

‘How can we ensure every voice is heard?’

Enabling meaningful participation within survey research

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Thanks to all who have facilitated and supported the survey process within services

The 2017 survey team

Hazelle Campbell

Kate Leavy - Tracy Christie - David Harkins - Amy Donlan - Jill Ferguson - Rebecca Goodsir-
Vicky McMillan -LucyChetty - Eileen McDade - Karen Gracie – Joe Long

Autistic consultants

Ewan Dunn - Joe Coe - Teag Rennie - Gig Smith

Fife service user forum and focus group

The 2018 survey team

David Harkins

Margaret A Hamill - Aamina Krauser - Sam Knapp

Michelle Kelly - Laura Cook - Marie Hart - Eve Brown

Joanna Parnese - Iain Campbell - Rachel Forbes - Rebecca Goodsir

Vicky McMillan – Lucy Chetty - Jill Ferguson –Tracy Christie

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Overview - How can we ensure every voice is heard?

A principle of participation *for all supported persons*

Support to ensure informed consent and participant well being

Detailed individualised process of consultation and engagement

Structured use of workspaces to provide cognitive support and frame questions within structured discussion

Use of autistic interests to support relationship building, lower anxiety, support emotional labelling and decision making

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What is the Survey for?



Background

National Involvement Network developed the 'Charter for Involvement' to ensure supported persons have a say in The development of their services.

Scottish Autism signed in 2015: Our task – to produce an

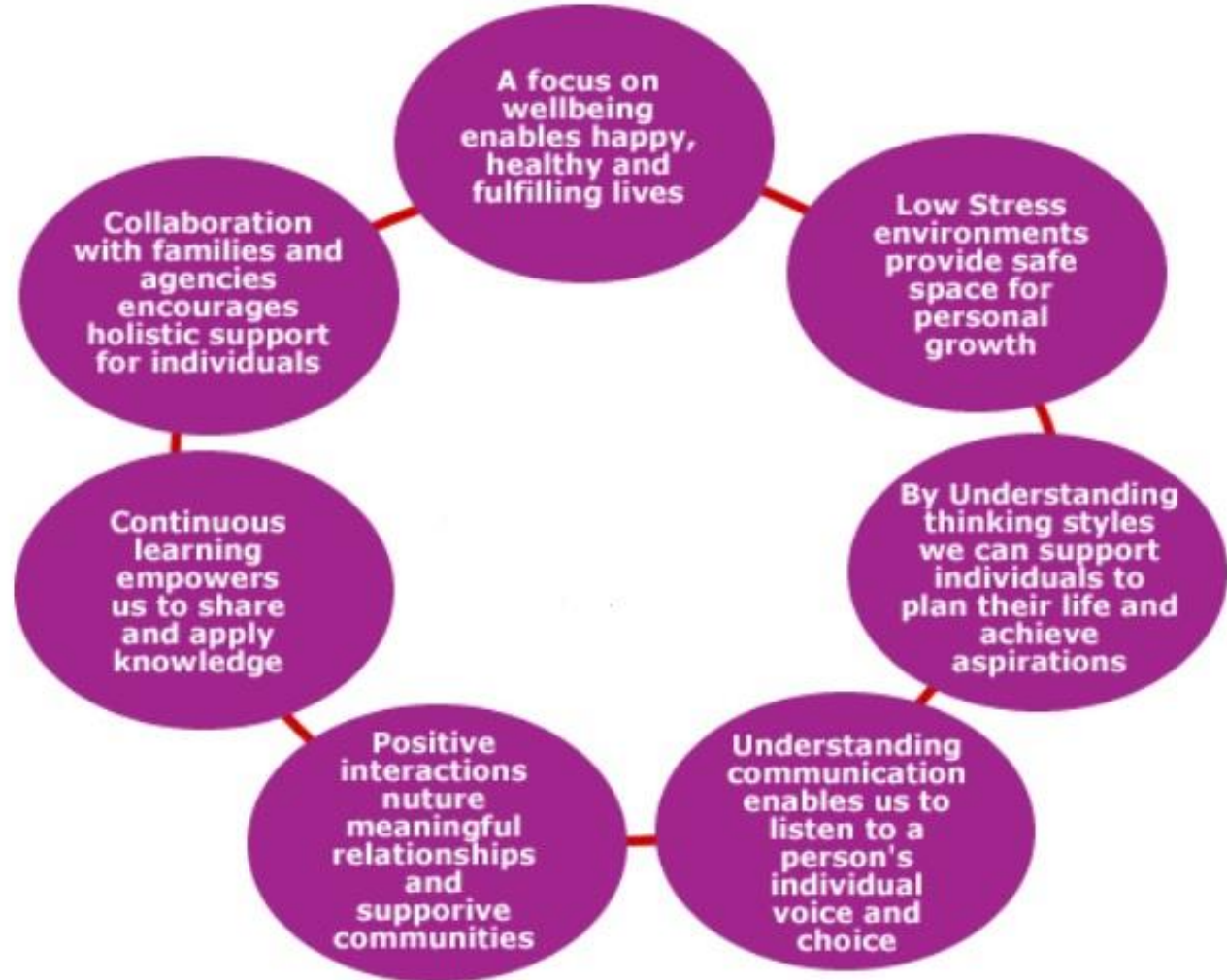
'Organisation-wide, systematic process that enabled our supported individuals to express their personal opinions and experiences about the services they receive'

