the Children's Services Framework standards and that these also are used as a benchmark for improvement. The publication of the Integrated Care Pathway for CAMHS will have implications for the current standards and any revision will need also to take into account the findings and recommendations from the Sense Maker survey.

## **What matters to children/young people/parents/carers in their health and social care experience?**

The richness of the narratives received through the 10,000 Voices methodology help us to build up a picture of what matters to people in their health and social care experiences. The learning points highlighted through the stories provided useful insights into care experiences and enabled identification of key messages and areas for improvement. Under each of the key messages, actions are proposed for both CAMHS and Autism services which focus on what will make a difference.

### **Key message - Having access to consistent, reliable and timely information**

#### **Proposed actions: CAMHS**

1. To build on the family support database to ensure that children/young people/parents/carers have a trusted, reliable, quality assured, “go to” source of information, resources and signposting.
2. This website should include information about services and other available supports across the STEP CARE model continuum for the benefit of both children, young people and their families, and referrers about what is available for different needs.

#### **Proposed actions: Autism Services**

1. Provide more information about what to expect at all stages, from referral to outcome, such as:
  - While on the waiting list provide information on what support is available, not just within health and social care systems;
  - What the assessment process will involve and how to prepare for it;
  - The range of supports available post assessment. This requires knowledgeable staff who can signpost and refer on appropriately as may be required;
  - Information available in a range of formats – verbal, written, pictorial and electronic.

2. Consider the development of a central multi-agency website which provides information on:
  - local initiatives – e.g. sensory shopping sessions, swimming lessons, etc
  - social enterprise initiatives to provide employment and training opportunities for young people for an agreed fixed time

### **Key message - Having personalised and holistic support**

#### **Proposed actions: (CAMHS)**

1. Invest in community development, outreach, group work and early intervention
2. Make good use of Trust information systems and the opportunity provided by the regional Northern Ireland Electronic Care Record (NIECR) to enable shared record and information
3. Develop software Apps to support young people and parents/carers
4. Review the provision of post diagnosis intervention and follow up support.

#### **Autism services**

1. Design autism services around the child, young person and their family ensuring that the services involved are co-ordinated across agencies, information is shared to reduce duplication and provide wider support for families and siblings. Support should be personalised and flexible recognising that “one size” does not fit all and that support and training should be appropriate to needs. There should be opportunity to “request” programmes or workshops to be developed, if not currently offered and parents and young people should be involved in the development and delivery of workshops, as appropriate.
2. Make better use of technology and innovation to improve experience
3. Pilot the provision of life coaching opportunities for parents and young people and review impact to inform service development in this area.

4. Develop specific “needs based” multi-agency workshops, designed in collaboration with parents, which would provide guidance, empower parents, children and young people to address issues which may require support, e.g. “ what to do if ...”.
5. Consider the use of peer support and positive role models using a broad spectrum of people from diverse backgrounds who have lived experience of autism.

### **Key message - Having access to wider support, including during out of hours periods**

#### **Proposed actions: CAMHS and Autism**

1. Provide appropriate Out of Hours contacts and telephone support details
2. Consider the use of peer mentoring to support individuals
3. Develop consistent crisis response arrangements at regional and local levels, for providing more effective family support to stabilise crisis situations. This includes 24/7 consultant cover.
4. Single point of entry to ensure access to the most appropriate service/ services, based on assessed need and minimise multiple contact points for accessing individual services
5. Provide information about other services to empower parents and provide better co-ordination through referral, screening and triaging before coming into CAMHS
6. Pilot a “Talking Therapies Hub” which would also offer telephone advice/consultation.

### **Key message - Having consistency in approaches to care**

#### **Proposed actions: Autism services**

1. Implement a Key Worker system which supports the family right through the care journey from the initial point of contact. The key worker role is to ensure
  - a. ‘needs led’ timely support, signposting and co-ordinating intervention

- b. information of what is available across services
- c. accessible contact –
  - out of hours contact
  - Staffed telephone
  - Various means of communication including e-mail

**Key message - Ensuring regional equity of services (this theme emerged in particular in relation to autism services)**

### **Proposed action for Autism services**

1. Map the level of demand and capacity across Autism services by Trust area and Educational area to establish the current capacity of services and address inequity of provision across health and education.
2. Profile the current skill mix and in light of the future requirement for specialized skill sets, develop a workforce plan to address and provide appropriate training.
3. Realign and redesign services which are better integrated to wrap around children young people and their families and which are targeted towards the provision of support for parents based on need and not confined to a confirmed diagnosis

### **Trust Actions**

In addition to the actions proposed above which apply regionally, individual Trusts have identified actions for progression based on the analysis of the information they have received. These actions are being progressed locally within the Trusts and will be incorporated into respective Trust service improvement plans and used to inform existing and future service delivery. Trusts' learning is based on the detail in individual stories and the identification of specific themes which were highlighted in order to identify areas for local action and improvement. Individual Trust reports are available on each respective Trust websites (see Appendix 1)

A final message that cuts across all areas is how we can **maximise the use of resources**. In this regard we will ensure:

1. Resources commissioned for services are protected as far as possible and organisations held accountable for the use of these resources i.e. within HSC and the Education Authority.
2. There is an appropriate balance between diagnostic and support services
3. There is better collaboration across other agencies and departments, e.g. Education and Further Education, Department of Communities and Councils etc. that supports effective and joined up response to people's needs and makes the best use of all available resources and investment.

## **Conclusion**

The overall themes and messages from the Sensemaker Survey are being integrated into and will help to inform the Regional Draft Framework for Children and Young People's Developmental and Emotional Well Being Services (2016), ensuring that the voices of children, young people and their parents are being used to influence the future delivery of services.

While it is acknowledged that the participants in this survey relating to Autism and CAMHS services represent a small proportion of the total numbers of people who use these services, the narratives have provided a very rich source of service user experience information which have and will continue to inform regional and strategic work in both CAMHS and Autism services.

It is important that the findings from the survey and the implementation of local and regional action plans provides the baseline for service improvement and development and consequently it is intended that the survey would be repeated in 18 – 24 months' time to monitor the impact of the recommendations and subsequent actions.

## Contents

Section	Content	Page
	Foreword	2
	Executive Summary	4
1.0	Introduction	12
2.0	Strategic context	13
3.0	The survey	14
4.0	Findings	16
4.1	Numbers of responses	16
4.2	Findings from pilot phase	16
4.3	Findings from main period of story collection	17
4.3.1	Returns by service	17
4.3.2	Returns by Trust	17
4.3.3	Returns by who completed the survey	18
4.3.4	Returns by setting	18
4.4	Responses to signifier questions	19
5.0	Short survey	38
6.0	Staff experience	40
7.0	Overall key themes and impact on policy implementation	44
8.0	What matters to children/young people/parents and carers	45
9.0	Conclusion	57
10.0	Acknowledgements	57
	Appendix 1 References and useful links	59
	Appendix 2 CAMHS and Autism services policy priorities	60
	Appendix 3 Survey tools	61

## **1.0 Introduction**

Involving patients, carers and their families in how health and social care services are shaped and delivered is an agreed commitment and priority for both the Health & Social Care Board (HSCB) and the Public Health Agency (PHA). In 2013, as a reflection of this commitment the 10,000 Voices Initiative was established.

10,000 Voices aims to develop a more person centred and co- produced approach to improving people's experience of using health and social care by capturing both qualitative and quantitative information, with a strong emphasis on the narrative gathered on peoples' lived experiences. National and international evidence demonstrates that patient stories have unique features which make them an appropriate methodology for quality improvement. Based on this evidence it was agreed that 10,000 Voices would use SenseMaker methodology, which enables the collection and analysis of a large quantity of stories which would be used to inform and affect change.

HSCB have worked in partnership with the PHA through the 10 000 voices Initiative to capture the experiences of people who use Child and Adolescent Mental Health Services (CAMHS) and Paediatric Autism Services – children, young people and their parents/carers, through “telling their stories” and commenting on key issues they have identified that matter to them. By adopting this approach it was hoped to gain new insights into services provided and use that information to identify areas where improvements to services could be made and to enhance the quality of care. This was the first time that the 10 000 Voices initiative had been applied to children's services. It was approved by the Regional Patient and Client Experience Steering Group who oversee all projects undertaken as part of 10,000 Voices.

The partnership approach adopted by the 10,000 Voices Initiative successfully blends qualitative and quantitative data using SenseMaker methodology and is based on the principles of Experience Based Co-Design. By applying this methodology the project complied with the Mental Health Services Framework (standards 7, 10 -15, 17-20, 22, 27-31, 53-54) (DHSSPSNI 2011) and is in keeping

with the aims of Transforming Your Care (DHHSPSNI 2012) in the promotion of personalisation of services delivered.

The key intended outcome from the CAMHS and Paediatric Autism service project was to establish a baseline of the experience of children, young people and parents/carers to improve and influence the future development and delivery of these services systematically. In addition to capturing these views, 10 000 Voices also makes provision for capturing the views of staff working in both service areas.

A Project Team was established to oversee the Sensemaker audit. The team met regularly through all phases of the audit – planning, conducting the survey, analysis and completing of the report.

## **2.0 Strategic context**

The strategic development of Child and Adolescent Mental Health Services (CAMHS) and the current service configuration have been based on a number of key strategic documents: Bamford Review Report (2006); RQIA Review of CAMHS (2011); Patient Client Council Report (2012) “*Young People Priorities*”; DHSSPS Guidance (July 2012) on the Service Model for CAMHS. All of these referenced the importance of involving young people and their families in the planning of services recommending the need for routinely capturing the user and carer experiences of services.

The HSCB published “*Six Steps of Autism Care*” (2011), which was designed in line with NICE guidelines. The pathway was developed in partnership with parents of children and young people with autism and aimed to improve the experience of children and their families. The cross departmental ASD strategy - Autism Strategy (2013 – 2020 DHSSPSNI) and Autism Action Plan (2013 – 2016, DHSSPSNI) placed a strong emphasis on ensuring more effective engagement with parents and children and that their involvement in shaping services was embedded in service practice. A key element in taking forward the aims of the DHSSPSNI strategy was to capture the views and experiences of families who were involved with HSC autism services.

### 3.0 The Survey

A Project Group was established involving all key stakeholders to oversee all tasks involved in conducting the survey and producing and disseminating the regional report. ***The aim and purpose of the project was:***

1. To establish a baseline of young people and parental experience of emotional and mental health services.
2. To benchmark services against the Mental Services Framework Standards 7, 10 -15, 17-20, 22, 27-31, 53-54 (DHSSPSNI)
3. To use the findings and recommendations to assist and in the establishment of user/carer participation framework/standards for CAMHS and paediatric ASD services.

#### ***The objectives were***

1. To develop a qualitative survey tool using SENSEMAKER Methodology.
2. To establish a baseline assessment to measure the impact of service developments against CAMHS and Autism Services.
3. To identify recurring themes from personal experience accounts to assist in the improvement of services and service user experience

### 3.1 Methodology

The survey, which uses Sensemaker® methodology, was designed with public engagement through two workshops at which young people, parents, carers, HSC staff and staff from Education sector participated. Following the analysis of the pilot phase, it was agreed that the story collection period would commence from 1 January 2016. Those completing the survey were asked to tell us about their experience of accessing and receiving care in CAMHS and paediatric autism services.

They could choose to share all or part of their experience and the survey could be completed by the child/young person or someone acting on their behalf. They were then asked to respond to a series of questions, known as ‘Signifiers’, which are in a triangle format. In each of these questions, the respondent reviewed 3 statements and placed their “dot” nearest to the statement that reflected their experience. In



Stakeholder workshop to design survey tool

some cases their choice may have been between choices, indicating that their response was a combination of two factors. If all three factors applied equally to their story, they would place their “dot” in the centre of the triangle.

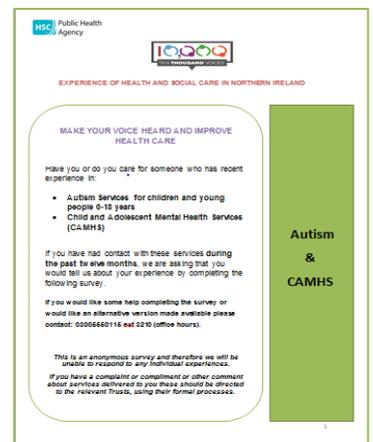
Respondents were asked not to give their name or to name of any staff who provided their care. They were advised not to worry about spelling or grammar and to write as much or as little as they wish.

All completed surveys (users and staff) were scrutinised by the 10,000 Voices Co-ordinator and forwarded to respective Trust project group members on a weekly basis to scrutinise and notify of any potential issues that may need to be brought to the attention of relevant managers/Directors/Heads of service. It was agreed that after the survey analysis and completion of the report the Trusts would destroy all data captured during the survey but that the original data would still be held by 10,000 Voices.

The survey was promoted widely through extensive regional and local engagement plans which included HSCTs, social media, and 3rd sector organisations.

Although the purpose of the survey was primarily to capture experience relating to HSC care, it was anticipated that some of the narrative may overlap with issues related to education, therefore colleagues from the education sector were also included in the project team. Respondents completed the survey using a paper copy, online or through a Digital App, with alternative formats available on request.

Staff within the Trusts encouraged participation through on-going engagement and promotion of the survey with children / young people /parents/carers. The period for story collection was extended from 3 to 6 months to maximise the inclusion of as many voices as possible. A target of 150 responses per Trust was agreed; however despite the extensive efforts by Trust staff this target was not achieved.



The survey tool



Information leaflet

## 4.0 Findings

### 4.1: Number of responses

In total **456** people shared their story in relation to experience of paediatric autism services and CAMHS, as follows:

<b>Pilot phase</b>	<b>43</b>
<b>Main period of story collection</b>	<b>357</b>
<b>Short survey</b>	<b>23</b>
<b>Staff stories</b>	<b>33</b>
<b>Total</b>	<b>456</b>

### 4.2 Findings from pilot phase

In order to test the questions and the process to capture the collection of stories, a pilot was conducted across all Trusts during November 2015, with a target of 10 responses per Trust across both services. In total **43** surveys were returned. Following the analysis of the information received appropriate changes were made to the survey tool in preparation for the main period of story collection.

Although the purpose of the pilot was to test the suitability of the survey tool and the processes used for story collection, some actions were also highlighted for action in relation to CAMHS, as follows:

- School has set plans in place on how endings of discussions/meetings with children and young people are managed.
- Review of the process for the selection and follow up and support for young people who attend groups

In conducting the pilot some very valuable learning points were gained in preparation for the main period of story collection. Based on the information obtained it was agreed that quality improvements in practice and in commissioning could be achieved, therefore this approach would allow the aims of this project to be fulfilled.

