

A decorative graphic on the right side of the page consists of three blue circles of varying sizes and two thin blue lines. One line starts from the top left and extends towards the middle of the page, passing near the top and middle circles. Another line starts from the top right and extends towards the bottom right, passing near the middle and bottom circles. The bottom circle is the largest and is partially cut off by the edge of the page.

NHSCT -Spectrum Star Evaluation

Pilot Project Report

Spectrum Star is an outcome tool that enables organisations to measure and summarise change. The tool can help service users to make changes by providing them with a clear picture of the journey of change.

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Spectrum Star Pilot Project Report

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1. Introduction

The National Autistic Society (www.autism.org.uk) describes an Autism Spectrum Disorder (ASD) as “a life long developmental disability that affects how a person communicates with and relates to other people. It also affects how they make sense of the world around them”. This highlights that a ‘whole life’ approach is required for working with children, adolescents and adults with ASD. The Strategic Action Plan (2009) and the more recent Autism Strategy (2013 – 2020) and Action Plan (2013 – 2016) both state the significance of improving access and support to services for people with ASD, their families and carers throughout their life.

The Northern ASD Trust Forum implemented a plan from the Strategic Action Plan (2009) and a key aspect was the focus on transitions from paediatric to adult services. From this forum, a Transition Work Stream was set up in July 2013 to focus on this key aspect of the action plan. This pilot project was developed through this work stream.

Transition is a key theme in the Autism Strategy (2013 – 2020) and Action Plan (2013 – 2016). Strategic Priority 9 states the following:

Transform the process of transitions for people with autism, so that a co-ordinated approach is adopted in planning and providing for transitional needs, programs and supports for people with autism across their lifetime.

There is widespread recognition that people with ASD have difficulty with transitions across their lifespan. Therefore, transitioning from paediatric to adult services may be a disruptive and unsettling time for these young people. It is important to consider that this is a difficult stage for any young person, with transitions from school to further education or employment, moving into adulthood, and perhaps moving into independent living. Consequently, the services people with ASD receive within health and education should aim to be as seamless as possible.

The key aims within this priority are to:

- Ensure that transition planning takes account of the needs of people with autism.
- Deliver co-ordinated and integrated seamless care across transition stages for people with autism throughout their lives.

This pilot project aims to take these aims into consideration in the following ways by:

- Using a tool that involves the person with ASD in assessment and action planning for their own individual needs. The assessment process also involves participation from parents/carers to ensure their needs are considered and for support for the young people to complete action plans in the home setting.
- Involving professionals across paediatric and adult services as well as health, education and voluntary sector professionals.

2. Methodology

Participant Sample

Participants in this Pilot Project were individuals with a diagnosis of Autism or Asperger's Syndrome who were between the ages of 14 and 18 years old at the time of the project. The term Autism Spectrum Disorder (ASD) will be used to cover both diagnoses. An L-CID¹ search was conducted for individuals who met these criteria and who had been diagnosed between July and December 2013. This search provided a list of fourteen young people. An information leaflet (Appendix 1) and letter requesting a response (Appendix 2) was sent to these young people requesting contact with the Paediatric ASD Service to take part in this project. Parents were also offered a leaflet on telling the young people about their diagnosis (Appendix 3) prior to attending the project. Eleven of the families contacted the service to take part in this pilot project. In order to increase the sample size, a further two young people were invited to attend the pilot project whose parents attended the Paediatric ASD Service Parents and Carers Education (PACE) Programme 'Teen Life' course. This gave a total of 13 participants.

Three of the participants failed to attend their appointments. A letter was sent requesting contact with the Paediatric ASD Service if they wished to continue with the pilot project. They failed to contact the service and consequently they were not included in the pilot project. Therefore, there were a total of 10 participants in the project. There were eight male participants and two female participants.

Assessment

The Spectrum Star™ (© Triangle Consulting Social Enterprise Ltd) was chosen as the assessment tool for the pilot project. The Spectrum Star is a tool designed for supporting and measuring change. It is an outcomes tool that can help service users to make changes by providing them with a clear picture of the journey towards greater independence and choice, enabling them to take manageable steps and plot their progress along the way.

The Spectrum Star focuses on nine core areas, which were felt to be critical in enabling people with ASD to develop the life skills they require (see Appendix 4 for a sample Spectrum Star chart):

- Physical Health
- Living Skills and Self-Care
- Well-being and Self-Esteem
- Sensory Differences
- Communication
- Social Skills
- Relationships
- Socially Responsible Behaviour
- Time and Activities

¹ L-CID is the statistical database used by the Paediatric ASD Service in the Northern Health and Social Care Trust to record service user contacts, assessments, intervention and diagnosis.

This assessment therefore provided a tool that assessed the participants in a holistic manner, rather than focusing on only one area of their life e.g. speech and language.

For each of the nine core areas, there is a ten-point scale that measures where a person is on their journey towards independence. These are based on an underlying model of change; moving from where ASD is a major barrier to leading a positive life, a stable stage in the middle, through to choice and self-reliance at the top of the scale.

The Spectrum Star is based on the theoretical foundation that it empowers the service-user to understand and make the changes themselves. It also works collaboratively with the service user to assess their own needs. This is a key factor in choosing this tool for the pilot project as in paediatric services, it is typically the professional or parent assessing the needs of the child, but this tool ensures responsibility is given to the service user. Owen, Hayett & Roulstone (2004, p.56) state that children and young people with disabilities “have a unique knowledge of their own needs and circumstances, and this means that their contribution is invaluable”.

There is widespread evidence that people with ASD are visual learners, i.e. they process information more easily when presented in visual format than auditory format. The Spectrum Star therefore supports this by presenting a clear and visual representation of areas of strength and difficulty for the young person.

The Spectrum Star assessment naturally leads to discussions regarding next steps and action planning, integrating with intervention planning in a very accessible manner. The action planning provides very practical and manageable steps for the service user to move forward in the journey of change.

The core belief underpinning the Spectrum Star is that people with ASD who have developed a good understanding of their condition, good self-management and have understanding from those around them, can lead safe, satisfying and meaningful lives.

Procedure

The participants in the project were divided into two groups: a) Rapport Building group and b) Star Only group.

a) Rapport Building group (n5)

Eight of the participants were selected to attend the rapport building group, however three did not attend which left a total of five young people in this group. They were selected based on the criteria that they did not attend the Diagnostic Assessment Group² held in December 2013 and on a ‘first come,

² Diagnostic Assessment Group is a group of 8-10 children/young people of similar age, who attend over four consecutive days for 1 hour and 15 minutes per day. The group members take part in a range of social activities and games. This enables the Paediatric ASD team to observe the children/young people over a longer period to observe difficulties across the Triad of Impairment which are core to an Autism Spectrum Disorder.

first served' basis i.e. the first to contact the service who met the criteria were placed in the rapport building group.

The rapport group consisted of two sessions, one week apart, at Ballykeel Youth Centre where there was access to a range of youth facilities including pool tables, football and basketball nets. Each session lasted for 1 hour 30 minutes and was facilitated by two of the professionals running the pilot project. This was an unstructured social group that allowed the young people attending to choose the activities and topics for conversation. At each session, participants were provided with some information on the Spectrum Star and what would happen next.

Two weeks after the second rapport building group, each participant attended an individual appointment in the same venue. The Spectrum Star assessment was carried out by one of the group facilitators.

The rationale for having two rapport building sessions was for the participants and facilitators to become more familiar prior to individual assessment.

A review Spectrum Star was conducted 8 weeks after the initial Star.

b) Star Only group (n5)

The second group of 5 participants attended an individual appointment with one of the facilitators of the pilot project at a local health or educational facility for the Spectrum Star assessment only.

A review Spectrum Star was conducted 8 weeks after the initial Star.

3. Results

Note: for ease of reading, all figures discussed have been rounded off to one decimal place.

Table 1: Initial Assessment, Review Star and Change for the Rapport Building Group (n5)

The table demonstrates the average scores in each of the star areas:

- At the initial Spectrum Star Assessment (First), averaged across the 5 young people.
- At the review Spectrum Star Assessment (Second), after eight weeks.
- The amount of change between the assessment and review (outcomes).