"Are we doing what we say we are doing?"

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Framework for Ethical Practice



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Survey Subscales



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Challenges for Survey Development

Requirements:

- Standardised (measuring the same thing in different places)
- Individualised (should be able to include every individual)

Wanted to avoid:

- Excluding less verbal individuals or those with different communication styles
- Third party reporting
- 'People Pleasing'

Led to 2 versions of the survey:

- Standardised written version for those that can complete with minimal support
- An adapted version – for those with different communication styles and complex profiles

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The Written Survey

Completed using paper format or online survey

The 7 sections:

- Being happy and healthy
- The places in which Scottish Autism support you
- Understanding the way you think
- Having your say
- Social relationships and social life
- Learning and trying new things
- The people that support you

Social relationships and social life

13. We would like to know how well Scottish Autism support you to have the social life you would like and to have positive social relationships. Please tell us how far you agree or disagree with the following statements.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	N/A
Scottish Autism staff support me to meet new people or to attend social events if I want to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scottish Autism staff support me to keep in contact with people that are important to me, such as family and friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel positive about the Scottish Autism team that support me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel isolated and would like to meet more people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get time and space to be on my own if I want to be.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel valued within my Scottish Autism service and feel like part of a group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have the social opportunities that I desire.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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The Adapted Survey

- **Your Staff**
- **Your Service**
- **You**
- **The people in your life**

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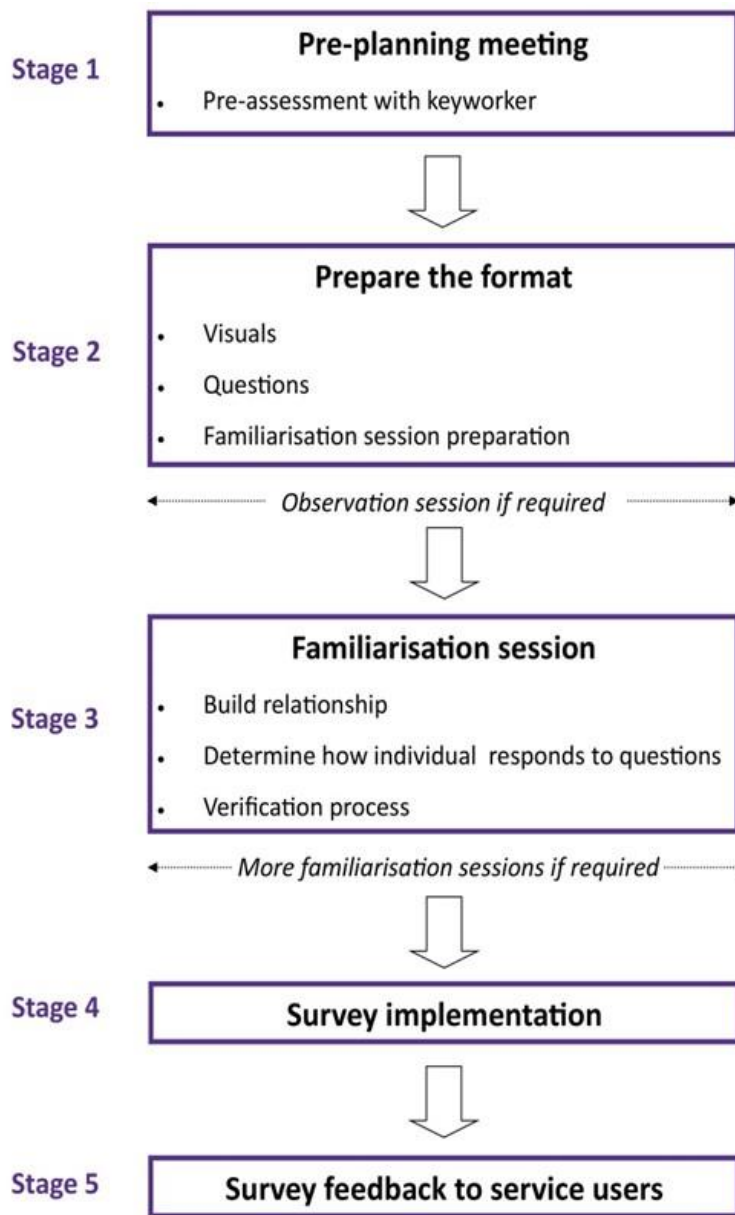
Adapted Survey Implementation