### 4.3 Findings from main period of story collection (January 2016 – June 2016)

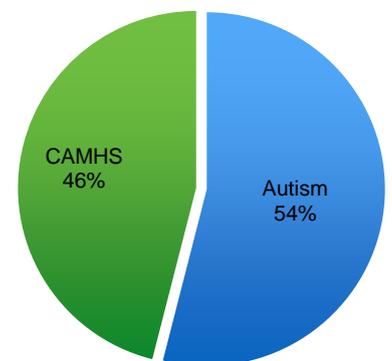
This section presents the findings from the main period of story collection using SenseMaker methodology from January 2016 – June 2016. In order to interpret and analyse the findings, the key stakeholders participated in workshops held in September 2016.

#### 4.3.1 Returns by service

##### How stories were indexed to service

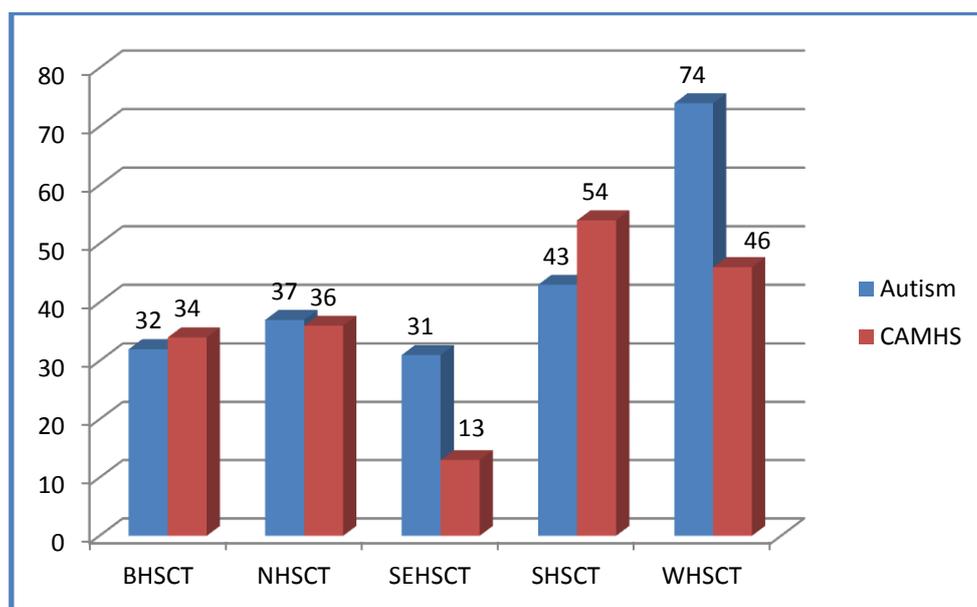
Autism – 217  
CAMHS – 183

**Overlap of 48 people who used both services  
(noted in responses to questions)**



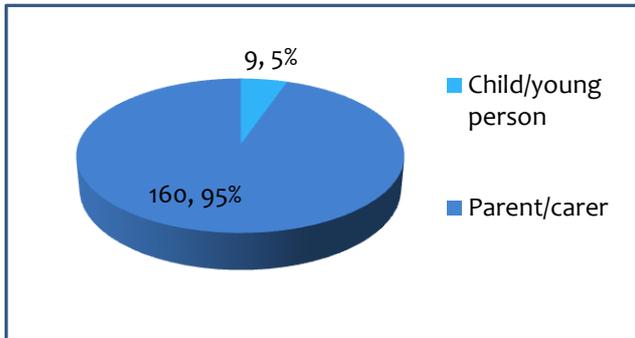
Percentage breakdown per service

#### 4.3.2 Returns by Trust

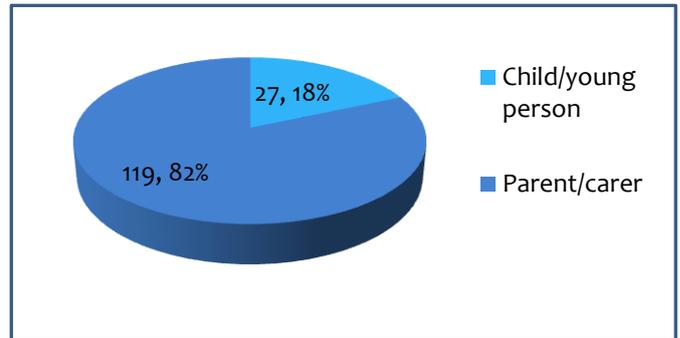


### 4.3.3 Returns by who completed the survey

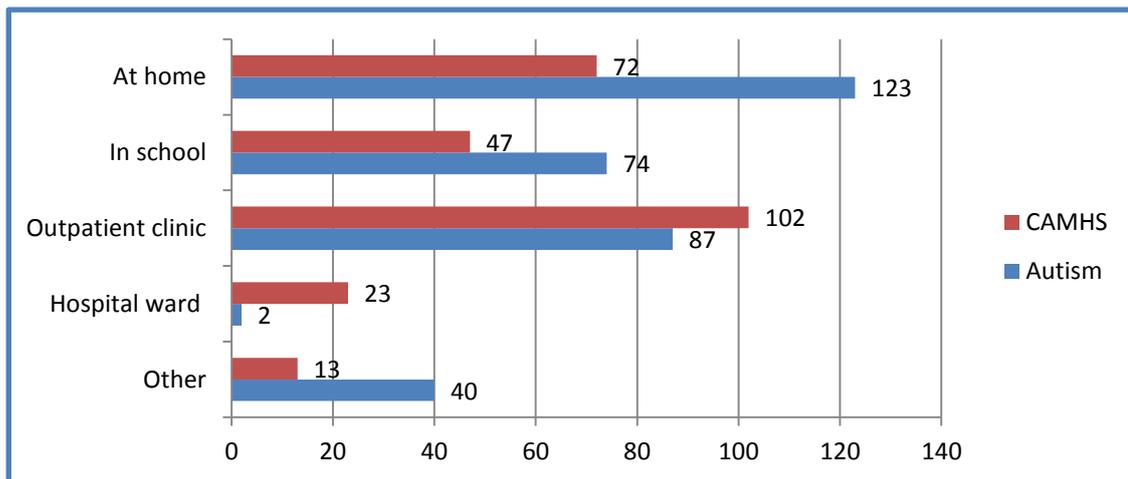
#### Autism



#### CAMHS



**4.3.4 Returns by setting:** Participants were asked to identify which setting their experience relates to, responses are as follows:



**Nature of health issue:** Participants were asked to identify the nature of the health issue and could select more than one option if required. The top 3 health issues identified for each service were as follows:

#### Autism services

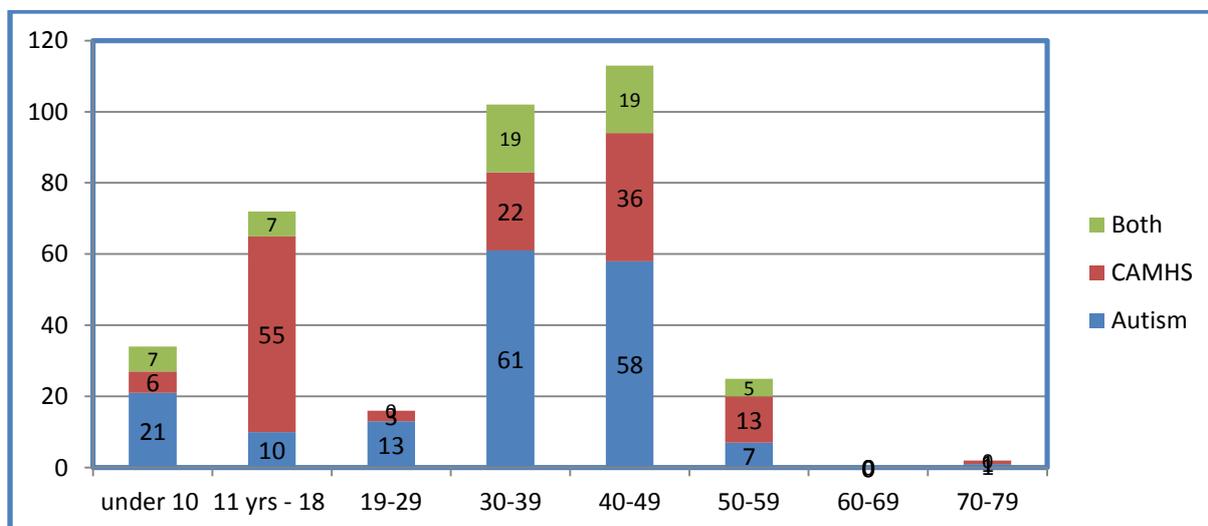
- Autism/Aspergers (96%)
- Anxiety (32%)
- Intellectual disability (10%)

#### CAMHS

- Anxiety (49%)
- Depression (30%)
- Self-harm (26%)

## Demographic overview:

Age profile relating to the person who shared their experience



- 74% identified as female
- 88% identified Northern Ireland as country of birth

### 4.4 Responses to signifiers

This section presents the combined responses from both services to the signifier questions, they have been colour coded as below:

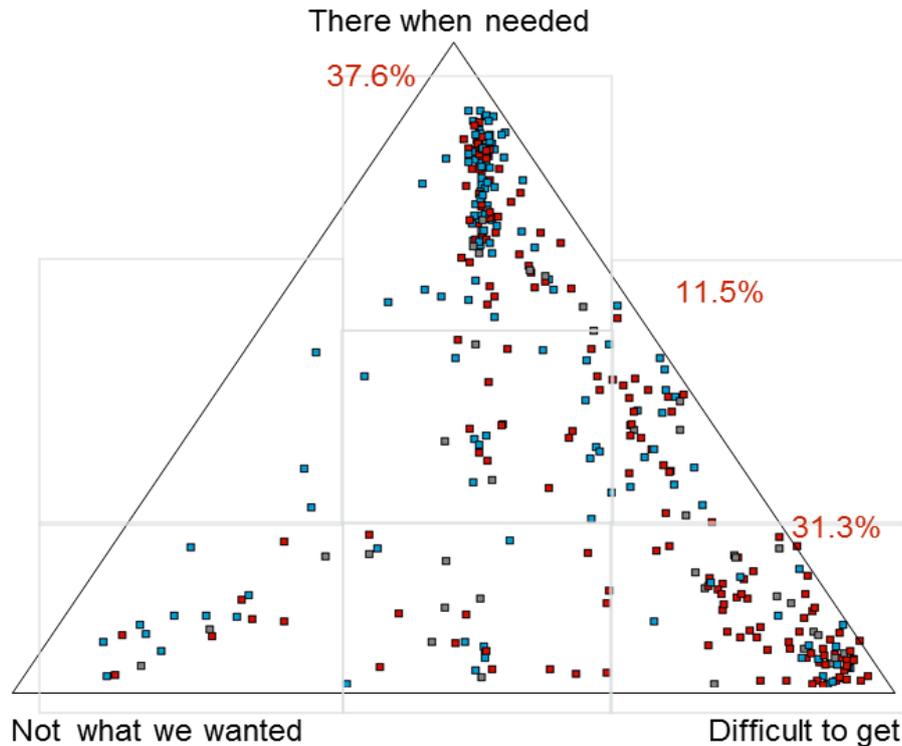
	<b>CAMHS</b>
	<b>Autism</b>
	<b>Both services</b>

Individual Trust responses have been stranded out for each service and have been included in the Trust reports which are available on Trust websites (see Appendix 1)

In order to analyse and interpret the responses to these signifier questions, results interpretation workshops were held, at which parents, practitioners and colleagues from the Education Authority worked in partnership to identify the strongest themes in the data. Discussion around the responses to each signifier was facilitated as well as opportunities to identify recommendations for future planning and delivery of services.

Each of the 11 signifier responses is presented below with a brief overview of the analysis of the data, extracts from stories to illustrate the key messages and a summary of the workshop discussions.

**Question 1: How did you feel about the services you received?**



**Analysis**

1. There were 348 responses to this signifier, giving it a 97.8% response rate.
2. More than a third of the responses (37.6%) were located towards the top of the signifier, indicating that services were there when needed.
3. Slightly below a third of stories (31.3%) indicated that it was difficult to get the services they required.
4. 11.5% indicated that the required services were available but also difficult to get.

**Extracts from stories**

*Child coming here for the last seven months. The staff are very helpful and caring with the help needed*

*They were a godsend*

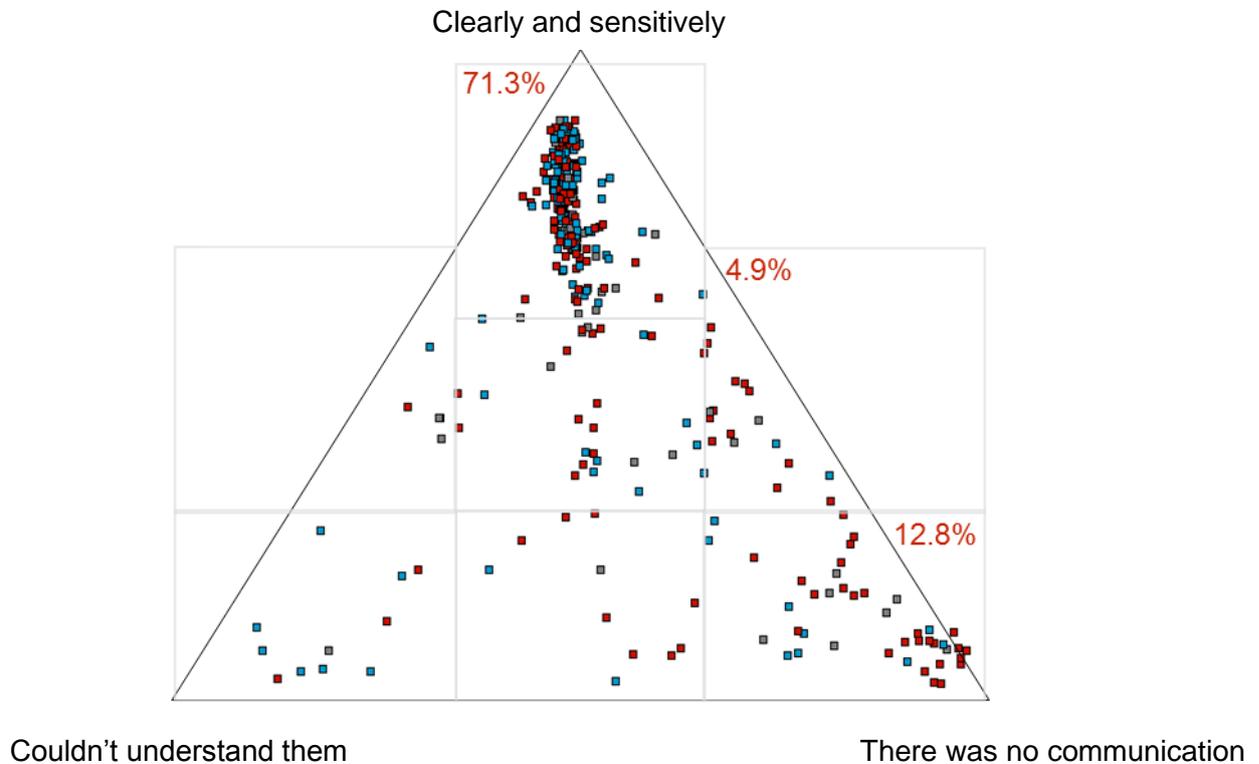
*I found the staff very helpful and informative, although the wait for diagnosis seemed endless. I would like to see more guidance for parents/carers*