Attended Rapport Building Group	First	Second	Change
Physical Health	5.8	7.2	1.4
Living Skills and Self-Care	6.4	7.2	0.8
Well-being and self-esteem	6	6.2	0.2
Sensory Difference	6.2	7.4	1.2
Communication	7.2	8	0.8
Social Skills	6.6	7.2	0.6
Relationship	6.4	6.6	0.2
Social Responsible Behaviour	8.4	8.6	0.2
Time and Activities	5.2	6	0.8
Average	6.5	7.2	0.7

Table 2: Initial Assessment, Review Star and Change for the Star Only Group (n5)

The table demonstrates the average scores in each of the star areas:

- At the initial Spectrum Star Assessment (First), averaged across the 5 young people.
- At the review Spectrum Star Assessment (Second), after eight weeks.
- The amount of change between the assessment and review (outcomes).

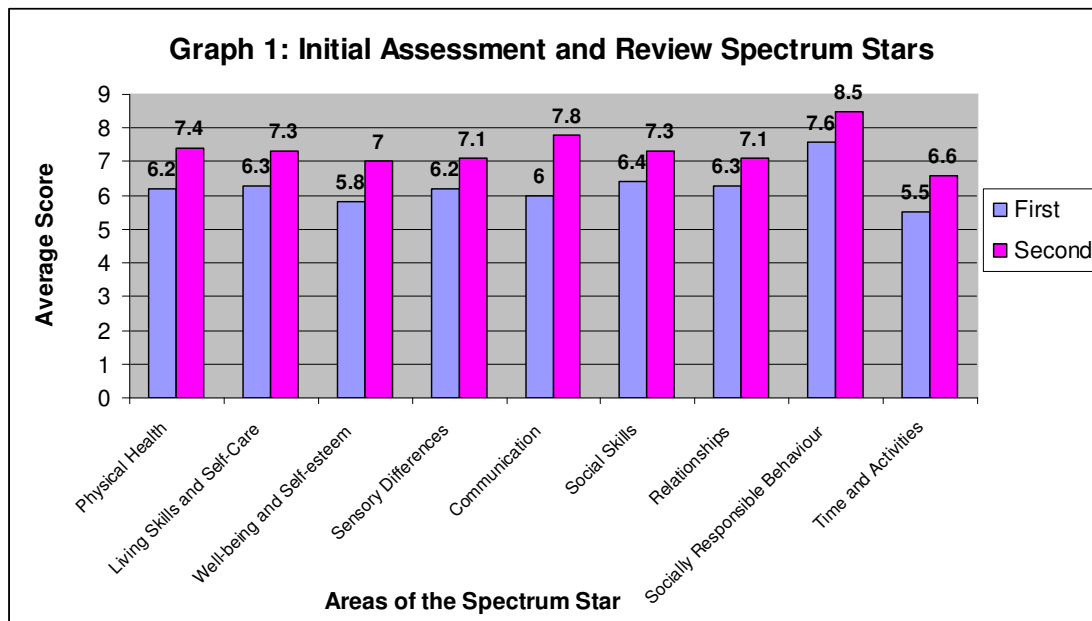
Attended Star only	First	Second	Change
Physical Health	6.6	7.6	1.0
Living Skills and Self-Care	6.2	7.4	1.2
Well-being and self-esteem	5.6	7.8	2.2
Sensory Difference	6.2	6.8	0.6
Communication	4.8	7.6	2.8

Social Skills	6.2	7.4	1.2
Relationship	6.2	7.6	1.4
Social Responsible Behaviour	6.8	8.4	1.6
Time and Activities	5.8	7.2	1.4
Average	6.0	7.5	1.5

Graph 1: Initial Assessment and Review Star scores for all participants (n10)

The graph demonstrates the average scores in each of the star areas:

- At the initial Spectrum Star Assessment (First), averaged across the 10 young people.
- At the review Spectrum Star Assessment (Second), after eight weeks.



For all participants (n10) the average scores were as follows:

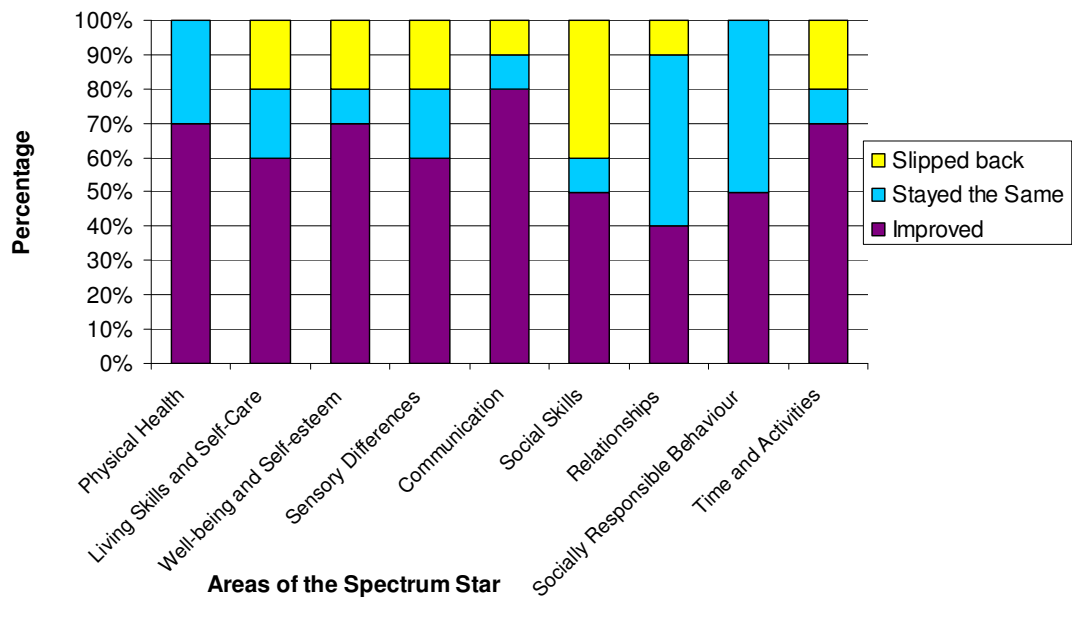
- First assessment: 6.3
- Second assessment: 7.3
- Change: 1.0

Graph 2: Percentage of change for all participants (n10)

The graph demonstrates the percentage of participants in each of the star areas who have:

- Improved between the initial and review Spectrum Star Assessment.
- Stayed the same between the initial and review Spectrum Star Assessment.
- Slipped back between the initial and review Spectrum Star Assessment.

Graph 2: Percentage of Participants Showing Change



4. Discussion and Interpretation of Results

What does this data say about the needs of people coming into this service?

- The overall score of the young people at the start of the pilot project was 6.2 (6.5 for rapport group participants and 6.0 for star only participants). This would indicate that typically participants were in the 'stable stage'. However it is important to note that individual participants were in different stages which are masked by the average mean of the group.
- At the start of the project, participants required most support in the areas of 'time and activities', 'well-being and self-esteem' and communication, indicating that these were the main areas targeted in individual action plans.
- The area 'Socially responsible behaviour' scored highly, indicating this was not an area of concern for the young people.

What changes were made?

- Firstly, it is important to note that on average, participants made improvements in all nine core areas of the Spectrum Star. The rapport building group improved by 0.7 and the star only group made overall improvements of 1.5. Average of 1.0 for all participants. This indicates that intervention provided through the action plans was successful.
- Although small variations were observed between the two groups, in general the areas that made the most improvement were 'Communication', 'Well-being and self-esteem', 'physical health' and 'Time and activities', key areas of need for participants.
- 70% of participants demonstrated improvements with an increase in their overall Star score.
- All participants either made improvements or stayed the same in at least five out of the nine Star areas.
- Differences across Star areas between the first and second star should noted. In the areas of 'physical health' and 'socially responsible behaviour', participants either improved or stayed the same, with no participants decreasing their score. In the other 7 areas, at least one participant 'slipped back'. In the area of 'social skills', 40% of participants decreased their score.

Were there differences between participants who attended the rapport building group and those that attended for the Spectrum Star only?