‘Engaging a representative sample meaningfully is better than including everyone tokenistically’

- **Random sampling of our support population**
- **Exclusion criteria not based on ability or profile but on wellbeing considerations**
- **Dedicated survey team**
- **Survey aim - 10% of supported persons within each region**
- **Thorough preparation with managers, staff and supported persons**
- **Time for observation and familiarisation dedicated as necessary**

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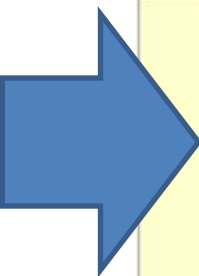


Adapted Survey Process

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Adapted survey workspace



Establishing question or statement using concrete references

Supporting question comprehension and engagement



Discussion Space

Supporting receptive language and communication

Emotional Labelling

Supporting cognitive / emotional response



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“Have you had a time when something went wrong in your service?”

10

?


Staff group photos



?

Who would you speak to if something was wrong?

Lee Ark (name)



Would you tell staff if something is wrong?

yes

No

11

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“Have you had a time when something went wrong in your service?”



Have you had a time when something went wrong in your service?

Yes / No



What happened and who did you tell?

I LOST CATH AT A SWIMMING POOL I TOLD MUM

I feel able to tell staff when something is wrong ..



Very able

Able

A little able

Not able

Not able at all

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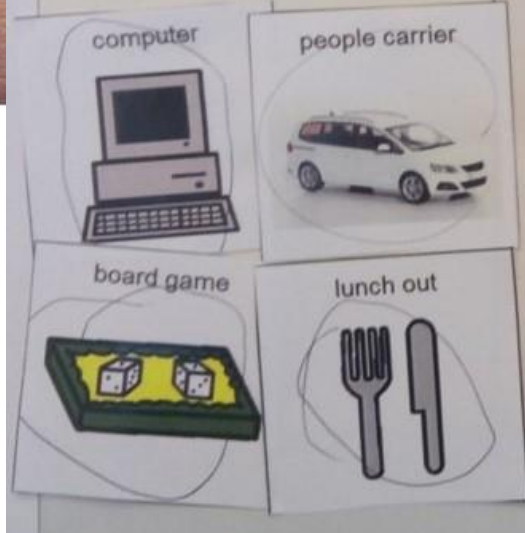


Adaptations in Practice



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What things make you happy about your work?




?

What things make you unhappy about your work?




My work makes me feel ..


Happy



Ok



Unhappy



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Adaptions in practice



Jack's Quiz Schedule 28.03.17

1PM Meet Alastair - "What's in the box?"