## Summary of discussion at workshops

- a) Some parents expressed surprise at the “difficult to get” response as they thought there would be more stories reported against this option. The parents who attended the workshops highlighted that waiting lists are a major issue and were concerned that the views of parents of children on the waiting list may be underrepresented and if this was the case, a different pattern of responses may have been produced. It was indicated at the workshop that the survey was to capture the experience of those who have been in receipt of the service within the previous 12 month period. It was acknowledged that in some Trusts there are significant waits for the assessment process to commence, however as these families had not yet accessed the service, their responses and experience of service delivery was limited.
- b) Support for parents is needed, i.e. guidance and information before and after diagnosis. When the child or adolescent is diagnosed, they need help with future life planning; it was suggested that it may be helpful for them to meet an adult who has had a diagnosis and who could provide mentoring. Children and young people have questions: “Am I different? What can I expect?” It would be invaluable for them to have a role model who can be a source of inspiration to them. Some parents reported that peer groups do not always work as some individual young people experience “peer stigma” about being part of such a group.
- c) Staff re-training for both CAMHS and Autism is necessary so they are able to respond effectively to both sets of needs, to recognise behaviours and respond appropriately.
- d) It is important to tailor services for individuals and to avoid a “one-size fits all” approach.
- e) The Youth Advocacy Programme is regarded as very worthwhile.
- f) There is a reported increase in the prevalence of autism and an increase in referrals for assessment and clearly there is a need for more research into causal factors and a need for generic access, rather than autism being a “specialist” service
- g) Rural access to services is a problem in terms of locating service delivery points.

- h) People's expectations are not "realistic" in the light of current provision which will lead to disappointment with the service provided.

**Question 2: How did the staff communicate with you?**



**Analysis**

1. There were 345 stories recorded for this question, giving it a 96.9% response rate.
2. There is a large cluster of responses towards the top of the signifier (71.3%), indicating that staff communicated in a clear and sensitive manner.
3. There is a small cluster of stories at the bottom right indicating that service users felt there was no communication (12.8%) between staff and the respondents.
4. There are a few stories indicating that the respondents could not understand staff communications.

### Extracts from stories:

*I was helped when feeling sad and tired. She was someone who listened to my problems no matter how big or small they were*

*No one knows who we should be speaking to. Everyone we speak to directs us to someone else. We go around in circles*

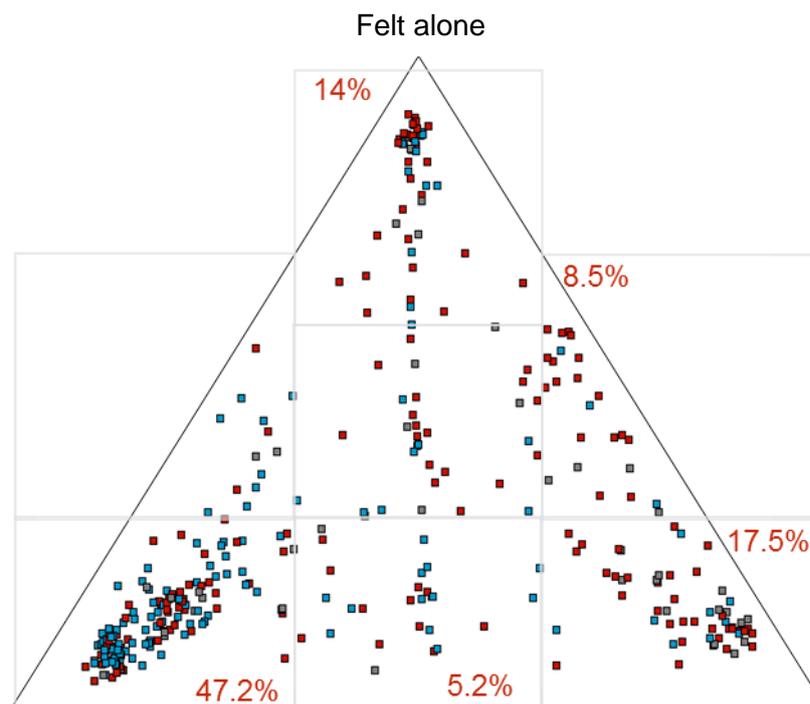
*I am always kept informed as to what is going to take place and get an explanation of everything*

*More teenage issues are needed to be addressed*

### Summary of discussion at workshops

- a) Parents were positive about the high level of “clear and sensitive” communication. Parents recognise that staff experience workload pressures: “are there enough staff in Autism?” and that this may affect staff’s time for communication.
- b) Parents feel that there is little or no communications when on the waiting list and felt that this is unacceptable in this “day and age” when parents could easily be contacted by text message, phone or email. Parents highlighted how important this communication is, especially when they feel alone and do not see any progress happening. For many, evening contact would be welcome as many parents work.
- c) Parents welcome reliable signposting to services: if they are being written to, they would like contact details, names, telephone numbers, and for the times where staff are available to be contacted and for access to reliable information to be extended.
- d) The one-stop shop multi-agency initiative for 16+ and adults with ASD is valued.
- e) While Family Support Northern Ireland is a very useful website, not everyone has computer access (‘digital divide’)
- f) It was suggested that a helpline and better communication channels in the Health and Social Care Trusts would be welcome, particularly to prevent gaps in communication.

### Question 3: How supported by staff did you feel in this process?



Found support easily

Had to fight to get needs met

#### Analysis:

1. There were 343 responses to this question, giving it a response rate of 96.3%.
2. The responses are broadly scattered across the signifier, but there appears to be about half of the responses (47.2%) indicating that support was easily found from staff during the process.
3. 17.5% of the responses indicated that they had to fight in order to get needs met, and 14% indicated that they felt alone in the process. 8.5% indicated that they felt alone and had to fight to get needs met.

#### Extracts from stories:

*I have no skills or training in this area. I would have loved professional input at the hard times*

*The support we received was great and all staff involved were helpful and very supportive*

*We were scared...we knew we had to talk to someone. It has been a long slow process, every step is painfully slow*

*What happens when the young person reaches 18?*

## Summary of discussion at workshops

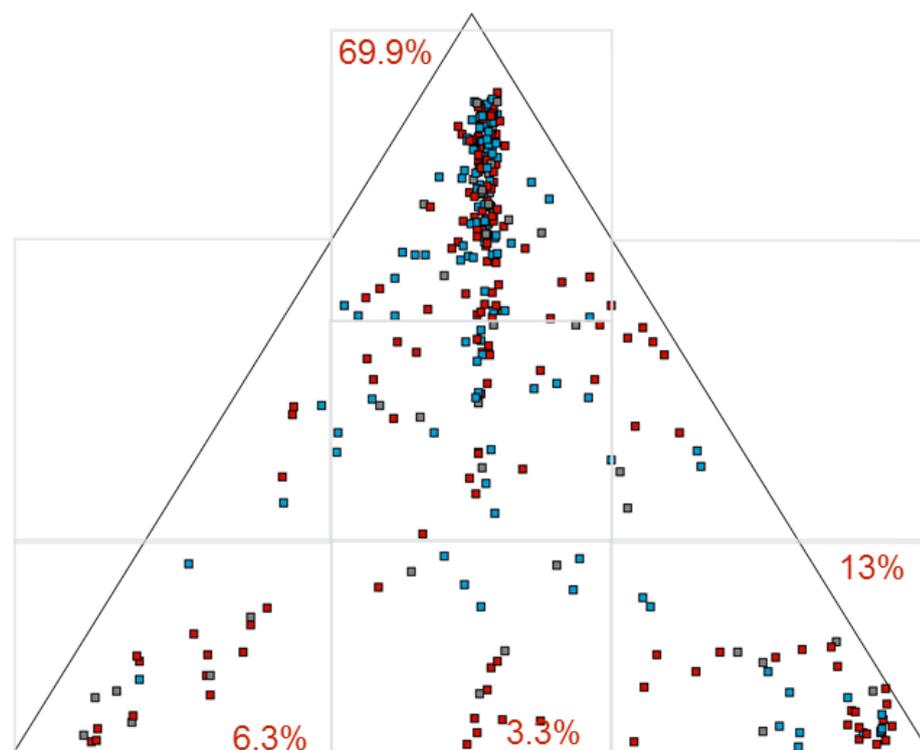
a) Parents recognise the “feel alone” response which generated concern among everyone; this can often be part of the parents’ experience as their young people begin to use services. Parents said they would welcome email and online help and support, and a “virtual helpline” to reduce their isolation and anxiety.

b) Parents value staff experience but emphasised that staff must not “over promise” what can be delivered. It is important to be realistic about what is possible and follow through on commitments.

c) The current Monday to Friday office hours’ availability was reported as unacceptable by parents, who would welcome a helpline available out of hours and evening appointments. One parent said they receive “30 minutes service and staff input per month” which is not enough.

### Question 4: In this experience how involved were you in making decisions?

I was fully involved in all decisions



I did not receive enough information to make a decision

I was not consulted

## Analysis

1. There were 332 stories were tagged to this signifier, giving it a response rate of 93.3%.
2. The majority of stories were near the top of the signifier with about 70% indicating that the respondent was fully involved in all decisions.
3. 13% of responses indicated that the respondent was not consulted in the decision-making process.
4. Even fewer responses (6.3%) indicated that the respondent did not receive enough information to make a decision.
5. Only 3.3% indicated that the respondent was not consulted and had received insufficient information to help make a decision.

## Extracts from stories

*I am always kept informed as to what is going to take place and get an explanation of everything. Everything was clearly explained and the staff were approachable and easy to talk to*

*I worried what they would think of me as a parent – I need not have worried. The advice they gave me worked really well...I am now a proud and happy mammy with a very content son*

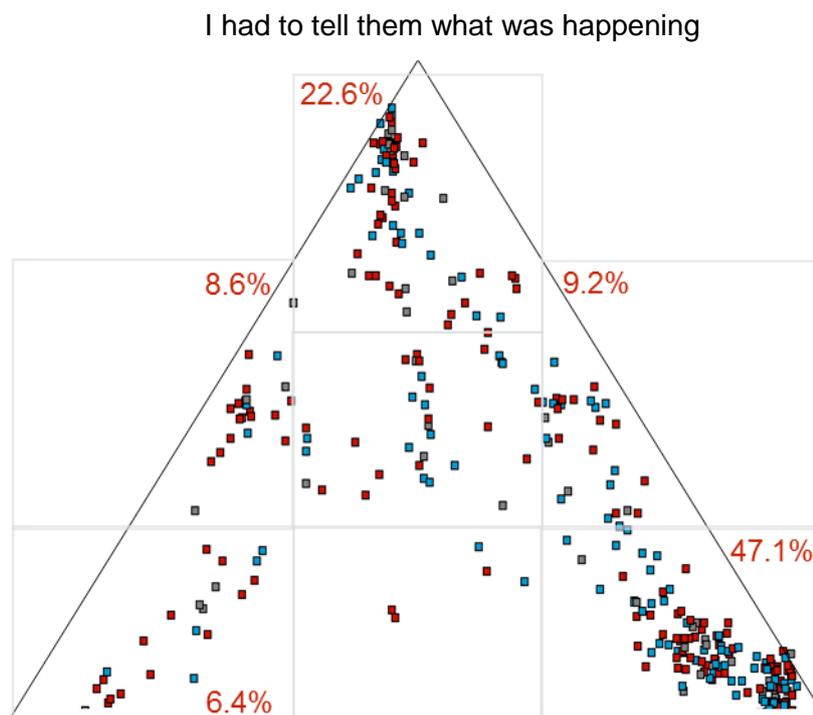
*I feel they could have explained better the assessment and what is available*

*I also felt the understanding of OCD wasn't as good as it could be*

## Summary of discussion at workshops

- a) Staff need to be aware that parents are sometimes affected negatively by the use of jargon and they do not feel able to say "I don't understand" as this makes them feel "stupid".
- b) Involvement requires understanding and is welcomed by parents.
- c) Sometimes the Multi-Disciplinary Team (MDT) discussion excludes parents.
- d) When there is conflict between parents and the child, staff have difficult choices to make, and need to handle communication and decision making carefully.

## Question 5: How well did the staff work together to help you?



They did not talk to each other

They all worked together to help me

### Analysis

1. There were 327 responses tagged to this signifier, giving it a response rate of 91.9%.
2. This signifier shows most of the responses towards the right. About half of all experiences shared indicated that the staff had all worked together to help the respondent.
3. However, 22.6% of the experiences shared indicated that respondents had to tell the staff what was happening in order for them to help out.
4. 9.2% indicated that while the staff worked together to help, there was some degree of initiation from the respondent.
5. There were some experiences recorded in the bottom left side of the signifier, which indicated that the staff did not talk to each other.