- In short, there was little difference observed between participants in each of the groups.
- Improvements were made across all Star areas for both groups, although those attending for the Star only did improve slightly more (rapport building group 0.7, Star only 1.5 average change).
- The rapport building group made more progress in the area of 'sensory differences' (rapport building group 1.2, Star only 0.6 average change) and the Star only group improved much more in the area 'communication' (rapport building group 0.8, Star only 2.8 average change).

5. Evaluation of Project

In order to evaluate the project and use of the Spectrum Star assessment, both the young people and parents were asked to complete an evaluation form on completion of the pilot i.e. after the review Star assessment (see Appendix 5 and Appendix 6 for young person and parent evaluation forms). These were designed to collect both quantitative data, via a five point rating scale, ranging from 'Strongly Agree' to 'Strongly Disagree' and qualitative data, through use of comment boxes with open-ended questions, from participants. Both evaluation forms followed the same structure, evaluating information sent prior to the pilot project, the Spectrum Star assessment, the review and general information.

Quantitative Data Analysis

Before the Star

Table 3: Responses to statement 'The information I received before the star was helpful' (percentage of responses).

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Young People	30%	70%	-	-	-
Parents	60%	10%	30%	-	-

The majority of young people and parents felt that the information provided prior to the project was helpful, with no one disagreeing with the statement.

Table 4: Responses to statement 'I was offered the star at the right time following diagnosis' (percentage of responses).

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Young People	40%	40%	-	10%	10%
Parents	50%	20%	20%	10%	-

The majority of young people and parents (75%) agreed that this assessment was carried out at the right time. Thirty percent of young people/parents disagreed with this statement with 20% remaining neutral. As some of the participants were selected through their parents' attendance at the PACE 'Teen Life' course, this meant that there was variation in the time post diagnosis, ranging from several months to several years. This may account for the young people and parents who disagreed with this statement.

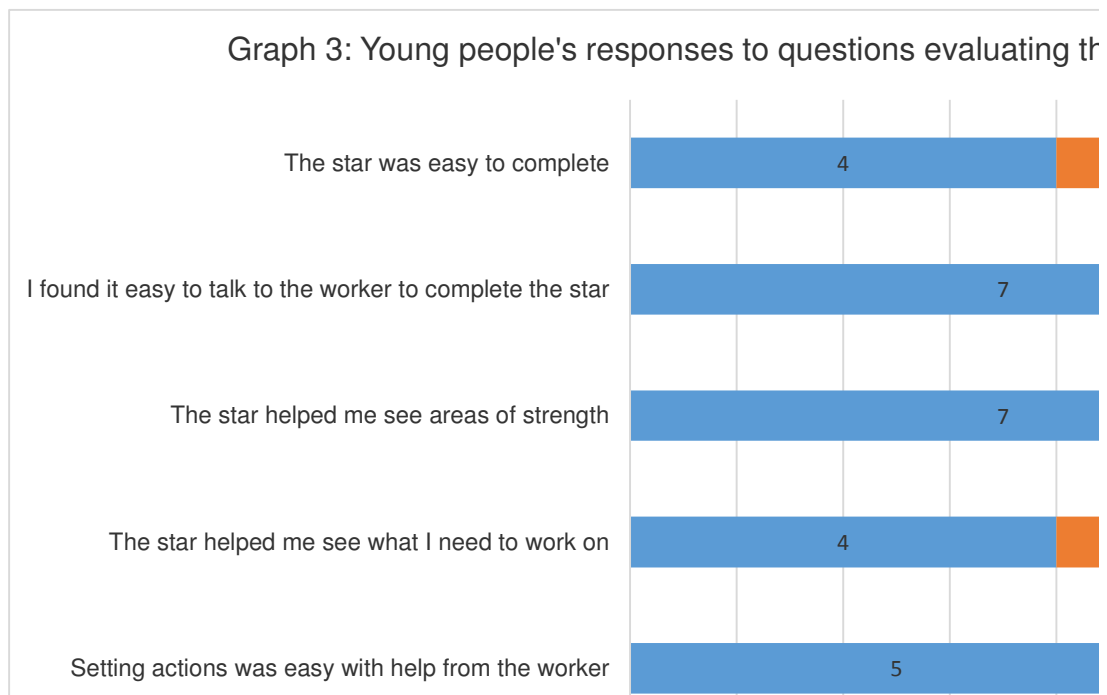
As it was imperative that the young people participating in the pilot project knew about their diagnosis of Autism/Asperger's Syndrome before completing the Spectrum Star, parents were offered an information pack on telling the young person about their diagnosis. This pack was designed by the Paediatric ASD Service and contains an information leaflet (Appendix 3). Parents were then asked in the evaluation form if they found this pack useful. Seven

parents used this pack and all of them agreed that it was useful, with two parents strongly agreeing and five parents agreeing.

Spectrum Star Assessment

The questions in the evaluation forms concerning the Spectrum Star assessment were different for the young people and parents, therefore responses from the young people will be considered first, then parent responses.

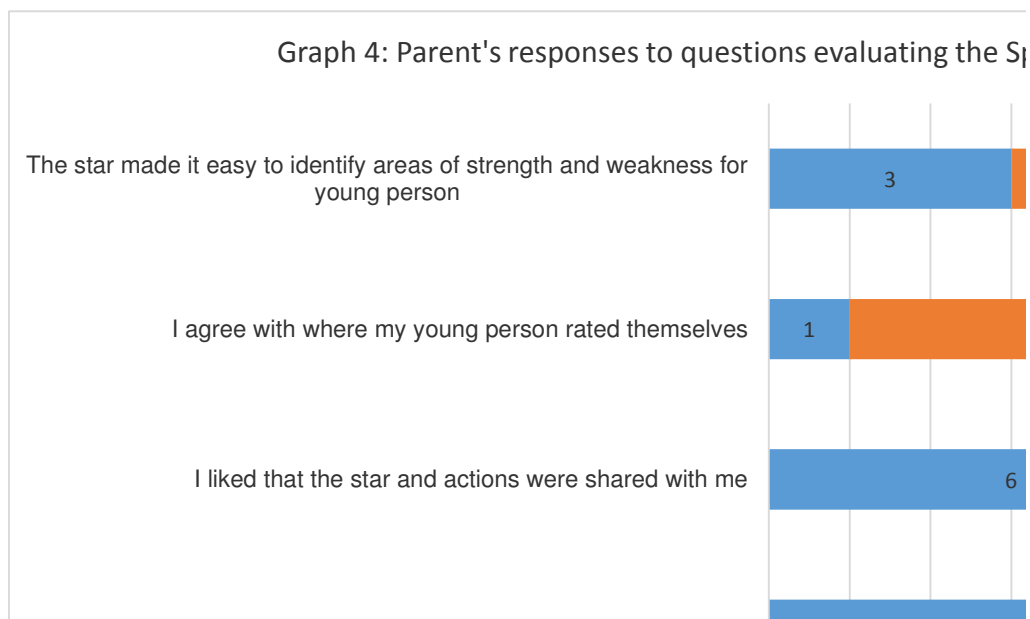
Graph 3: Young People's responses to questions evaluating the use of the Spectrum Star assessment (n10).



It is firstly important to note that the majority of the responses from the young people were positive (rating of strongly agree or agree) regarding the use of the Spectrum Star Assessment. This indicates that the Spectrum Star assessment is an appropriate tool to use with this client group.

The only statement that did not produce a positive rating from the majority of the participants was when they were asked if they liked sharing their star and actions with their parent(s). This may be indicative of communication and relationship difficulties with parents, as often identified as an area of difficulty within the Star assessment. It is also important to take into account the age of the participants and common teenage attitudes of sharing information with parents at this age. However, for purposes of action planning and parents continuing to work with the young people using the Spectrum Star in the home environment, it is vital that the star is shared with those with parental responsibility.

Graph 4: Parents responses to questions evaluating the use of the Spectrum Star assessment (n10).



Parent evaluations demonstrate overwhelming positive feedback for use of the Spectrum Star assessment, with only three neutral responses in total and no responses disagreeing with the statements.

It should be noted, that in contrast to the young people’s responses on sharing the Star and action plan with parents, 60% of parents strongly agreed and 40% agreed that they liked that these were shared with them.