Quiz questions 1-3

5 minute Break - Laptop

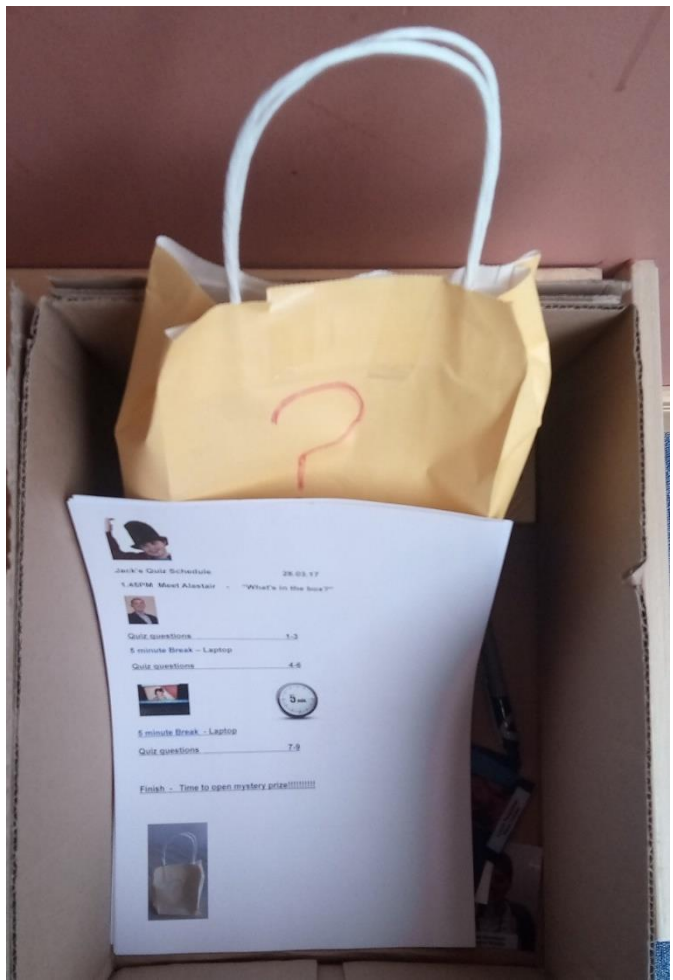
Quiz questions 4-6



5 minute Break - Laptop

Quiz questions 7-9

Finish - Time to open mystery prize!!!!!!!



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Adaptions in practice



Conference sponsors:



Adaptions in practice



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Adaptions in Practice

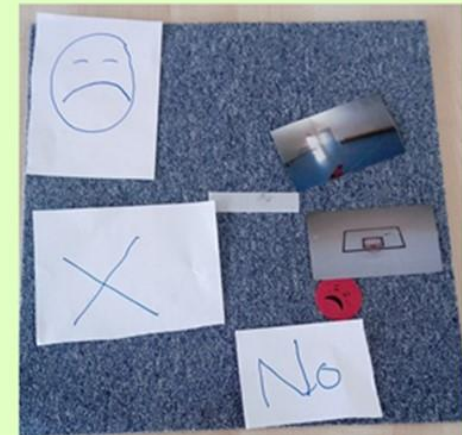


Where is this?



How does April feel when she is here?

Place photo on happy or sad mat



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Adaptations in Practice

“How does April feel in this place?”



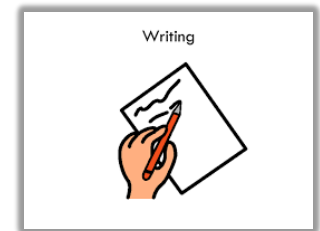
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Outcomes for supported persons

Ethical issue - Individuals decide whether they wish their answers to be passed on to their support teams:

Examples of changes already made:



- **Change in daily activities**
- **Work with support team on understanding autism**
- **Direct input into review process**
- **Adoption of survey techniques for engagement**

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What can you tell me about your autism?

I don't understand why I have got autism. Nobody has told.

I don't know why you had it since you a little boy.

In [redacted] I didn't like the noise of service

user called [redacted] I slept in room 10 and he was 11.

I was crying real tears.

I asked him to stop, he

made a lot of noises. Sometimes I can't sleep well.



Do your staff understand this?

was going to find out, but she will tell me why.