## Extracts from stories:

*Help was so much needed at the eating disorder clinic as a family we couldn't have helped ... the team are so helpful and are always there for us*

*The ASD service has been extremely co-ordinated, cohesive and joined up and since my daughter's diagnosis it has enhanced our quality of life*

*Disjointed*

*More understanding with school and other professionals involved*

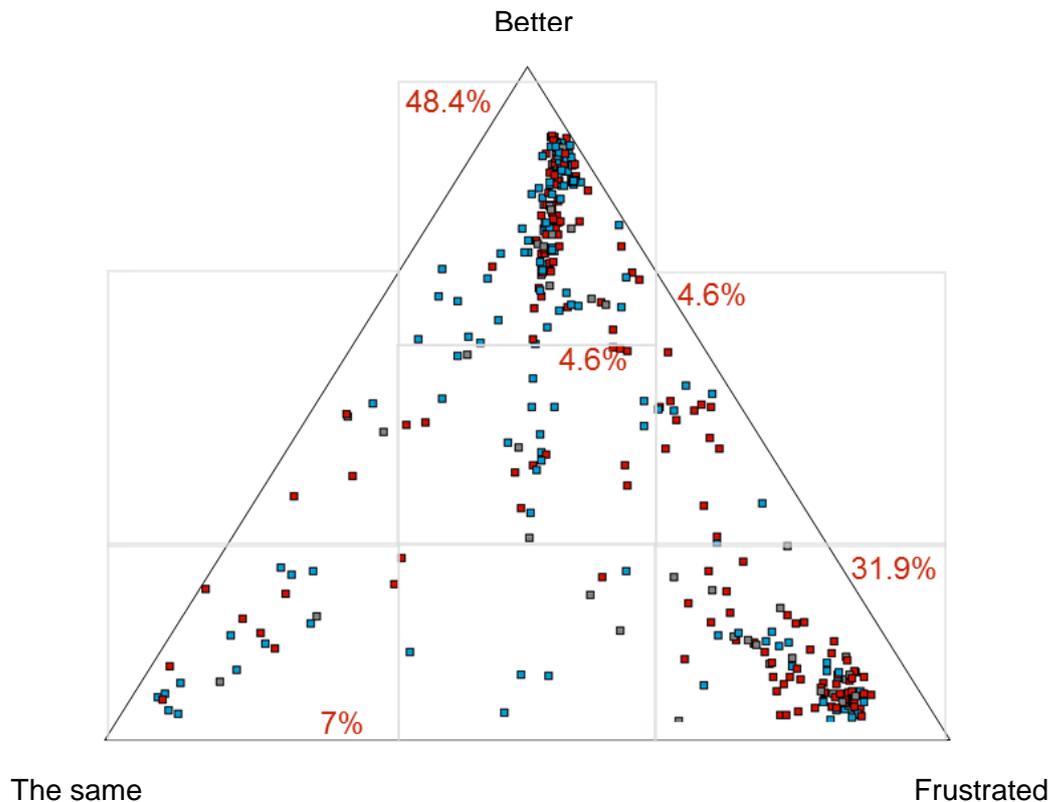
## Summary of discussion at workshops

- a) Responses are in relation to health and social care experience; however some respondents reported that health and education sectors need to collaborate more effectively to meet the needs of children and young people and their families
- b) It is vital that there is shared information between professionals.
- c) It was acknowledged that staff and personnel may change as the needs of the child/young person and family are assessed and assessment and support are delivered within the most appropriate model of service delivery, for example the STEP CARE model
- d) There can be a negative impact on the child if there is no preparation for a member of staff leaving.



Participants at analysis workshop

## Question 6: Following your experience did you feel...



### Analysis

1. There were 345 responses to this signifier, giving it a 96.9% response rate.
2. The majority of responses were on the right of the signifier, indicating that respondents mostly either felt better or frustrated following their experience.
3. About a third of the experiences shared indicated that the respondent felt frustrated following the experience. Some of these frustrating experiences were related to long waiting times, delays, poor assessments, lack of or no support, and so on.
4. Only 7% of the experiences shared indicated that respondents felt the same.

### Extracts from stories:

*CAMHS services for young people with ASD has been very helpful in managing emotions and having a safe place to talk about and express feelings*

*Felt relief when my child was diagnosed but also mixed emotions*

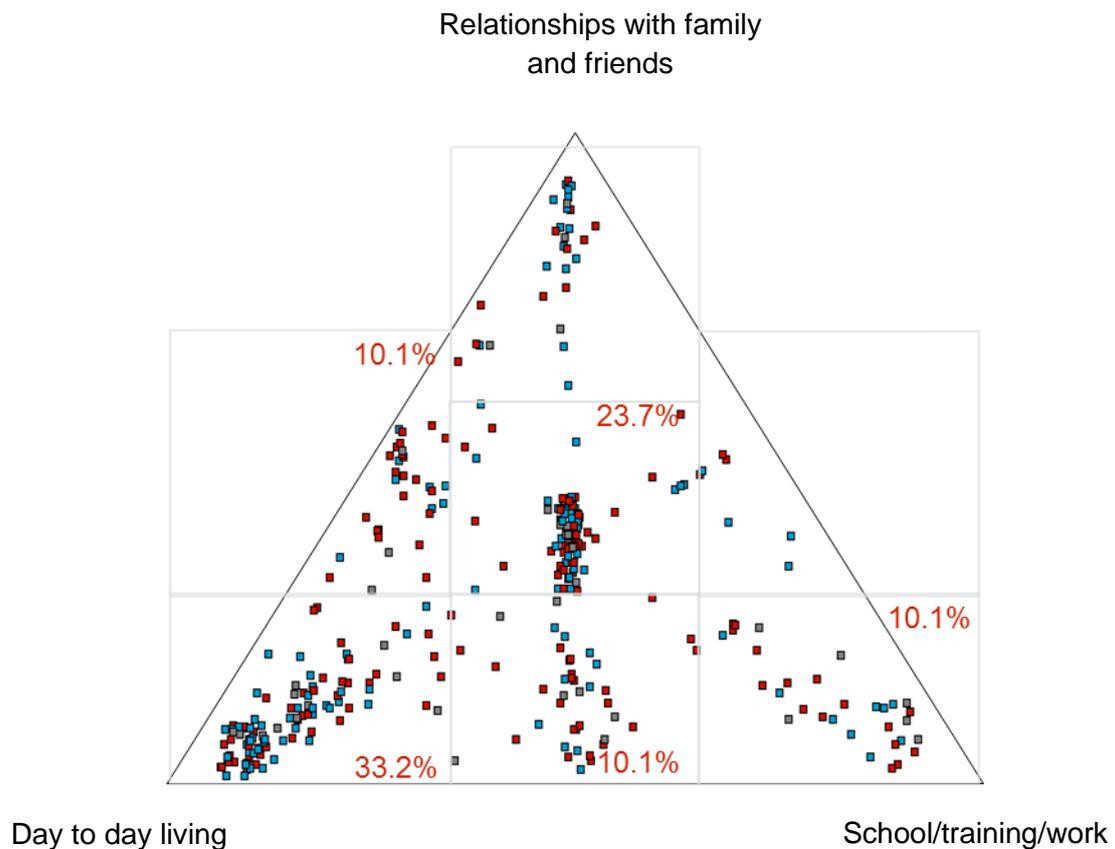
*Our family are under extreme pressure*

*They helped me work through my problems. It can be a scary experience at start but it's not as bad as it seems, CAMHS has really helped me*

### Summary of discussion at workshop

- a) Parents feel frustration at not getting the services they feel they need; there are postcode differences, e.g. some intervention and support services are not delivered across Northern Ireland because of resource constraints.
- b) Staff need to ensure parents' expectations are realistic about what services and support are available.
- c) It is vital that services empower parents to self-manage the situation as far as possible. Staff need to equip parents with techniques and resources to enable a self-help approach and reduce as far as possible dependence on services.
- d) Parents reported frustration with a lack of an integrated and flexible system
- e) Parents need support and empowerment to build their confidence.
- f) Personalisation of service design and response.
- g) Staff training.
- h) There needs to be a move from "diagnostic led" support and intervention services for children and young people to a "needs' led" model of support with increased personalisation

### Question 7: Which area of your life was most affected in this experience?



### Analysis

1. There were 337 responses to this signifier, giving it a 94.7% response rate.
2. About a third of responses indicated that their day-to-day living was most affected by their experience.
3. 23.7% indicated that it was a combination of things i.e. relationships with family and friends, day-to-day living, and school/training/work which was impacted on by the service they receive

### Extracts from stories:

*My child is lonely because she is not in school due to her mental health issues*

*Son's difficulty in school, getting from class to class*

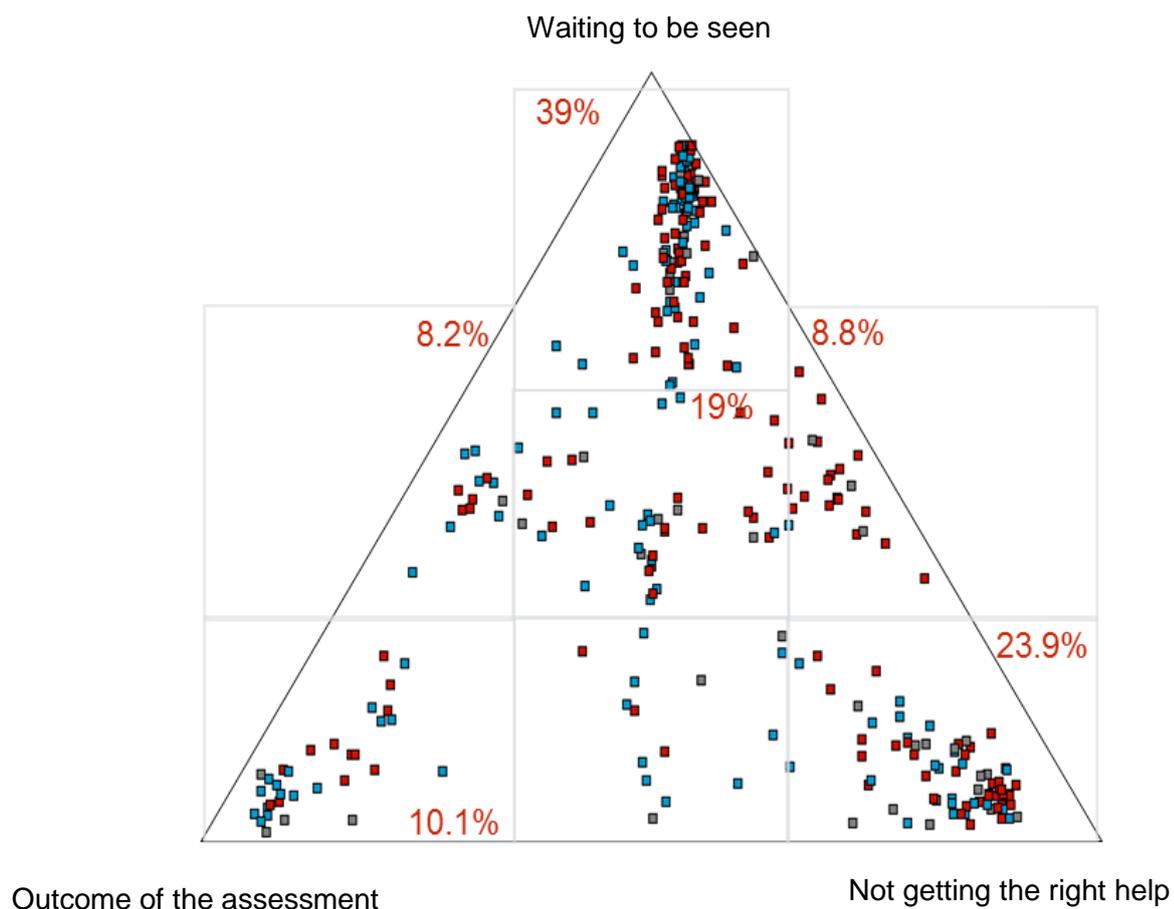
*Sibling support groups – not adequate*

*He would get really concerned about his school work or overwhelmed and needed to talk to someone*

## Summary of discussion at workshops

- a) These events highlight the importance of support for parents.
- b) The impact on children and young people's resilience was emphasised and additional strengthening factors need to be put in place. This requires a response that is cross agency involving councils, Further Education, education, employment and finding inspirational role models.
- c) Increase public acceptance and awareness of CAMHS and Autism and de-stigmatise by promoting positive "role models".
- d) The education sector has an important role in increasing support.

## Question 8: What was the hardest part of your experience?



## Analysis

1. There were 318 responses to this signifier, giving it a 89.3% response rate.
2. The majority of responses were located towards the top and right side of the signifier, indicating that respondents felt that the hardest part of their experience was either waiting to be seen or not getting the right help.
3. More than a third of responses indicated that waiting to be seen was the hardest part of the experience.
4. 23.9% indicated that not getting the right help was the toughest part of the experience. Responses located in this corner of the signifier also tended to view their overall experience as poor or very poor
5. 19% indicated that it was a combination of all three factors that made their experience difficult.

### Extracts from stories:

*Quicker time from referral from school to diagnosis after initial appointment*

*Getting the help quicker*

*More advice and training on how best to help my son with his problems*

*Not just being told our son has autism but finding things to help now, not in a year's time*

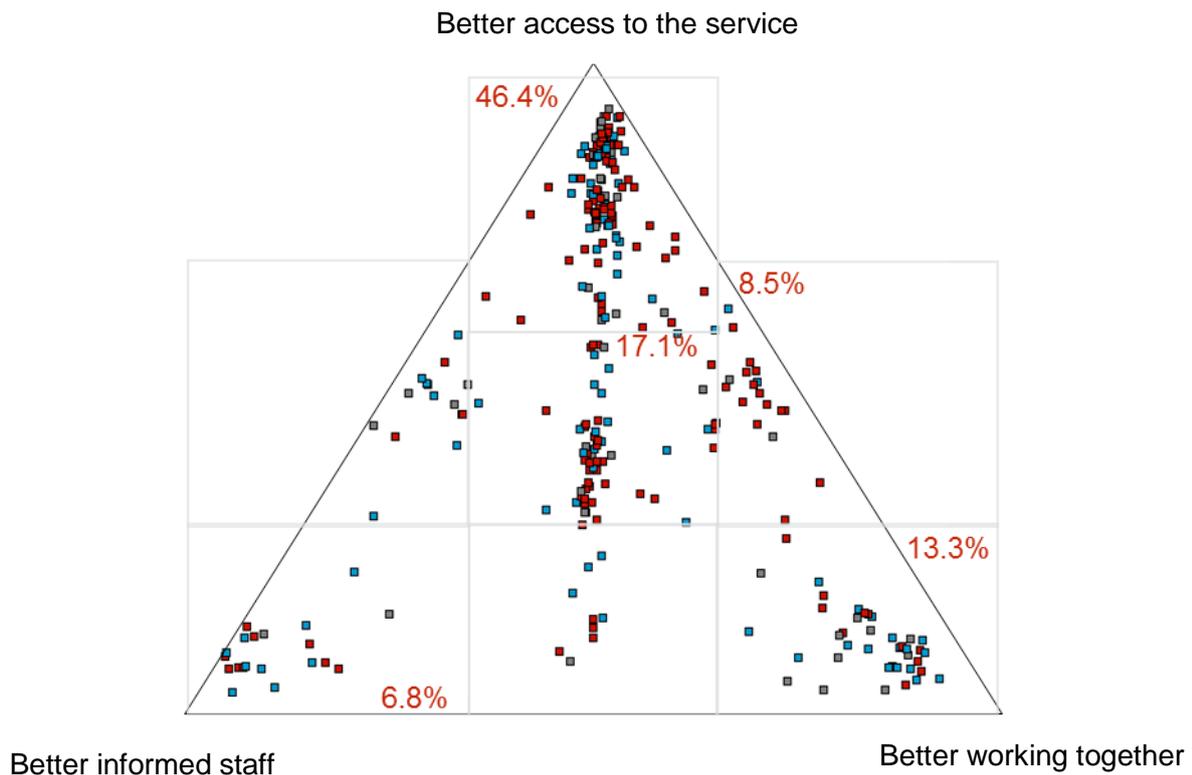
### Summary of discussion at workshops

- a) The patterns in the response to this signifier confirmed the issues which had already been discussed (as indicated in previous questions)
- b) There was some discussion around the area of girls regarding diagnosis and if there were gender differences



Participants at analysis workshop

## Question 9: What would have improved your experience?



### Analysis

1. There were 293 responses to this signifier, giving it a 89.3% response rate.
2. About half of the responses indicated that better access to the service would have improved the respondents' experiences.
3. Only 6.8% indicated that better informed staff would have improved the experience. Most of the experiences in this corner of this signifier also reported that their overall experience was very poor.
4. 17.1% indicated that a combination of factors would have improved their experience.
5. A small cluster of stories (8.5%) indicated that better access to the service and better working together would help to improve the experience.