Rapport Building Group

Five participants attended the Rapport Building group at Ballykeel Youth Centre prior to carrying out the Spectrum Star Assessment. When these young people and their parents were asked if they found this useful, all responses were rated as ‘strongly agree’ (2 young people and 3 parents) or ‘agree’ (3 young people and 2 parents).

Review

The review Spectrum Star Assessment was carried out eight weeks after the initial Star. Young people and parents were asked if there was enough time between the first and second Star and 100% of responses were in agreement.

In addition, the young people were asked if it was useful having the same worker to complete the both stars and 70% agreed, one participant (10%) rating this statement as ‘neutral’ and 20% did not complete a response.

General

This section asked participants to consider the accommodation and appointment time. 95% of young people and parents agreed that the accommodation was good (one 'no response'), showing no variation between Ballykeel Youth Centre facilities (Rapport Building group) and Health or Education facilities (Star only group).

All appointment times were offered during normal working hours of 9am and 5pm and the project was held during the school term. When asked about the time of the appointments offered, again the majority of responses from young people/parents were in agreement that the time suited, 30% 'strongly agreeing', 55% 'agreeing' and 10% 'neutral' (5% 'no response').

Qualitative Data Analysis

Young People's comments

The young people were asked a range of open ended questions to gather further information on the Spectrum Star Pilot, as follows:

Question 1: What did you like about the Spectrum Star Pilot?

- "It helped me."
- "I liked being able to share my problems with someone and sorting them out in an easy way."
- "I found it interesting and fun to do because I got to learn about myself."
- "The way it shows your weaknesses."
- "I liked how it got me to go out and improve myself socially and improve my faults."
- "It helped me find areas in which I wasn't overly satisfied with and it has encouraged me to do new things."
- "The ease of its use and simplistic design."

All comments were positive and the young people highlighted positive aspects of the Spectrum Star assessment including how visual this assessment is to highlight areas of strength and weakness. Participants also appeared positive in using the assessment as a motivator or starting point to work on areas of difficulty.

Question 2: What did you find most helpful or useful?

- "The way we wrote down things to help me."
- "Seeing the bits that I had improved on and trying to improve others for the future."
- "Everything was helpful and useful for me."
- "Getting [the worker] to talk to my mother."
- "The advice given to me by the worker."
- "Keeping and recording areas in the action plan."
- "The easy analysis of different stars from different periods."

Again the theme of how visual the Spectrum Star assessment is for the young people to see how they are functioning in each area in the initial and review Star and having a clear and written action plan to follow. It is also evident that participants benefited from support from the worker in completing the star and helping to communicate with parents.

Question 3: What did you not like about the Spectrum Star Pilot or find unhelpful?

- “I didn’t like the action plan because bits of it I wasn’t sure on how to do but generally I found it alright.”
- “Goals aren’t very useful.”
- “The vagueness or oversimplification of certain areas.”
- “I did not find anything unhelpful with this pilot.”
- “Nothing.” (2 young people wrote this in response to the question)

Only three participants highlighted areas of the pilot which they did not find helpful or did not like. Three other young people stated there was nothing which they did not like or find helpful.

Question 4: How else could the Paediatric ASD service have helped you following your diagnosis?

- “By sending me/telling me more information about what it is exactly and ways to cope with it.”
- “I don’t really know, they did their jobs well.”
- “Told me what I’m supposed to do.”
- “The service has helped me with everything possible.”
- “Possibly offering more support services.”








Comments made in response to this question were positive in nature. The key theme that emerged was that the young people would like more direct work to help them manage their ASD.

Additional Comments:

- “Just saying thank you for helping me and helping me realise that I am capable to do things myself.”

Table 5: Responses for ‘how you are feeling at the end of this pilot’ by the young people (n10).

At the end of the evaluation form, participants were asked to circle an emotion picture/label that best represents how they feel at the end of the pilot.

Emotion picture and label	 Happy	 Disappointed	 Hopeful	 Confused	 Ready to Start	 Frustrated	 Other (label)
Number of young people	3	1	3	-	1	-	2 “great but nervous” “Neutral”

It is evident that the significant majority of the young people felt positive about their experience of the pilot project and use of the Spectrum Star Assessment.

Parent's Comments

Parents were asked the same open ended questions to gather further information on the Spectrum Star Pilot, as follows:

Question 1: What did you like about the Spectrum Star Pilot?

- “That [young person] was able to talk about her difficulties.”
- “Pointed out areas that needed attention to my child as well as myself.”
- “I have someone to talk to.”
- “Indicated problems.”
- “Plan put in place – easy to follow for my son.”
- “It was a visual aid which not only helped [young person] but also myself in showing where [young person] was having his most difficulties.”
- “[Young person] liked making his own decisions and took pride in achieving this.”
- “It help to show his strengths and weaknesses.”
- “Informative about how my son was feeling referring to certain areas of concern for him.”

Similar to the themes arising through the young people's evaluations, the visual presentation of the Spectrum Star assessment was reflected through the parent's comments. Another theme from the comments is giving the young person the opportunity to identify areas of strength and weakness rather than parents/professionals assessing how they are managing. Parents highlighted that the Star recognises areas of difficulty and provides a starting point for the young person and parents to work on.

Question 2: What did you find most helpful or useful?

- “Being able to go through the difficulties with [young person] and [worker].”
- “[Young person]’s independent evaluation of himself.”
- “The advice for [young person].”
- “Scoring system.”
- “My son’s idea how he coped with some of the points.”
- “The whole thing – it was easier to understand that previous “chatting” appointments – again being visual really helps.”
- “It helped me understand his thoughts on things.”
- “To help identify problems.”
- “Having a plan set out to improve the situation for my son.”

As per question 1, the same themes were arising.

Question 3: What did you not like about the Spectrum Star Pilot or find unhelpful?

- “Just chatting afterwards.”
- “We as parents were not asked where we thought our child was on the star.”
- “My son was able to say how he thought things were.”
- “Nothing.” (3 parents wrote this in response to the question)

Overall, parents found the Spectrum Star Pilot to be helpful, with 3 stating that there was nothing they did not like or find unhelpful. One theme that parents did not like was that they disagreed with how their young person had rated themselves and there was not opportunity for parents to rate the young person on the star.

Question 4: How else could the Paediatric ASD service have helped your YP following the diagnosis?

- “[Young person] was diagnosed many years ago and this is the first real intervention and help that we’ve had therefore earlier intervention.” would have been great.”
- “More links with education.”
- “More activities that involve [young person].”
- “I feel for my son’s diagnosis they did everything needed to start him to become a well-adjusted teenager with Asperger’s.”
- “Maybe a course like the parents one on what is ASD.”
- “The service was very helpful.”








The main area for additional support raised by parents was the need to have more direct intervention with the young people themselves rather than indirect intervention through parents.

Additional Comments:

- “Thank you for your help.”
- “I know this is an ongoing thing for my family but the tools we received will help us all along brilliantly and my son can have a ‘normal’ life – thank you.”

Table 6: Responses for ‘how you are feeling at the end of this pilot’ by parents (n10).

At the end of the evaluation form, participants were asked to circle an emotion picture/label that best represents how they feel at the end of the pilot. One parent did not respond to this question.

Emotion picture and label	 Happy	 Disappointed	 Hopeful	 Confused	 Ready to Start	 Frustrated	 Other (label)
Number of parents	3	-	5	-	1	-	-

Parents all selected positive emotions to represent how they were feeling at the end of the pilot project.

6. Clinical Implications and Recommendations

A number of clinical implications and recommendations have emerged from this small pilot project, although it has also evoked important questions into the practical application of the Spectrum Star Assessment within the Paediatric ASD Service.

Professional to complete assessment

This tool is a holistic tool that looks at all aspects of the young person's life, therefore questions have emerged with regards to what is the most appropriate service to carry out the initial star and monitor it on a regular basis. As these young people are in full-time education, should this assessment be carried out by educational professionals who are involved with the young people on a more consistent basis, rather than through the Paediatric ASD Service, where input is on a short-term basis. However, it would be essential that the professional carrying out the assessment would have a good understanding of ASD in order to generate appropriate goals with the young person. Session plans have been devised since the pilot project (appendix 7) to support professionals in the administration of the spectrum star assessment & the follow up review. This should allow for consistency and reliability scoring.