I think staff do

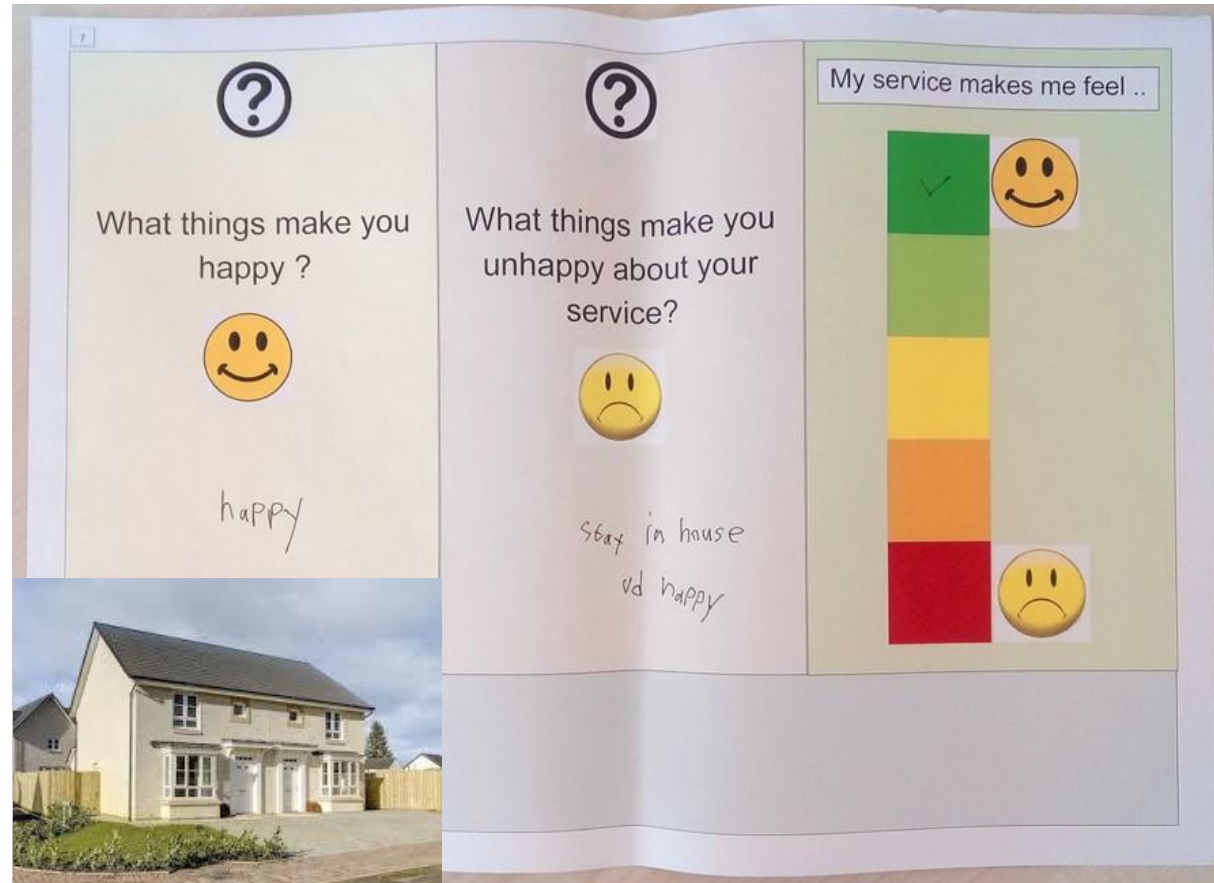
Staff understand my autism ..



Survey outcomes

Outcomes for supported persons

- Feedback from questions not previously considered or asked
- Sense of inclusion and being listened to
- Expectation of sharing experiences with others
- Experience suggests supported individuals exceed expectations