Participants at analysis workshop

## Extracts from stories

*Nothing, I am so grateful for all your help and support Thank you*

*It would have been great if he had been picked up sooner in primary school. School life would have been so much easier and there would have been a greater understanding of why he behaved in the manner he did*

*I would have preferred to write down for the social worker what we needed and only deal with two or three contacts relevant to my child's age and severity of ASD diagnosis*

*A little more privacy*

*There are so many different groups and sections all with different initials and we feel almost completely in the dark, not sure who to contact just when we need it most*

## Summary of discussion at workshops

- b) The single most important issue discussed at the workshops in relation to this signifier was access to services.



Participants at analysis workshop

**Rating of overall experience:** Respondents were asked to rate their overall experience in the following categories:

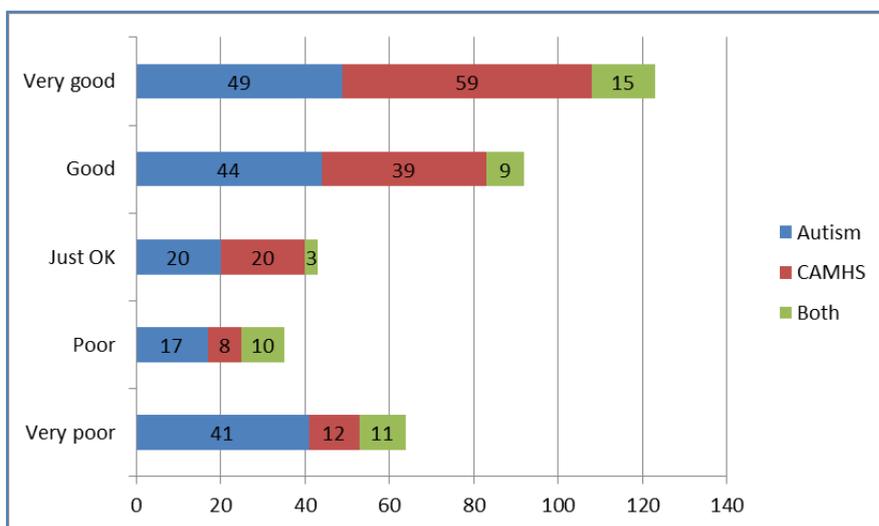
<b>Very good</b>	😊
<b>Good</b>	🙂
<b>Just OK</b>	😐
<b>Poor</b>	😞
<b>Very Poor</b>	😡

Young people at the initial stakeholder workshop to design the survey suggested using an emoji symbol in addition to the words

The overall results in relation to how people have rated their experience is as follows:

60% rate their overall experience as very good/good  
 12% rate their experience as just OK  
 23% rate their experience as poor/very poor

The breakdown of the rating for each service is as follows:

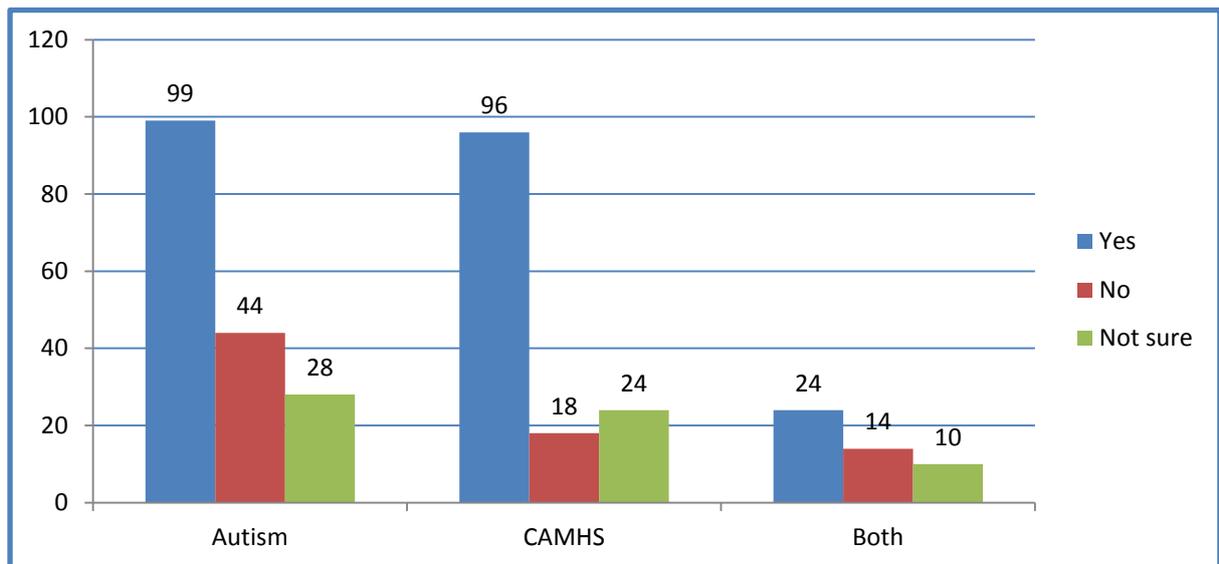


Respondents were also asked if they would recommend the service to a friend of family member, overall results are as follows:

**Would you recommend this service to a friend or family member?**

61% said they would recommend the service  
21% said they would not recommend the service  
18% said they weren't sure

The breakdown for each service is as follows:



## 5.0 Short survey

Some of the children/young people and their parents felt that it may be challenging for some to grasp the concept of “telling their story” and answering the accompanying signifiers. In order to address this, a shortened survey was designed with the children and young people. The project group agreed that this would be used with supervision from staff/parents directly following an appointment. A target of 10 per Trust was set, in total 23 surveys were returned, which was disappointing. There were three questions developed to capture the health and social care experience of the child/young person.

Results are as follows:

### Did you like the room?

---

<b>I liked it</b>	<b>21</b>
<b>It was ok</b>	<b>2</b>
<b>I didn't like it at all</b>	<b>0</b>

---

### Did the people help you?

---

<b>They really helped me</b>	<b>20</b>
<b>They were ok</b>	<b>3</b>
<b>They didn't help</b>	<b>0</b>

---

### When my visit was over I felt.....

---

<b>Happy</b>	<b>16</b>
<b>Ok</b>	<b>5</b>
<b>Sad</b>	<b>2</b>

---

## Extracts from stories

*The staff gave me an idea on what to expect in the coming weeks and were very helpful*

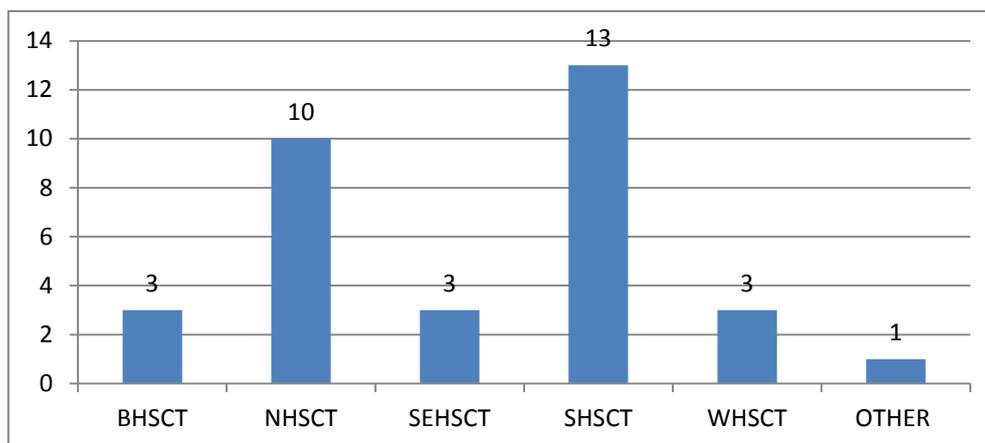
*You have already made things better*

The children and young people were also asked which three words would describe their visit to the clinic. These words are collated in a word cloud, which highlights most frequently used words in larger text



## 6.0 Staff experience

In keeping with the principles of experience based co-design which underpin the 10,000 Voices model, staff were also given the opportunity to attend and participate in the workshops and also to tell their story, using SenseMaker methodology. In total 38 staff attended the analysis workshop and 33 responses were received via SenseMaker from a range of staff, including doctors, psychologists, nurses, administration staff, speech and language therapists and occupational therapists. The breakdown of responses received from each Trust is as follows:



### Key messages from staff experience stories

In general, analysis of the staff experiences reflected and supported the experience of children/young people and their parents/carers. A recurring theme in virtually all responses was the demands and pressures on the service and how this can at times compromise the delivery of a good quality service. A number of key messages emerged from the analysis of the responses including the following:

1. The commitment of staff and opportunities for innovation, enhancing skills and learning. Staff also referred to being provided with opportunity to use their initiative and take forward ideas for innovation.
2. Staff seeing themselves as being advocates for children and families with a strong focus on improving the experience
3. Staff do experience positive feedback from service users, which unsurprisingly provides a further motivation for improvement

4. Importance of team working and deriving support from colleagues in what can be demanding, pressurised and challenging services.
5. Increased demands on staff which has had an impact on morale, feeling undervalued and not appreciated as well capacity to deliver good quality service, but despite this one staff member described the Autism service as:

*“The most innovative and dynamic service I have worked in. It is always looking at new and better ways to provide care to its clients”*

6. The impact of waiting times and the need for this to be addressed (relates to increased demand). There also needs to be a higher priority given to intervention prior to diagnosis. These issues were viewed as a key element to making a difference for children/young people and their parents/carers.
7. Importance of giving adequate time for Continuous Professional Development
8. Staff recognised that there are constant pressures and demands. Responses referred to feeling they were doing thankless work, undervalued and unappreciated. Despite this they acknowledged it can be a very dynamic environment with hard working colleagues, good opportunity for learning and stressing the importance of good clinical supervision
9. Recognised need for flexibility in delivering the service, for example extending the service beyond 9-5 and viewing this flexibility as improving family engagement for those families who may be ambivalent and also looking at opportunities to work with families in their own homes.
10. There was one perception that “commissioners” perceived only numbers and targets and not the individuals

## Extracts from staff experience stories

### **Title: Innovation of the sake of the child and family**

*All staff are very committed to the service and client group.....They spoke in glowing terms regarding the intervention they had received from the service and used phrases like life changing gave us our son back. I hear stories like this regularly and it motivates me to continually develop and improve the service*

### **Story title: Engaging with Parents**

*I like to help them make sense of their experiences and then guide them along the next stage of their journey*

### **Story title: Racing against the clock/swimming upstream**

*For me the intervention is the most important provision for a family and will make a difference to their lives. As a member of the team working with ASD every day I would like to see the focus to be on intervention rather than diagnostics.*

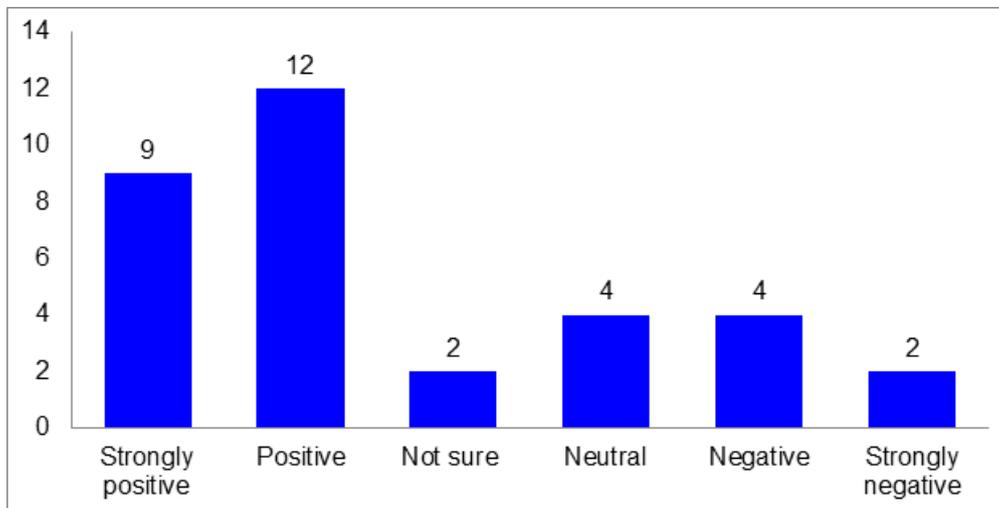
*...and acting as a support and advocate for the children and families I work with.*

### **Story title: Lucky dip - I pulled CAMHS**

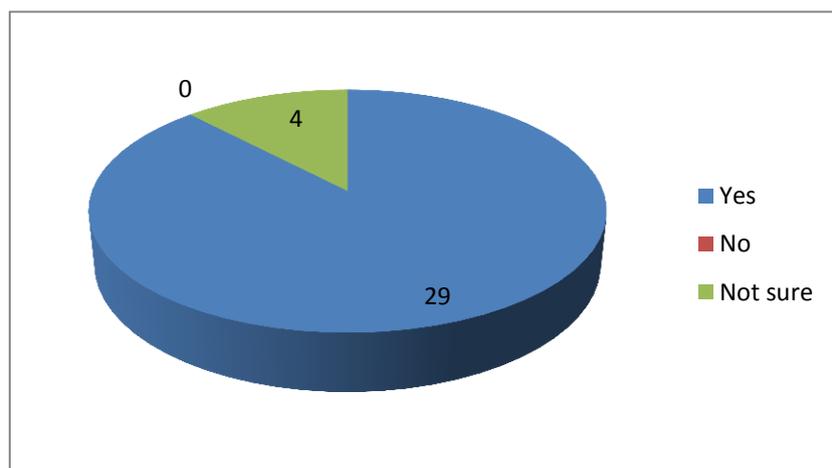
*It's one of the more demanding areas of work I... have experienced both in terms of service pressures and the dynamics of in a complex multiagency network around a young person. The young people are a pleasure to work with. The clinicians in CAMHS are focused and hard working. At times it can feel like thankless work- at other times it is very enjoyable work and it is a pleasure to see young people doing well as a result of input*

## Rating of overall experience

How would you rate your overall experience?