Gaps in service

It is evident from the comments made by both the young people and their parents, that there is a gap in the service provided to these young people for direct intervention. Therefore, there is a need for the Paediatric ASD Service to develop intervention programmes for these young people, whether in the form of group or individual intervention. Key areas of difficulty from the Spectrum Star assessment could be used to guide intervention and provide an individualised approach for these young people.

A key theme that also emerged during this pilot project was that although these young people knew they had a diagnosis of Autism or Asperger's Syndrome, they did not understand the impact of their diagnosis on everyday functioning or have strategies in place to manage difficulties. This therefore is a gap in the service provided at this time.

Sharing the Star

For the purposes of the pilot project, the completed Spectrum Star assessments (initial and review) and action plans were shared only with the Paediatric ASD Service who conducted the assessment, the young person and their family. However, when implementing this star as a tool within the Paediatric ASD Service, it is necessary to consider who this star should be shared with to encourage a holistic approach for the young person. Ideally, education professionals should receive a copy of the completed assessment and action plan, particularly when there are education-based goals in the action plan such as homework planning (time and activities), social goals (social interaction) etc. It would also be beneficial to share the star with any other professionals involved with the young person for example health professionals, voluntary sector workers and medical professionals for

information on what service is being provided and in order to encourage completion of actions.

It is obviously essential that consent would be gained for sharing of the Star and action plan. This should be gained formally from parents/carers as they hold parental responsibility for this age group, however verbal consent should also be gained from the young person to continue to empower them in decision making.

Implementing of the Star into the Paediatric ASD Service

The results of this pilot project were overwhelmingly positive and demonstrated a need for direct intervention for this age group of young people with a diagnosis of Autism or Asperger's Syndrome. The Star has been shown to be a very effective tool with these young people with ASD. Therefore, consideration needs to be taken as to how to implement this tool into the service provided by the Paediatric ASD Service. Questions are raised whether this tool should be offered to all 14 to 18 year olds who receive a diagnosis through the Paediatric ASD Service or whether it should be offered on a more restricted basis once a referral is received for additional support via the ASD Service. The age this star is offered to young people also requires consideration, should this start at 14 years old, as in this project, or should it be available for all those in post-primary education. These questions require further debate at a service lead level.

Service impact

The impact upon the Paediatric ASD Service should be considered when implementing this tool as an intervention programme. Issues with regards to the capacity available in the Paediatric ASD Team will ultimately inform many of the decisions with regards to implementation of the Star. To provide the 'ideal service' of implementing the Spectrum Star and developing further direct intervention programmes for these young people, an increase in staffing of the Paediatric ASD Service would be required.

Timeframe for involvement

This pilot project was conducted over a relatively short timeframe of eight weeks between the initial Spectrum Star assessment and the review Star. Only one review star was carried out, with no further follow-up intervention with the young person. Triangle Consulting Social Enterprise Ltd state that, "the Star is designed to be completed at regular intervals, usually around every three months." (Organisation guide, p. 36) However, they do note that there is some flexibility in this when integrating the Star assessment into individual services. Therefore, when considering how the Star can be used practically within the Paediatric ASD Service, the timeframe for involvement with the young person may be longer i.e. a three month period between the initial and review Star. It may also be beneficial to carry out more than one review Star assessment in order to ensure continued improvement and maintenance across star areas.

What happens after the Star Assessment?

The pilot project involved an initial Star and review Star. Following this, the parents/carers and young people were discharged from the service with

advice on how to contact the service again if further support is required. It is important to consider what support the young person and family could be offered to continue to use the Star in a useful manner in the home environment following discharge from the service. An information leaflet has been devised since the pilot project (Appendix 8) to encourage continued use of the Star at home. This leaflet should be explained in detail to parents/carers and the young person before discharge. This leaflet also has contact details of the Paediatric ASD Service should further input be required.

Transition between Paediatric and Adult services

The focus of this pilot project was on the transition period into adulthood and therefore into adult services. Closer working relationships are required between paediatric and adult ASD services to encourage a seamless transition between services. Consideration should be given to the use of the Spectrum Star Assessment as a tool to transition a young person from paediatric to adult services as it provides a holistic review of how the young person is functioning at the time and areas of need for further input.

The Northern Adult Autism Advice Service (NAAAS) (see Appendix 9 for information leaflet) should also be considered as a useful link between paediatric and adult services. This service is available for those aged 16 years or above who have a diagnosis of ASD. It may be beneficial for 16 to 18 year olds known to the Paediatric ASD Service to be directed to the NAAAS for completion of the Spectrum Star as professionals from the adult service could carry it out and then transition them into adult services as and when required.

7. Summary and Conclusions

It is evident from government legislation such as the Autism Strategy (2013-2020) that there is an increasing focus on the need to develop services for young people with ASD transitioning into adulthood in order to provide a 'whole life' approach given that ASD is a lifelong diagnosis.

This pilot project aimed to investigate whether the Spectrum Star assessment was an appropriate tool to use with this client group. Results highlighted that the Spectrum Star Assessment is a very useful tool to use with young people with ASD, given its holistic and visual approach to the assessment. It also empowers the young people to make decisions with regards to intervention, while still including parents/carers at the action planning stage. It would therefore be a valuable tool to implement into service delivery within the Paediatric ASD Service. This pilot project also raised the need for further development in the services provided directly with these young people, for example individual or group intervention.

A number of clinical implications, recommendations and questions for clinical implementation of this tool have been raised that require further consideration within the Paediatric and Adult ASD Services.

References

The Autism Strategy (2013 – 2020) and Action Plan (2013 – 2016). Department of Health, Social Services and Public Safety, Northern Ireland Executive.

Owen, R., Hayett, L. and Roulstone, S. (2004). Children's views of speech and language therapy in school: consulting children with communication difficulties. *Child Language Teaching and Therapy*, 20 (1) 55-73.

Appendices

Appendix 1: Information Leaflet on Pilot Project



Paediatric Autism Spectrum Disorder (ASD) Service



Spectrum Star Pilot **Information for Young Person**

The Spectrum Star's aim is to enable you to manage Autism/Asperger's so that you can have a positive and fulfilling life and make the choices that are right for you. The Spectrum Star helps to focus on what needs to happen for you to do that.

When completing the star we will look at nine areas that you might need support with now or in the future.

1. Physical Health
2. Living skills and self-care
3. Well-being and self-esteem
4. Sensory difficulties
5. Communication
6. Social skills
7. Relationships
8. Socially responsible behaviour
9. Time and activities

How does it work?

You will complete the Spectrum Star Chart and Action Plan with one of the Autism Team and choose a score for yourself for each of the areas above. You will look at the scales one at a time with staff. On each, you will agree together the point that best describes where you are now in that area of your life.

When you and staff have completed and marked all nine scales, you can draw a line to join all the points. This will create a shape, you and staff will look together to see where you may need support to progress up one or more of the scales.

Making progress takes commitment, an understanding of your condition, self-management and support from others. It can be helpful to see this progress as a journey involving a series of steps – we call it the journey of change.

Who is involved?

This pilot is for teenagers 14years + who have recently had a diagnosis of Autism/Asperger's and are aware of this diagnosis.

If you were part of the assessment group you will be asked to attend an individual appointment with one of the staff who was part of your group to complete your star.

If you attended a clinic appointment you will be asked to attend two 'getting to know each other sessions' then you will be given an individual appointment with one of the staff to complete your star.
On completion of your star, you will be able to share this with your parents.

What is the follow up?

Following the completion of your star, you and staff will agree an action plan for the area that you may require some support. After two months you will be asked to attend a further appointment with the same staff and at this stage your star and supports required will be reviewed.

At this stage you will be discharged from autism service but it is envisaged that you will complete more star charts in the future and, as you make progress the shape on your star becomes bigger and more rounded. Not everyone starts at the beginning and not everyone gets to the end but everyone can make progress.

Outcomes of Pilot

Following the Spectrum Star pilot you and your parents will be asked to take part in an evaluation, this will be important information to establish and will help us shape services for others.