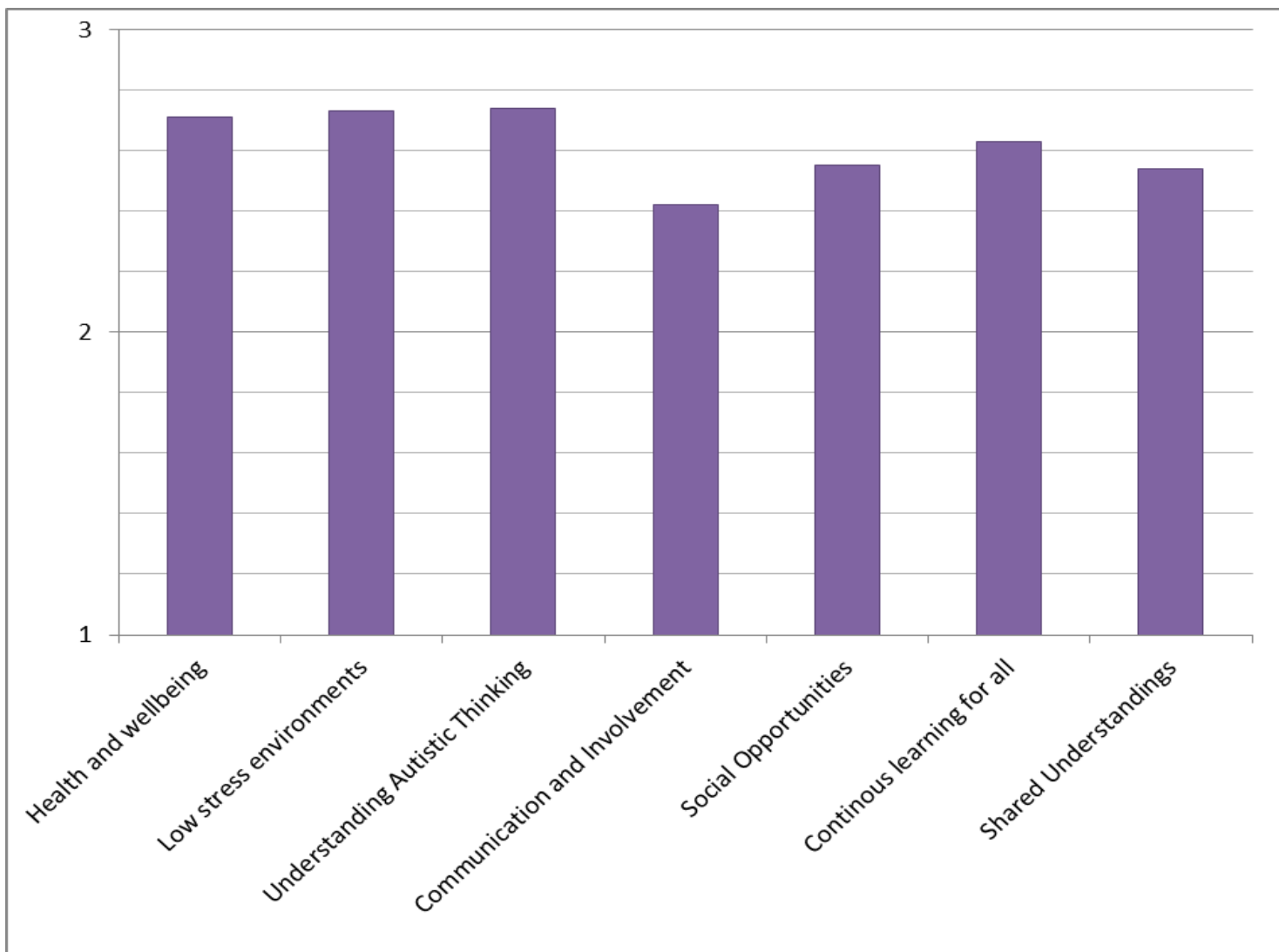
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2017 Combined Survey Results

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Summary of 2017 Survey Results

Positive findings - All subscales scored positive overall

**Individuals' relationships with support staff
Feeling safe and calm in service environments
Practitioners' understanding of autistic thinking**

Relative areas for improvement:

**Greater involvement for supported persons within staff selection
Greater involvement for supported persons in service documentation
Aspects of the survey highlighted a need for some supported individuals to better understand their own autism and their feelings and emotions
Supporting individuals in outreach services to access social opportunities**

Scottish Autism has identified key points for action which will address the findings of the survey

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2018 - Organisational challenges

In 2017 the majority of survey staff were managers or CPI staff

In 2018 survey staff were mainly service staff who received survey training.

Challenges included:

- Ring fencing of staff time - freeing up time to complete survey work
- Staff demands of their own service commitments – logistical issues
- Varying opinions about supported person ability
- Significant increase in project management resources in order to meet required targets – negotiating management structures
- Refinements to the process ongoing

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A principle of participation for all autistic persons regardless of profile

Support to ensure informed consent and ethical protection

Individual exclusions based on well being considerations rather than ability

Detailed process of consultation and design of individualised engagement

Use of workspace to frame questions and provide cognitive support as part of a structured, facilitated discussion and promote a considered response

Use of autistic interests to support relationship building, reduce anxiety and support emotional labelling

Meaningful feedback and research output

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