Would you recommend the service to a friend or family member?



## Key actions in relation to information from staff experience stories

It is clear from the messages in the staff experience stories that there is a need to address the current pressures and demands within the service. This needs to be progressed through a number of key actions:

- 1) The development of a consistent evidence based service model which is standardised across the region supported by appropriate integrated care pathways

- 2) Ensuring adequate resources and maximisation of capacity
- 3) A proactive application of a consistent learning and development framework with staff targeted for skill development consistent with evidence of what works in services and treatment interventions
- 4) Establish more effective approaches to encourage and support staff innovations for improving services

## **7.0 Overall key themes and impact on policy implementation**

The key themes that emerged from the overall information received are as follows:

1. The variance between
  - a. demand for services
  - b. service capacity
  - c. Skill mix
  - d. waiting times
  - e. access to services
2. The importance of 'personalising' the service, with a focus on recovery and hope for the future.
3. Extending the availability of support provision for parents, children and young people when needed, including contact point for outside of regular working hours, as well as information, signposting and self-help resources.

These themes were discussed in terms of how they impact on the implementation of the current policy priorities for CAMHS and Autism services. The policy priorities are detailed in Appendix 2. The analysis of the themes in relation to policy priorities highlighted the different stages of development of both services. It was the view of participants at the workshops that CAMHS had been addressing these issues over the last number of years and were 'further ahead' of Autism services.

The findings may also be considered against the standards identified in the Mental Health Service Framework which are relevant for CAMHS and Autism Services. While the Sensemaker survey was not an audit of service user experience against the standards, it is evident that there are aspects of the survey findings which indicate that the requirements of the standards are being fully met. Consequently it

is important that service developments and improvements continue to make reference to the standards and that these also are used as a benchmark for improvement.

## **8.0 What matters to children/young people/parents/carers**

The richness of the narratives received through the 10,000 Voices methodology help us to build up a picture of what matters to people in their health and social care experiences. There are very valuable learning points from stories which reflect positive aspects of care as well as insights into care experiences which can be improved. On the basis of the accounts and clear learning points we have been able to draw key messages and identify where improvements should be considered.

Under each of the key messages we have provided examples of stories to illustrate these messages as well as the proposed actions we will progress in order to ensure that we are planning and delivering services which focus on what will make a difference to the people who access and use our CAMHS and Autism services.

### **Key message - Having access to consistent, reliable and timely information**

#### **Story title: 16 months later**

*My son was referred ....ASD paediatric service we found the process frustratingly slow and was often faced with disbelief and treated as if I were exaggerating. ...The lack of information offered prior to diagnosis was incredibly poor therefore we are only receiving what little support there is now.*

#### **Story title: A Child with ASD does not mean life has to stop!**

*Very friendly environment. A lot of information & advice given. Felt more at ease & reassurance that I'm not alone, Pointed in the right direction for extra help. Excellent course! My child recently been diagnosed with ASD & at that time I did not fully understand this, from doing the course today I have learned I'm not alone & my child is able to achieve the same things as any other child*

#### **Story title: Great help**

*My son has recently been diagnosed with Autism and he is 4 years old. I have been helped greatly regarding receiving information about Autism as I had no idea of what*

*it was beforehand. I have now been equipped with tools and ideas of how to help my son.*

### **Story title: Turning point**

*My daughter was introduced to CAMHS in ...when she was diagnosed with anorexia nervosa, my daughter was very nervous and I was just thankful she was getting help. We met with a team of three people counsellors and dietician, they dealt with my daughter in a caring, understanding manner but able to get across the seriousness of her illness. We have been given amazing support by the team and given all the information on how to help in my daughter's recovery from trying to refeed her at home to gaining weight and dealing with her anxiety.*

### **Proposed actions: CAMHS**

1. To build on the family support database to ensure that children/young people/parents/carers have a trusted, reliable, quality assured, "go to" source of information, resources and signposting.
2. This website should include information about services and other available supports across the STEP CARE model continuum for the benefit of both service users and referrers about what is available for different needs.

### **Proposed actions: Autism Services**

1. Provide more information about what to expect at all stages, from referral to outcome, such as:
  - While on the waiting list provide information on what support is available, not just within health and social care systems;
  - What the assessment process will involve and how to prepare for it;
  - The range of supports available post assessment. This requires knowledgeable staff who can signpost and refer on appropriately as may be required;
  - Information available in a range of formats – verbal, written, pictorial and electronic.

2. Consider the development of a central multi-agency website which provides information on:

- local initiatives – e.g. sensory shopping sessions, swimming lessons, etc.
- social enterprise initiatives to provide employment and training opportunities for young people for an agreed fixed time

### **Key message - Having personalised and holistic support**

#### **Story title: Poor access to services, children left without support**

*Upon diagnosis of ASD there is little support or follow up from the HSC Autism Services, only support ever offered in past few years was 5 evenings of ASD training. Children and parents attend numerous assessments and appointments but once a diagnosis is obtained there is nobody to offer advice or support, especially for children who remain in mainstream education. The onus is on the parents to seek support, thus if parents do not seek support their children will lose out. No visible link up between EA Autism services and HSC Autism Service. Our child 'fell off' the HSC Autism services books, apparently said child was not known to the service meaning further referrals required. It is really a poor experience to date.*

#### **Story title: Timely and informed support saves money**

*You need to know what support you can receive, as this is not always presented clearly. When we were referred to the AS (>3 years ago), we did not realise we had to request the services that the consultant specified. We waited > 9 months to receive these services. We availed of all training/workshops provided and tried to cope as best we could. We are (or at least were) not pushing/demanding people, but have learned that we need to be (demanding) to get appropriate support for our son. We realise staff are doing their best and finances are stretched, but why should the children with better advocates get better service - we don't think it is fair.*

#### **Story title: Experienced and supportive CAMHS workers.**

*It was difficult to access CAMHS initially; professionals seemed to discourage us as parents from seeking referral eg GP said our son did not meet the criteria ie 'he was not suicidal or self-harming'....this is ridiculous. We managed to access the service*

*through private consultation... appointment followed fairly soon afterwards. Consultant Child Psychologist and Nurse Therapist allocated to us...both very knowledgeable and supportive though service mainly consisted of monitoring medication, appointments were relatively short and infrequent (2-3 monthly) with little exploration of impacts of condition on family dynamics, support on managing symptoms etc. ...however input was limited by refusal of son to attend for individual service which he could have availed of and benefitted from and this is still open to him. Nurse Therapist very supportive in liaising with school and CAMHS influential in getting diagnosis of ASD alongside ADHD which opened up additional support within the classroom setting...our son was 14 before he finally received this...he should have got such support when he was 4 or 5 ! While we would prefer he is not on medication we recognise that this is an essential part of his treatment regime.*

**Story title: A helping hand**

*Very good. My son was diagnosed in.... Since then we have attended a couple of workshops and have been allocated a support worker on his behalf. We have found the staff to be warm and supportive. As a family we are learning new skills to assist us in making his life run smoother and in turn ours. We are learning how to appreciate our little boy's quirks and he is achieving a calmer self every day. He had been seen prior to the session when he was diagnosed. We understand that he is a complex case to diagnose due to his copying/learned responses.*

*...is very high functioning. It would have been nice to have got the diagnosis sooner and accessed the support earlier, but at the end of the day since we have had access to the support it has been amazing - our support worker is amazing with us and our SW invaluable.*

**Story title: The lost little girl who is finding her way home.**

*With depression and self-harm and does help me to talk an express how I feel at CAMHS times it helps me and other times I just feel down to care but I do get the support from CAMHS that does help me.*

**Story title: Unsupportive**

*I have found that CAMHS are not willing to accept that one treatment plan does not fit all and that they are unwilling to accept that some children need to follow a*

*different path, they consistently quote text book and theory and are very unwilling to divert from that system*

### **Proposed actions: (CAMHS)**

1. Invest in community development, outreach, group work and early intervention
2. Make good use of Trust information systems and the opportunity provided by the regional Northern Ireland Electronic Care Record (NIECR) to enable shared record and information
3. Develop software Apps to support young people and parents/carers
4. Review the provision of post diagnosis intervention and follow up support.

### **Autism services**

1. Design autism services around the child, young person and their family ensuring that the services involved are co-ordinated across agencies, information is shared to reduce duplication and provide wider support for families and siblings. Support should be personalised and flexible recognising that “one size” does not fit all and that support and training should be appropriate to needs. There should be opportunity to “request” programmes or workshops to be developed, if not currently offered and parents and young people should be involved in the development and delivery of workshops, as appropriate.
2. Make better use of technology and innovation to improve experience
3. Pilot the provision of life coaching opportunities for parents and young people and review impact to inform service development in this area.
4. Develop specific “needs based” multi-agency workshops, designed in collaboration with parents, which would provide guidance, empower parents, children and young people to address issues which may require support, eg “ what to do if ...”.

5. Consider the use of peer support and positive role models using a broad spectrum of people from diverse backgrounds who have lived experience of autism.

### **Key message - Having access to wider support, including during out of hours periods**

#### **Story title: A Happy ending**

*I was worried about my 10 year old son who was so obsessed with me dying & death that he said he would kill himself if anything happened to me I was sick with my worry..... When I made the phone call & got an appointment I worried what they would think of me as a parent. I need not have worried, the 2 girls involved, social worker & child psychologist were excellent, they gave me support & advice gave me phone calls to see how I was getting on. The advice they gave me worked really well and even my husband understood. I am now a proud happy mammy with a very content son. Thank you so much*

#### **Story title: A little too late!**

*My daughter has experienced severe challenging behaviour in this past. Several professionals suggested a referral being made to CAMHS on her behalf this referral was made quite a number of times and took a few 'Years' to come into action. In the meantime I had to deal with these behaviours on my own as a single parent - with another younger child to protect. I had limited input from other professions and always advised to seek a referral from psychiatry. When the referral came through 'years' later my daughter's behaviour had become more manageable...I felt we survived on a trial and error basis for a long time. I would try something and if it didn't work try something else. I have no skills or training in this area and went in blind. I would have loved professional input at the very hard times. When we got the referral through, things were pretty quick with appointment times and the input that was given. The support we received was great and all staff involved were helpful and supportive. Unfortunately I felt it was a little too late though as most of the difficulties has already either been sorted or had calmed themselves. I found it excruciatingly difficult to get accepted for referral and I still don't fully understand why!*

**Story title: Frustrating**

*Once diagnosed my daughter has been left with No support, left to seek help ourselves. Also my son hasn't had any support either. It's like they make you wait ages then your child is diagnosed. Ok now get on with it...life. For our family this has been very frustrating.*

**Story title: Autism needs CAMHS involved.**

*The Autism services are excellent support in the direction of the external services but Autism services are trying and do have a community on their own. When it comes to CAMHS becoming involved they don't want to know beyond the ASD services. I'm the parent of 4 on the spectrum my oldest is nearly 19 yrs old. I'm still waiting 10 years for him to get there. His case never got to the door. He has limited eating disorder with select food and very high anxiety and another boy with extremely high anxiety who was born and displays it in a worrying way. I feel CAMHS need to help Autism.*

**Story title: Ok when everything stable but difficult in crisis**

*My son has been attending CAMHS for past 7 years as he suffers from chronic OCD and was diagnosed with ASD...over the years he has received various CBT therapies and attended family services as well. Up until last year service worked well as he was stable however a number of crisis and suicide attempts have made me question CAMHS usefulness in a crisis situation .I've often needed to call outside of our appointments and found it nigh on impossible or extremely difficult to get help when needed. ....anyone with a child with mental health problems will only ask for help when they are desperate like I was. It made the situation even more stressful and I know I would hesitate to call them again. I know calling for help on a Friday afternoon is not convenient but when you worried about your child time doesn't matter*

**Story title: Left to cope on my own**

*My teenage son has autism and does not like going out of the house. All support agencies keep suggesting CAMHS as the solution to my problems. When my son was first referred to CAMHS he was suffering from anxiety now this has turned into depression and because he has difficulty attending appointments we keep getting*

*referred back to the G.P. who in turn re - refer us back. I have had to get the Crisis team out because my son went into total shut down and would not engage with anyone including the crisis team. After a few weeks we were sent to appointments that I said would not work but had to comply with policy. The result was he did not attend the appointment and we were again referred back to doctor.*

### **Story title: Crisis Management**

*My child (Aspergers/ADHD, primary school age) began showing signs of extreme anxiety and talking of wanting to end his life. He was already part of the CAMHS service for monitoring of ADHD medication. I got in touch and was quickly rung back by his consultant who helped us embark on a series of interventions.*

### **Proposed actions: CAMHS and Autism**

1. Provide appropriate Out of Hours contacts and telephone support details
2. Consider the use of peer mentoring to support individuals
3. Develop consistent crisis response arrangements at regional and local levels, for providing more effective family support to stabilise crisis situations. This includes 24/7 consultant cover.
4. Single point of entry to ensure access to the most appropriate service/ services, based on assessed need and minimise multiple contact points for accessing individual services
5. Provide information about other services to empower parents and provide better co-ordination through referral, screening and triaging before coming into CAMHS
6. Pilot a "Talking Therapies Hub" which would also offer telephone advice/consultation.