Appendix 2: Letter requesting a response for participation in the pilot project



Date:

Person with parental responsibility for:

Dear Person with parental responsibility,

The Paediatric ASD Service are running a pilot project using the 'Spectrum Star' - please see the attached information sheet and example star. This project is to focus on transitions from adolescence to adult hood.

We have selected **NAME** to take part in this pilot programme.

To confirm that you want to be part of this pilot and to receive an appointment(s), please ring Adele at the Paediatric ASD Service on 028 9442 4551 between 9.00am – 12.15 pm.

If we do not hear from you by Friday 3rd January, we will assume that you do not wish to take part in this project and your place will be offered to another young person.

The young person must be aware of their diagnosis of autism or Asperger's syndrome in order to take part in this pilot. If you would like an information pack on how to tell your child about their diagnosis prior to taking part in this pilot programme, please request one from Adele when confirming your place.

Yours sincerely

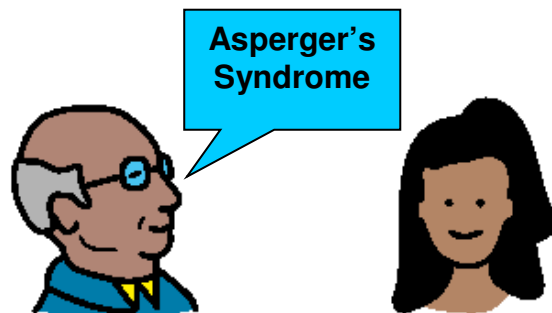
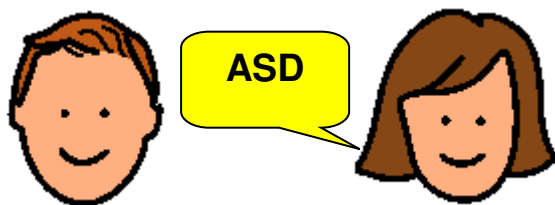
On behalf of the Paediatric ASD Service

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Appendix 3: Telling young person about their diagnosis pack – leaflet and question bookmark



Paediatric Autism Spectrum Disorder (ASD) Service



**Telling your child/young person about their
ASD Diagnosis**

TOP TIPS for telling your child about their ASD diagnosis

There isn't one 'right' way to tell your child about their diagnosis. However, here are some 'top tips' for you to consider.

The term Autism Spectrum Disorder (ASD) will be used to cover both diagnostic terms of Autism and Asperger's Syndrome.



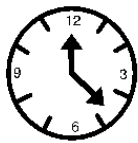
1. Think about **who** is the best person in the family to help bring up the subject? If your child is comfortable with a grandparent or aunt, it might be a good idea to get them involved, too.
2. When you do tell your child make sure you're both in a **calm mood**, and in a familiar place where you both feel comfortable. People with an ASD can find it difficult to process new information - more so if they're feeling anxious, stressed or are in an unfamiliar environment.
3. Try to make sure you **won't be interrupted**. Your child may need time to think about what you're saying or to ask questions. Siblings interrupting in the middle of this could lead to unnecessary frustration.
4. You may **start the conversation** about ASD by first talking about differences. For example, you could write a list of family members' strengths and weaknesses. Then talk about what your child is good at (Qualities) and what they find difficult (Difficulties). You could point out that there is a name to this particular pattern of strengths and weaknesses – ASD.

Here is an example table for a child with ASD:

Qualities	Difficulties
<ul style="list-style-type: none">▪ Honest▪ Determined – expert on the Titanic▪ Kind▪ Honest▪ A reliable friend▪ Good at drawing▪ Excellent at remembering things others have forgotten▪ A perfectionist▪ Observant of details others do not see	<ul style="list-style-type: none">▪ Accepting mistakes▪ Making friends▪ Taking advice▪ Managing anger▪ Knowing what other people are thinking▪ Explaining thoughts using speech▪ Coping with surprises▪ Tolerating specific sounds▪ Handwriting

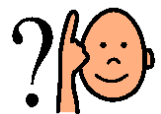
5. Some children will become concerned that there is something seriously wrong with them which will affect their health. You may need to **emphasise that an ASD is not a disease** and no one can die from it. Although an ASD cannot be 'cured' there are ways of helping to overcome some of the difficulties it brings. For example, your child might have a support worker at school who helps them with tasks they find difficult. (You could also point out that your child is good at some things at school which other children need help with.)

6. Your child may have met other people with an ASD. It's worth explaining that although people with an ASD share some difficulties, they are also all different.



7. **Allow time** for your child to process the information you give them. Reassure your child that they can come to you to ask further questions. A good idea is to have a “question box” where your child can post questions in so they do not have to ask you face to face. This also allows you time to think about your response before answering your child. Alternatively, get your child to text or email you with any questions or use the ‘question bookmark’ provided.

8. Use **language** that your child understands. Check with them that they have understood what you have said as you go along – you may want to ask them to re-tell you the information to check they have understood it correctly. Write down some of the information you tell them, so they can think read it over in their own time.



9. Keep it **positive!** Highlight the child's strengths, particularly the ones that are characteristics of ASD e.g. honesty, expert on certain topics, ability to focus on tasks. Reassure your child that having ASD does not mean that he or she is mad, bad or defective – but that they have a different way of thinking.



10. Discuss the benefits of getting help from professionals or family to help the child/young person to make friends and to help in learning and achieving success with school work.

Who else needs to know?

Children and young people may be concerned about how their peers will respond to the diagnosis and any potential negative responses. It is important to respect the child/young person's opinion about who they want to tell about their diagnosis. It may be an idea to role play with your child how they will tell their friends, then you can make suggestions on any changes.



Resources:

The National Autistic Society have produced the following books which are available through their website:

- “What is Asperger Syndrome and how will it affect me?” –a good resource for the child/young person to read themselves.
- “Talking together about an Autism Diagnosis” – a guide for parents and carers.

Other book recommendations are provided on the websites mentioned below.

Useful **Websites** for parents and the person with ASD:



National Autistic Society
www.autism.org.uk

Autism NI
www.autismni.org

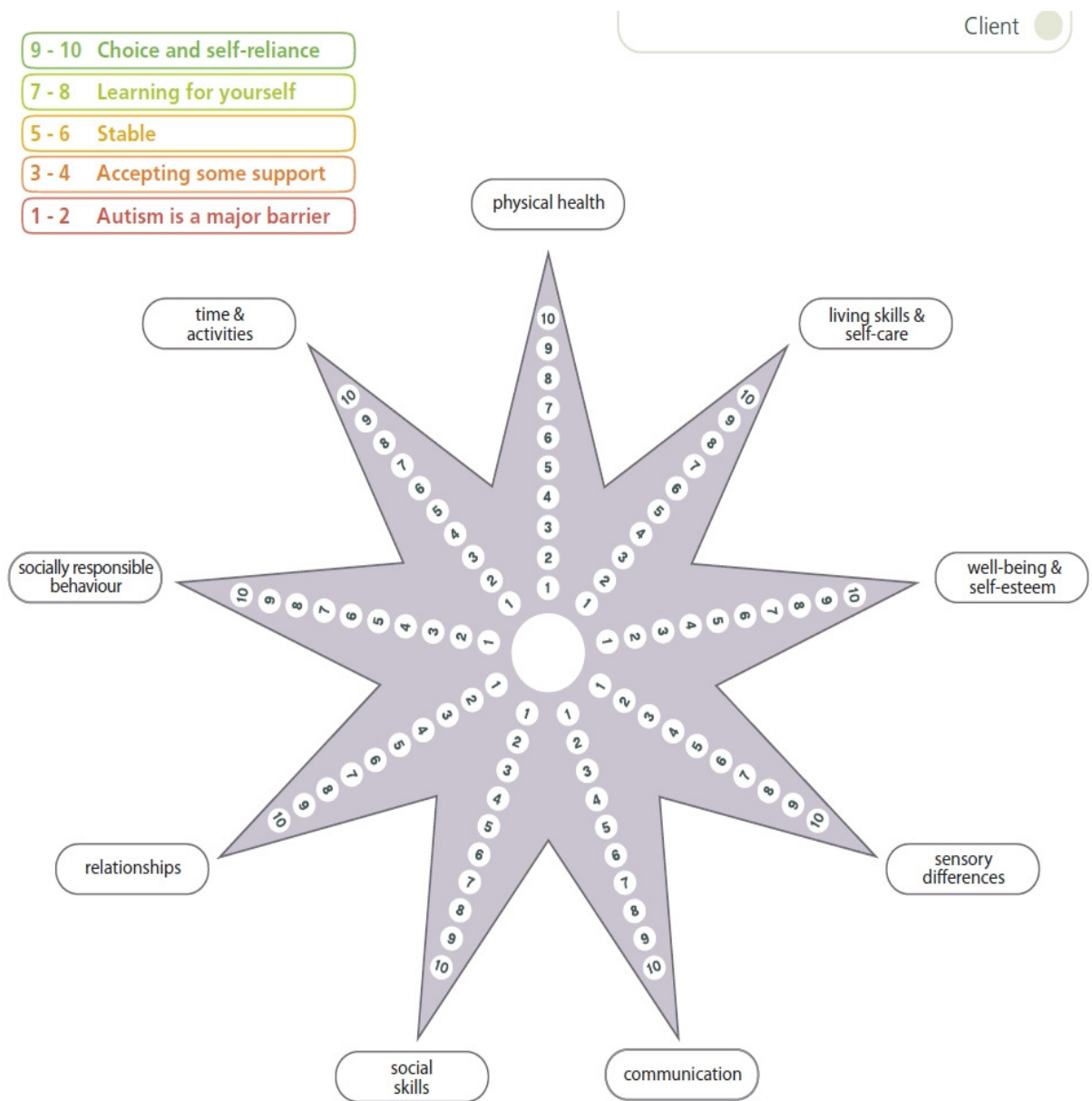
Contact details:

Paediatric ASD Service

The Cottage, 5 Greenmount Avenue,
Ballymena, BT43 6DA

Tel: 028 2563 3777

Appendix 4: Spectrum Star Chart



Appendix 5: Evaluation Form: Young Person



**Northern Health
and Social Care Trust**
Paediatric Autism Spectrum Disorder (ASD) Service

Evaluation Form – Spectrum Star (Young Person)

For official use only:

Diagnosis: *Diagnostic group* *ADOS*

Star group: *Star only* *Rapport Group*

About You:

Age: _____ Do you have (tick) Autism Asperger's Syndrome

When did you find out about your diagnosis? _____

Who told you? _____

How did you feel when you got your diagnosis?

Please rate the statements below using the following scale:

1 ☺	2	3 ☺	4	5 ☹
Strongly agree	Agree	Neutral	Disagree	Strongly Disagree

Circle the appropriate number.

Before the Spectrum Star:

The information received before Spectrum Star was helpful.....

1 ☺	2	3 ☺	4	5 ☹
-----	---	-----	---	-----

I was offered the Spectrum Star at the right time following diagnosis.....

1	2	3	4	5
---	---	---	---	---

Spectrum Star:

The star was easy to complete.....

1	2	3	4	5
---	---	---	---	---

I found it easy to talk to the worker to complete the star..

1	2	3	4	5
---	---	---	---	---

The star helped me see my areas of strength.....

1	2	3	4	5
---	---	---	---	---

The star helped me see what I need to work on

1	2	3	4	5
---	---	---	---	---

Setting actions was easy with help from the worker.....

1	2	3	4	5
---	---	---	---	---

My actions were all possible to do

1	2	3	4	5
---	---	---	---	---

I liked sharing my star and actions with my parent(s).....

1	2	3	4	5
---	---	---	---	---

If you went to the 'getting to know you group'

I found the group useful.....

1	2	3	4	5
---	---	---	---	---

Review:

There was enough time between the first star and second star to complete my actions.....
It was useful having the same worker to complete my star.....

1	2	3	4	5
1	2	3	4	5

General:

The accommodation was good
The time of the appointment suited me

1 😊	2	3 😊	4	5 😊
1	2	3	4	5

Comments:








What did you like about the Spectrum Star Pilot?

What did you find most helpful or useful?

What did you not like about the Spectrum Star Pilot or find unhelpful?

How else could the Paediatric ASD service have helped you following your diagnosis?

Please circle how you are feeling at the end of this pilot:

 Happy  Disappointed  Hopeful  Confused  Ready to Start  Frustrated  Other____
(draw)

Any other comments

Thank you for completing this evaluation form

Appendix 6: Evaluation Form: Parent



**Northern Health
and Social Care Trust**
Paediatric Autism Spectrum Disorder (ASD) Service

Evaluation Form – Spectrum Star (Parent)

For official use only:

Diagnosis: *Diagnostic group* *ADOS*

Star group: *Star only* *Rapport Group*

About You and Your Young Person:

Relationship to young person (YP): _____

Age of YP: _____

Do they have (tick) Autism Asperger’s Syndrome

Who told YP about their diagnosis? _____

How did you feel this went?

Please rate the statements below using the following scale:

1 ☺	2	3 ☹	4	5 ☹
Strongly agree	Agree	Neutral	Disagree	Strongly Disagree

Circle the appropriate number.

Before the Spectrum Star:

The information received before Spectrum Star was helpful.....

1 ☺	2	3 ☹	4	5 ☹
-----	---	-----	---	-----

The Spectrum Star was offered at the right time following diagnosis.....

1	2	3	4	5
---	---	---	---	---

Did you received pack on ‘Telling the YP about their diagnosis’? Yes No

If yes, I found this information pack useful.....

1	2	3	4	5
---	---	---	---	---

Spectrum Star:

The star made it easy to identify areas of strength and weakness for my YP.....

1	2	3	4	5
---	---	---	---	---

I would agree with where my YP rated themselves.....

1	2	3	4	5
---	---	---	---	---

I liked that the star and actions were shared with me..

1	2	3	4	5
---	---	---	---	---

The actions set were appropriate for the YP.....

1	2	3	4	5
---	---	---	---	---

The actions set were achievable for the YP.....

1	2	3	4	5
---	---	---	---	---

If your YP went to the ‘getting to know you group’

The group was helpful for my YP.....

1	2	3	4	5
---	---	---	---	---

Review:

There was enough time between the first star and second star to complete the actions.....

1	2	3	4	5
---	---	---	---	---

General:

The accommodation was good

1 ☺	2	3 ☹	4	5 ☹
1	2	3	4	5

The time of the appointment suited

Comments:








What did you like about the Spectrum Star Pilot?

What did you find most helpful or useful?

What did you not like about the Spectrum Star Pilot or find unhelpful?

How else could the Paediatric ASD service have helped your YP following the diagnosis?

Please circle how you are feeling at the end of this pilot:

						
Happy	Disappointed	Hopeful	Confused	Ready to Start	Frustrated	Other ___ (draw)

Any other comments

Thank you for completing this evaluation form

Spectrum Star Initial Assessment: Session Plan

Remember:

- This is the young person's star and rating scale – it is not for professionals or parents to score them.
- Allow time for the young person to read through each of the descriptors.
- Encourage them to ask for clarification if required.