## Key message - Having consistency in approaches to care

### Story title: My experience with CAMHS

*I have used this service since I was 14 and have had mixed experiences with it. It was difficult at the start as I was moved between three psychiatrists which was difficult trying to build a relationship with them. My experience with my first psychiatrist was very negative as she didn't understand me, lied to me and my parents and was pushing me to answer questions for a criteria for psychosis which I DO NOT have. I however had a good relationship with my psychologist as she was really trying to help me, which she did. She helped me immensely with CBT for OCD and depression and also helped support me for problems I had outside her field of expertise. I hold her in the highest regard however I have a poor view towards the psychiatrists.*

### Story title: Supporting client and carer

*My son recently became very depressed because he had opted out of education, had no job and was at home alone most days doing very little. He has been seeing the CAMHS counsellor for over a year now. I contacted the counsellor immediately to advise him about my son's low mood and the counsellor came down to see him the next day. He spent a considerable amount of time speaking to him, encouraging him to pursue the activities he is interested in, going for a run and doing exercises to improve his mood and trying to motivate him to re-engage in the education system. He kept in regular contact by phone with my son over the next couple of days. My son responds very well to the counsellor and takes on board what he says, much more than he does with me or his father. I really could not have dealt with this situation on my own. We had a prearranged appointment with the CAMHS psychiatrist. She was excellent with my son - really got down to his level and engaged with him calmly even when she needed to get him to curb his language.*

### Proposed actions: Autism services

1. Implement a Key Worker system which supports the family right through the care journey from the initial point of contact. The key worker role is to ensure
  - a. 'needs led' timely support, signposting and co-ordinating intervention
  - b. information of what is available across services
  - c. accessible contact –
    - o out of hours contact

- Staffed telephone
- Various means of communication including e-mail

**Key message - Ensuring regional equity of services (this theme emerged in particular in relation to autism services)**

**Story title: Reality**

*It's been an uphill struggle from the start. Prepare yourself for a fight, sorry, but true. Getting on the referral list is hit and miss. GPS play a big part and knowing the right words and terminology to use is a benefit. Be prepared for a long wait, and unless your child lashes out in school, you're on your own. Even after diagnosis, yes good educational courses are available to the parents, but any support for my children I've yet to discover.*

**Story title: An experience of two halves**

*My son has autism, a severe learning disability, ADHD, epilepsy and behaviour that can be challenging because of his profound disability. We moved to ....trust from a nearby trust nearly three years ago and that experience was really difficult. We were in receipt of direct payments and trying to get the two trusts to liaise to sort out the transfer was extremely difficult. It resulted in contact with my local MLA and it was then resolved quickly. However in order to access respite took over a year despite my son and our family being assessed as in need of this service. My son is now seen by the Learning Disability team, the disability nurse, psychiatry at ....social worker and behaviour team and accesses respite at.....*

*We have had a number of crisis situations recently and I have found that the whole team involved in his care works extremely well. The people involved are very empathetic and understanding of the difficulties and they work closely with the school. Practitioners are on the whole mostly very good; the problem is getting access to the services and support. Often issues such as direct payments go to panel but are not necessarily agreed and support not given. My experience of the practitioners involved in my sons care and support is very good, the problem is accessing the services initially and the pressure on what is a limited service which needs more resources urgently.*

## Proposed action for Autism services

1. Map the level of demand and capacity across Autism services by Trust area and Educational area to establish the current capacity of services and address inequity of provision across health and education.
2. Profile the current skill mix and in light of the future requirement for specialized skill sets develop a workforce plan to address and provide appropriate training.
3. Realign and redesign services that are targeted more towards the provision of support for parents and not confined to a confirmed diagnosis

## Trust Actions

In addition to the actions proposed above which apply regionally, individual Trusts have identified actions for progression based on the analysis of the information they have received. These actions are being progressed locally within the Trusts and will be incorporated into respective Trust service improvement plans and used to inform existing and future service delivery. Trusts' learning is based on the detail in individual stories and the identification of specific themes which were highlighted in order to identify areas for local action and improvement. Individual Trust reports are available on each respective Trust' websites (see Appendix 1)

A final message that cuts across all areas is how we can **maximise the use of resources**. In this regard we will ensure:

1. Resources commissioned for services are protected as far as possible and organisations held accountable for the use of these resources i.e. within HSC and the Education Authority.
2. There is an appropriate balance between diagnostic and support services
3. There is better collaboration across other agencies and departments, e.g. Education and Further Education, Department of Communities and Councils etc. that supports effective and joined up response to people's needs and makes the best use of all available resources and investment.

## **9.0 Conclusion**

The overall themes and messages from the Sensemaker Survey are being integrated into and will help to inform the Regional Draft Framework for Children and Young People's Developmental and Emotional Well Being Services (2016), ensuring that the voices of children, young people and their parents are being used to influence the future delivery of services.

While it is acknowledged that the participants in this survey relating to Autism and CAMHS services represent a small proportion of the total numbers of people who use these services, the narratives have provided a very rich source of service user experience information which have and will continue to inform regional and strategic work in both CAMHS and Autism services.

It is important that the findings from the survey and the implementation of local and regional action plans provides the baseline for service improvement and development and consequently it is intended that the survey would be repeated in 18 – 24 months' time to monitor the impact of the recommendations and subsequent actions.

## 10.0 Acknowledgements

### We would like to acknowledge and thank the following:

- Children/young people/parents/carers/staff who gave so willingly of their time to attend and participate in the workshops and took the time to “tell their story” by completing the survey
- Members of the project team:
  - Catriona Rooney, HSCB
  - Joy Peters, HSCB
  - Briege Quinn, PHA
  - Christine Armstrong, 10,000 Voices
  - Gail Mullan, 10,000 Voices
  - William Young, HSC Leadership Centre
  - Dr. Karen McWhinney, NHSCT
  - Heather McCarroll, NHSCT
  - Shirley Dennison, SHSCT
  - Hilary McFaul/Denise Caroll, SHSCT
  - Karen Clarke, WHSCT
  - Billie Hughes, BHSCT
  - Julie Walsh, BHSCT
  - Alison Wilson, SEHSCT
  - Marie Louise Hughes, Ed.LB
  - Gillian Gamble, Ed.LB
  - Anne McMurray Development Ltd

**References and useful links**

DHSSPSNI (2006) Bamford Review Report

DHSSPSNI (2013 – 2020) Autism Strategy

DHSSPSNI (2013 – 2016) Autism Action Plan

DHSSPSNI (2011) Service Framework for Mental Health and Well Being

Health and Social Care Board (2011) “Six Steps of Autism Care”

Patient Client Council Report (2012) “Young People Priorities

Regulation and Quality Improvement Authority (2011): Review of CAMHS

Stepped Care Model: CAMHS Service Model (The Stepped Care Mode) issued by DHSSPS available from:

<https://www.health-ni.gov.uk/publications/child-and-adolescent-mental-health-services-service-model-july-2012>

**Individual Trust reports are available on Trust websites as follows**

Trust	Website
Belfast Health and Social Care Trust	<a href="http://www.belfasttrust.hscni.net">www.belfasttrust.hscni.net</a>
Northern Health and Social Care Trust	<a href="http://www.northerntrust.hscni.net">www.northerntrust.hscni.net</a>
South Eastern Health and Social Care Trust	<a href="http://www.setrust.hscni.net">www.setrust.hscni.net</a>
Southern Health and Social Care Trust	<a href="http://www.southerntrust.hscni.net">www.southerntrust.hscni.net</a>
Western Health and Social Care Trust	<a href="http://www.westerntrust.hscni.net">www.westerntrust.hscni.net</a>

**CAMHS Policy Priorities: (reflected in the DHSSPS Service Model for CAMHS)**

1. Integration of CAMHS with wider children services – primary care, child health, social care and specialist CAMHS.
2. Early Intervention based on stronger partnership and collaborative working across and between sectors.
3. Improve access –Single Point of Entry (SPoE) and to identified vulnerable groups – Looked After children (LAC), Intellectual Disability.
4. Improve and capture service user experience.
5. Streamlining and consistency in provision and practice, (e.g. Managed Care Network for Acute CAMHS; Regional in-patient Unit, Trusts Crisis Resolution and Home Treatment Teams (CRHT); links with secure care and youth justice; interventions that are evidenced based)
6. Transitions to adult services.

**Autism Services Policy Priorities:**

1. Improve access to services including Early Intervention and support – independent of confirmed diagnosis.
2. Streamline assessment and diagnostic process.
3. Greater co-operation and integration between Health and Education.
4. Effective family support at key stages – primary, secondary and transition to adult services.
5. Emphasis on life coaching and mentorship to help and support individuals with autism and their families with daily living and supporting achievement of maximum independence.
6. Improve interfaces with other Departments and agencies in support provision.

**Survey Questionnaires  
(Main Survey and Short Survey)**



## EXPERIENCE OF HEALTH AND SOCIAL CARE IN NORTHERN IRELAND

### MAKE YOUR VOICE HEARD AND IMPROVE HEALTH CARE

Have you or do you care for someone who has recent experience in:

- **Autism Services for children and young people 0-18 years**
- **Child and Adolescent Mental Health Services (CAMHS)**

If you have had contact with these services **during the past twelve months**, we are asking that you would tell us about your experience by completing the following survey.

If you would like some help completing the survey or would like an alternative version made available please contact: 03005550115 ext 3210 (office hours).

*This is an anonymous survey and therefore we will be unable to respond to any individual experiences.*

*If you have a complaint or compliment or other comment about services delivered to you these should be directed to the relevant Trusts, using their formal processes.*

**Autism  
&  
CAMHS**

Please can you tick which **one** of the following **best** describes you:

- I am a young person who has used **Autism services** during the past 12 months
- I am the parent/carer of a child or young person who has used **Autism services** during the past 12 months
- I am a young person who has used **CAMHS** during the past 12 months
- I am the parent/carer of a child or young person who has used **CAMHS** during the past 12 months
- Other (please specify)

### **Your Experience**

Imagine you met with someone who is just about to start using CAMHS or Autism services. Describe a recent real experience you have had in the last 12 months that would help them understand what to expect.

What experience of yours would you share with them to show what works really well and what did not work well? Your experience can relate to any aspect of services, any setting – as long as it is recent and real!

**Please note that by taking part in this experience survey you are consenting to your anonymous information being used in a variety of ways, including reports and in presentations at meetings. Your experience will help to improve the services you and others receive, the design of services in the future and education and training of staff**

- I consent to my anonymous information being used as described above (please click in the box)

Write your experience in the box below. Don't worry about grammar, spelling or punctuation. Just describe the situation, what happened and the impact on the people involved. **Please do not name anyone.**

***My experience is.....***

Please add additional pages if necessary

Please give your experience a title?

What could have improved your experience?

## Next Steps

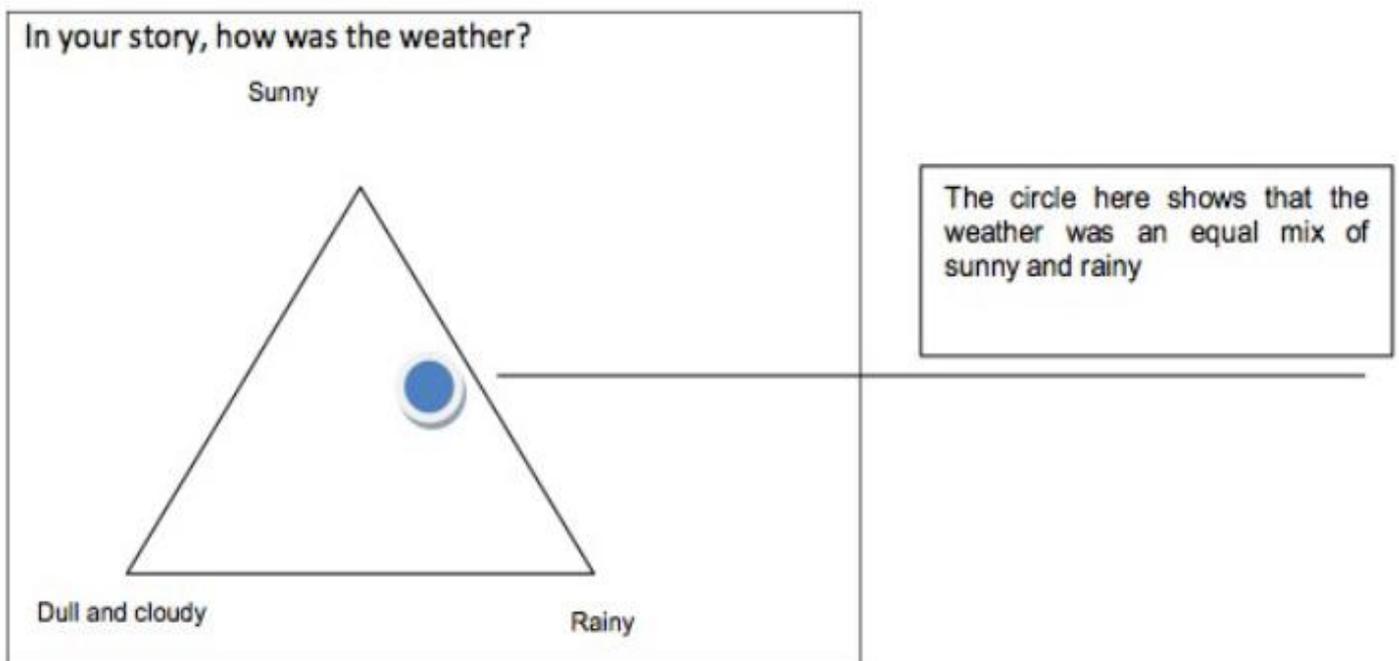
Please answer the triangle questions to think further about your experience.

For each triangle, please mark the spot in each triangle which best reflects how you see your story.

- You can choose one specific corner if that fits best, or between two corners or in the middle if it is a bit of all three.
- If none of the answers apply to your story, then just tick the N/A box (not applicable)

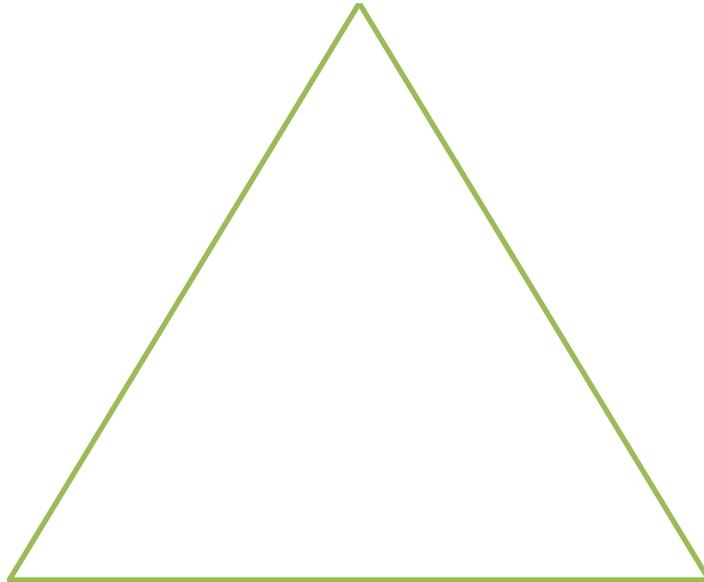
Please see the example below:

Example:



**Question 1: How did you feel about the services you received?**

**There when needed**

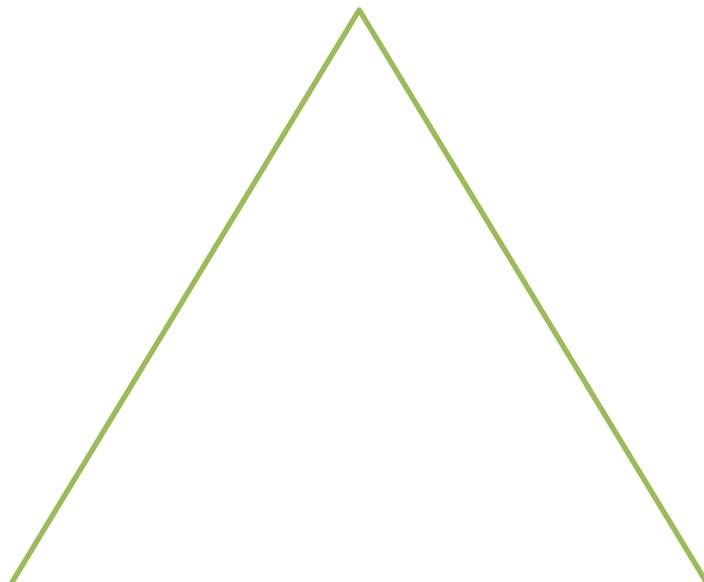


**Not what we wanted**

**Difficult to get**

**Question 2: How did the staff communicate with you?**

**Clearly and sensitively**

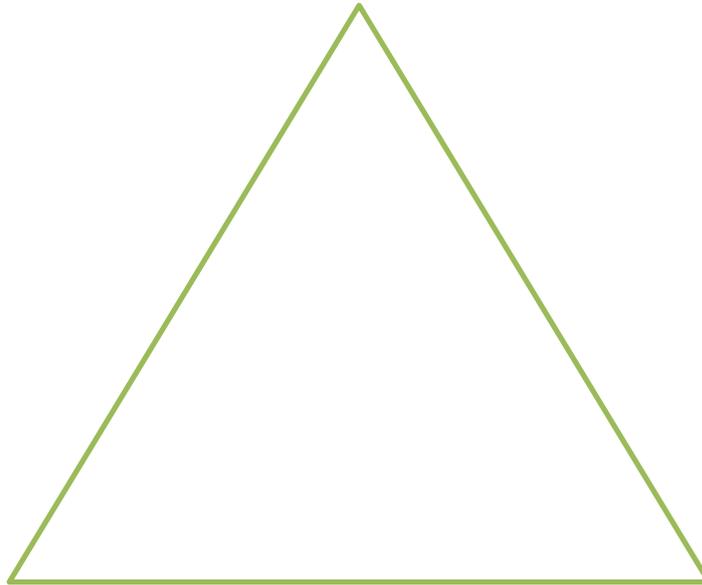


**Couldn't understand  
them**

**There was no communication**

**Question 3: How supported by staff did you feel in this process?**

**Felt alone**

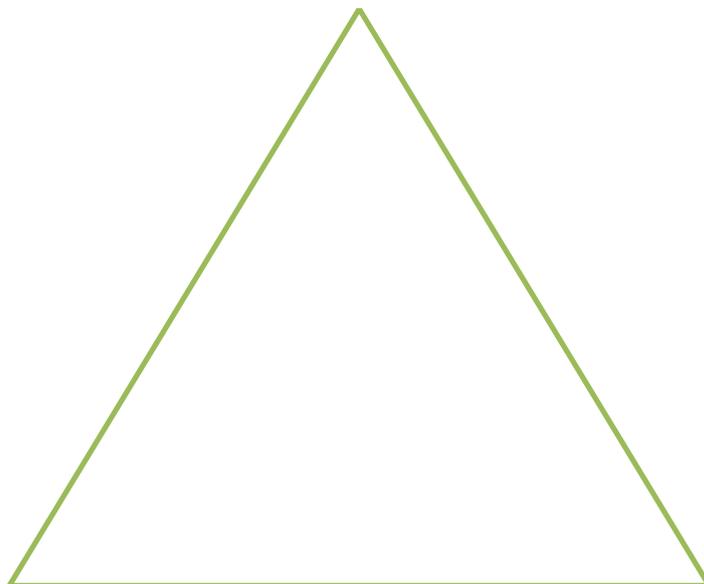


**Found support easily**

**Had to fight to get needs met**

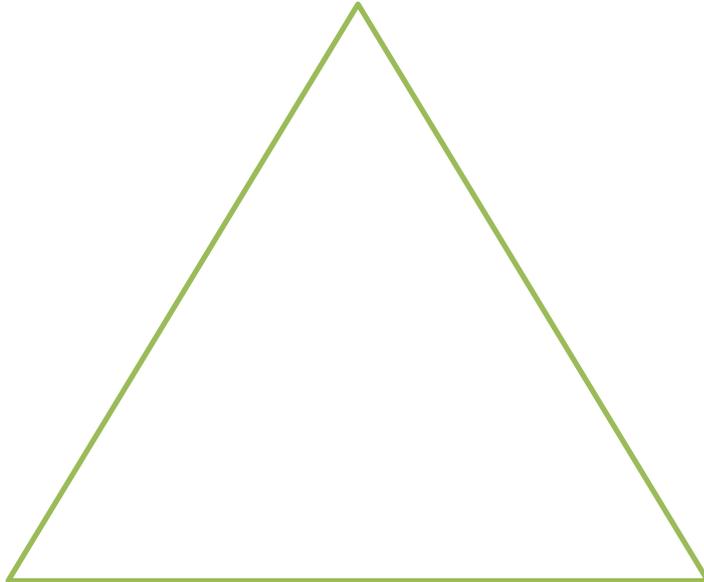
**Question 4: In this experience how involved were you in making decisions?**

**I was fully involved in all decisions**



I did **Question 5: How well did the staff you met work together to help you?**

**I had to tell them what was  
happening**

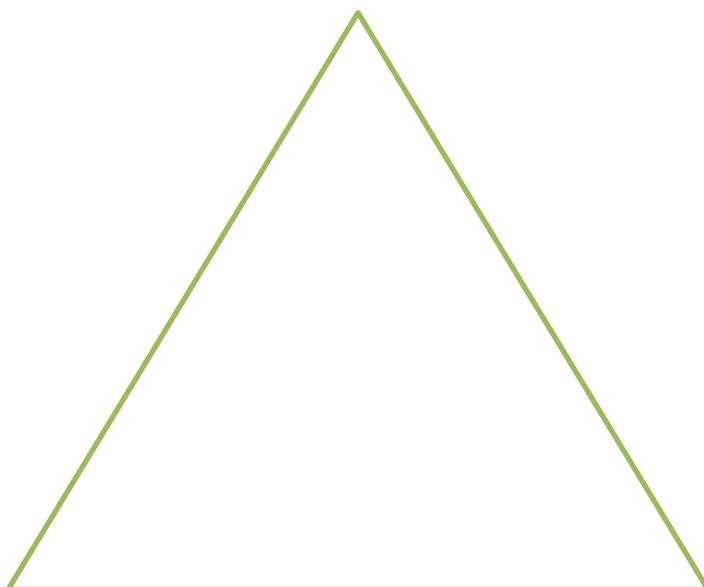


**They did not talk to each other**

**They all worked together to help me**

**Question 6: Following your experience did you feel.....?**

**Better**

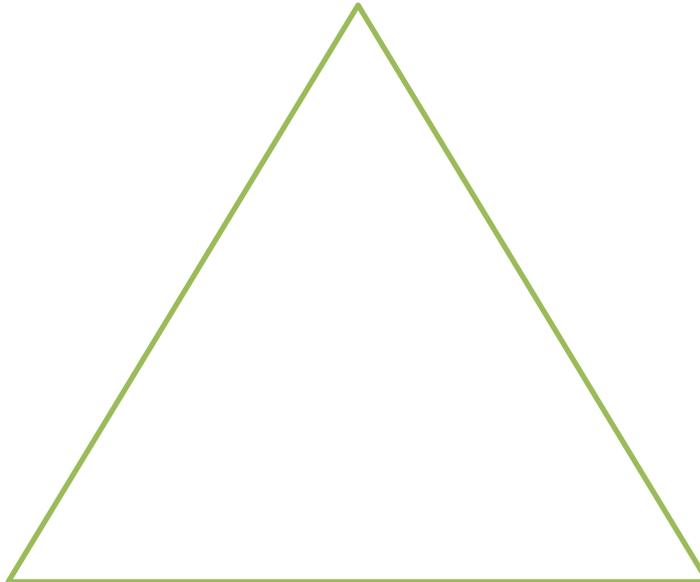


**The same**

**Frustrated**

**Question 7: Which area of your life was most affected in this experience?**

**Relationships with family and friends**

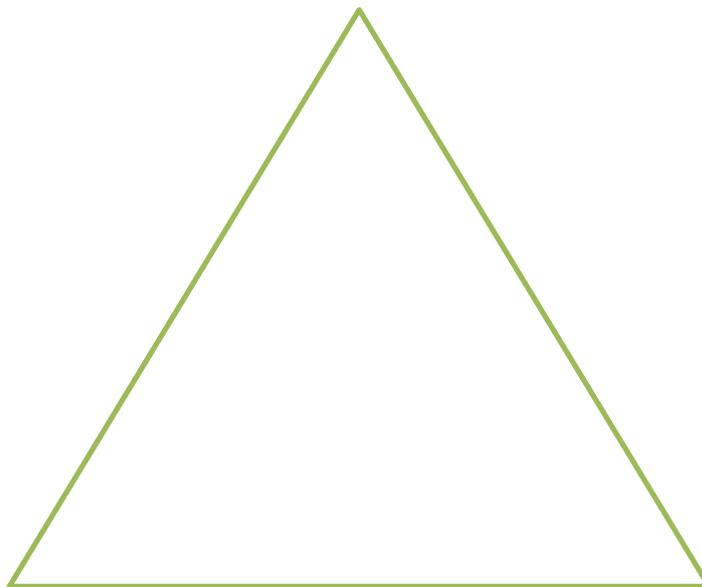


**Day to day living**

**School/Training/Work**

**Question 8: What was the hardest part of your experience?**

**Waiting to be seen**



**Outcome of the assessment**

**Not getting the right help**

**Question 9: What would have improved your experience?**



Overall how would you rate your experience?			Which service does your experience relate to?	
Very good			Autism	
Good			CAMHS	
Just ok			Would you recommend this service to a friend or family member?	
Poor			Yes	
Very poor			No	
			Not sure	

<b>Which Trust does your experience relate to?</b>	
Belfast Health and Social Care Trust (BHSCT)	
Northern Health and Social Care Trust (NHSCT)	
South Eastern Health and Social Care Trust (SEHSCT)	
Southern Health and Social Care Trust (SHSCT)	
Western Health and Social Care Trust (WHSCT)	
<b>Which setting does your experience relate to?</b>	
At Home	
In School	
Hospital ward	
Outpatient clinic	
Other (please specify)	

**Please indicate which of the following staff and services were involved in your experience**

Advocacy	
Autism therapist	
CAMHS practitioner	
Community Psychiatric Nurse (CPN)	
Community voluntary organisation	
Dietician	
GP	
Health visitor	
Nurse	
Occupational therapist	
Paediatrician	
Physiotherapist	
Probation	
Psychiatrist	
Psychologist	
Social worker	
Speech and Language Therapist	
Teacher	
Voluntary organisation	
Youth Justice	
Other (please specify)	

<b>What is the nature of the health issue - (please tick all that apply)</b>	
Addiction	
ADHD	
Alcohol misuse	
Anxiety	
Autism/Aspergers	
Bipolar disorder	
Depression	
Drug misuse	
Eating disorder	
Intellectual disability/ Learning disability	
Legal highs	
Not sure	
Obsessive compulsive disorder	
Personality disorder	
Psychotic illness	
Post-Traumatic Stress Disorder	
Requiring crisis / emergency support	
Schizophrenia	
Self-harm	
Undiagnosed	
Other (please specify)	

Finally, we would like to ask you some questions relating to the **person who has shared this experience**. All responses will be treated within the principles of confidentiality and anonymity. Use of monitoring information will involve statistical summaries only. No information which could be used to identify you will be made available in any way. All responses are processed in line with our strict and robust data protection obligations

Your Age: (✓)	Under 10 years	11-18 years	19 – 29 years	30 - 39 years	40 – 49 years	50 – 59 years	60 – 69 years	70- 79 years	80 years +	Prefer not to comment	
What is your country of birth?		Northern Ireland	England	Wales	Scotland	Republic of Ireland	Elsewhere, write in the current name of country				
What is your ethnic group?	White	Chinese	Irish Traveller	Indian	Pakistani	Bangladeshi	Black Caribbean	Black African	Black other	Mixed ethnic group	Any other ethnic group

**Gender:** Male  Female  Other (please specify) \_\_\_\_\_

**Disability:**

**In accordance with the Disability Discrimination Act 1995, a disability is defined as a physical or mental impairment which has a substantial and long-term effect on a person's ability to carry out normal day-to-day activities.**

Under this definition, do you consider yourself as having a disability?

Yes  No  Prefer not to say

**If yes, please indicate which type of impairment(s) applies to you.**

Physical Impairment, such as difficulty using arms or mobility requiring a wheelchair or crutches	
Sensory Impairment, such as blind/visual impairment or deaf/hearing impairment	
Mental health condition, such as depression or schizophrenia	
Learning disability, such as Down's Syndrome, Dyslexia or Cognitive Impairment such as Autism	
Long standing illness, such as cancer, HIV, diabetes, chronic heart disease or epilepsy	
Other (Please specify)	
Prefer not to say	

Thank you for taking the time to complete this survey, we really appreciate it.

If you are completing a paper copy, please return to the Freepost address below:

Public Health Agency

Nursing, Safety, Quality & Patient Experience

12-22 Linenhall Street

Belfast

BT2 8BS

### **Support**

You may find that you would like to have someone to talk to about your responses to the questions – a friend or family member, or someone who provides you with support. You can also contact the helpline: Telephone (**03005550115 ext 3210** Monday – Friday, 09.00am – 5.00pm).

## CAMHS / AUTISM (Short questionnaire)

Please tell us about your visit to the clinic.

---



---



---

Did you like the room?			
	I liked it	It was OK	I didn't like it at all
Tick one box			

Did the people help you?			
	They really helped me	They were OK	They didn't help
Tick one box			

When my visit was over I felt.....			
	Happy	OK	Sad
Tick one box			

What three words would describe your visit?

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_

How could we make things better?

---

**Thank you for giving your views.**

**They will help us to try and improve what we do.**