1. Introduction and Rapport Building		
Introduction	Resources: None	Introduce who you are and talk briefly about purpose of appointment i.e. to complete the Spectrum Star (will have had information sent out to explain what the star is prior to session)
Rapport Building	Resources: None	Explain that you would like to get to know the young person a little before you start the Star. Spend 5-10 minutes in conversation with the young person.
Rapport Building game (optional)	Resources: 'Favourites Cards'	<i>If conversation is difficult for the young person, use this game to build rapport. Take turns to turn over a card a talk about favourite things until all cards are finished.</i>
2. Discussion of ASD Diagnosis		
Discussion	Resources: None	Explain to the young person that this appointment is to talk about their diagnosis of Autism/Asperger's Syndrome and how it is affecting their everyday life. Ask the young person what they know about ASD. This may lead to some discussion about ASD. Try to keep this discussion brief.
3. Spectrum Star Assessment		
Introduction	Resources: Individual Star Chart	Introduce the Spectrum Star by explaining the following to the young person: <ul style="list-style-type: none"> • This is <u>their</u> star • You will look at each area/point of the star and that <u>the young person will rate themselves</u> in each area on the scale (1-10) • After you will talk about why they have chosen that number

		<ul style="list-style-type: none"> • They will be able to see what areas are easier for them and what areas are more difficult/need some help with. • At the end, parent(s) will be asked to come into the room and an action plan will be made jointly with the young person, parent and professional.
Assessment: Rating each area	Resources: User's Guide, Individual Star Chart, Notes page	<ol style="list-style-type: none"> 1. Open the user's guide to page 6/7 titled 'Physical Health'. 2. Introduce the topic by explaining the areas this covers (box in top left hand corner of page 6) i.e. doctors, treatment etc. 3. Give the guide to the young person on page 7. Check if they are okay to read through the boxes themselves or if they would like you to do it (look in file prior to session to assess if there are any learning/literacy difficulties). 4. Encourage them to read through each box and see which one they think they fit into. If they are unsure which number to pick in a box e.g. a 5 or 6 – tell them you can help them work it out by using the stepped guide on page 6. Tell them to take their time. 5. Circle the number they have selected on the Star Chart. 6. Once they have rated themselves with a number, ask 'Why have you selected a ... (number they have chosen)?' Write their answer down on the notes page. You may have to prompt/question them further if you think they may have rated themselves incorrectly e.g. if they have scored a 9/10 but are talking about difficulties in this area. You may want to ask about other sub-topics in the area e.g. if they only talk about exercise, you could ask about healthy eating and sleep to gather more information. 7. Repeat the above for each section of the star using the User Guide until all areas are scored. 8. When all areas have been scored, join each point together to make a web effect and show to the young person.
Invite Parent(s) into the room	Resources: Completed Star Chart	<ol style="list-style-type: none"> 1. Ask the young person if it is alright for their parent(s) to join the session to share the star and help make the action plan (encourage this). 2. When the parent comes into the room, advise them that this is the young person's star and they have scored it. It is not for parents or the professional to choose a score.

		<ol style="list-style-type: none"> 3. Look at the star together. Highlight areas of strength first (i.e. higher scoring points). 4. Then look at the areas that are more difficult for the young person (i.e. those points that scored lower).
5. Complete the Action Plan		
Action Plan	Resources: Action Plan, Completed Star Chart and Notes	<ol style="list-style-type: none"> 1. Get the young person to choose a lower scoring area of the star (i.e. an area that requires some work). Read the notes page back which will detail why the young person has chosen that area and may highlight an area to work on. 2. Ask the young person what action they can think of to improve this area. You or parents may have to help if young person cannot generate ideas, but remember that the young person is more likely to complete actions if they help make them or agree on them. 3. Help guide the young person in order to make the goals SMART (see leaflet on setting SMART goals). 4. Complete the action plan with the agreed SMART goals. 5. Generate 1-5 goals depending on the young person and how many areas require support.
6. What's Next?		
Close the session	Resources: None	<ol style="list-style-type: none"> 1. Ensure that young person and parent(s) understand and are in agreement with goals set. 2. Advise the young person that you will post the Star Chart and Action Plan home for them once a photocopy is made for their file. 3. Agree on plan (one of the following): <ul style="list-style-type: none"> • Review appointment in 2-3 months to review action plan and reassess using the star • Discharge if young person is scoring 7 or above in all areas • Meeting with parent to be arranged to discuss parental concerns – with young person consent • Parents to attend PACE Programme Level 1 or 2 • Onward referral to another service (with parental consent) 4. Allow for any questions from the young person or parent. 5. Close session.



Spectrum Star Review Assessment: Session Plan

Remember:

- This is the young person's star and rating scale – it is not for professionals or parents to score them.
- Allow time for the young person to read through each of the descriptors.
- Encourage them to ask for clarification if required.

1. Review		
Introduction	Resources: None	<p>Introduce who you are as a reminder and talk briefly about purpose of appointment i.e. to review how the young person has been since the last appointment and repeat the Spectrum Star.</p> <p>Ask the young person how things have been going at home/school since the last appointment.</p>
Review of Action Plan	Resources: Last action plan	Review the action plan previously agreed. Ask the young person how they got on at completing each action. If they didn't complete an action try to gently find out why but focus on the positives.
2. Spectrum Star Assessment		
Introduction	Resources: Individual Star Chart	<p><i>Do not show the young person their last star until new star is completed.</i></p> <p>Revise the following with the young person:</p> <ul style="list-style-type: none"> • This is <u>their</u> star • You will look at each area/point of the star and that <u>the young person will rate themselves</u> in each area on the scale (1-10) • After you will talk about why they have chosen that number • They will be able to see what areas are easier for them and what areas are more difficult/need some help with and to compare with the last star • At the end, parent(s) will be asked to come into the room and an action plan will be made jointly with the young person, parent and professional.

<p>Assessment: Rating each area</p>	<p>Resources: User's Guide, Individual Star Chart, Notes page</p>	<ol style="list-style-type: none"> 9. Open the user's guide to page 6/7 titled 'Physical Health'. 10. Introduce the topic by explaining the areas this covers (box in top left hand corner of page 6) i.e. doctors, treatment etc. 11. Give the guide to the young person on page 7. Check if they are okay to read through the boxes themselves or if they would like you to do it (look in file prior to session to assess if there are any learning/literacy difficulties). 12. Encourage them to read through each box and see which one they think they fit into. If they are unsure which number to pick in a box e.g. a 5 or 6 – tell them you can help them work it out by using the stepped guide on page 6. Tell them to take their time. 13. Circle the number they have selected on the Star Chart. 14. Once they have rated themselves with a number, ask 'Why have you selected a ... (number they have chosen)?' Write their answer down on the notes page. You may have to prompt/question them further if you think they may have rated themselves incorrectly e.g. if they have scored a 9/10 but are talking about difficulties in this area. You may want to ask about other sub-topics in the area e.g. if they only talk about exercise, you could ask about healthy eating and sleep to gather more information. 15. Repeat the above for each section of the star using the User Guide until all areas are scored. 16. When all areas have been scored, join each point together to make a web effect and show to the young person. 17. <i>Now show the young person the last star to compare. Focus on areas that have improved and reassure young person around areas that may have slipped back a little.</i>
<p>Invite Parent(s) into the room</p>	<p>Resources: Completed Star Chart</p>	<ol style="list-style-type: none"> 6. Ask the young person if it is alright for their parent(s) to join the session to share the star and help make the action plan (encourage this). 7. When the parent comes into the room, remind them that this is the young person's star and they have scored it. It is not for parents or the professional to choose a score. 8. Look at the star together. Highlight areas of strength first (i.e. higher scoring points) and areas of improvement. 9. Then look at the areas that are more difficult for

		the young person (i.e. those points that scored lower) or areas that have slipped back.
3. Complete the Action Plan		
Action Plan	Resources: Action Plan, Completed Star Chart and Notes	<p>7. Get the young person to choose a lower scoring area of the star (i.e. an area that requires some work) or area that has slipped back. Read the notes page back which will detail why the young person has chosen that area and may highlight an area to work on.</p> <p>8. Ask the young person what action they can think of to improve this area. You or parents may have to help if young person cannot generate ideas, but remember that the young person is more likely to complete actions if they help make them or agree on them.</p> <p>9. Help guide the young person in order to make the goals SMART (see leaflet on setting SMART goals). Also, consider how the young person got on with their last action plan – if they were not able to achieve the last actions, make sure that new actions set are smaller and easier for them to achieve.</p> <p>10. Complete the action plan with the agreed SMART goals.</p> <p>11. Generate 1-5 goals depending on the young person and how many areas require support.</p>
4. What's Next?		
Close the session	Resources: None	<p>6. Ensure that young person and parent(s) understand and are in agreement with goals set.</p> <p>7. Advise the young person that you will post the Star Chart and Action Plan home for them once a photocopy is made for their file.</p> <p>8. Agree on plan (one of the following):</p> <ul style="list-style-type: none"> • Review appointment in 2-3 months to review action plan and reassess using the star • Discharge if young person is scoring 7 or above in all areas or if they are making improvements and parent(s) can manage – give leaflet to parents on how to continue to use the star at home • Meeting with parent to be arranged to discuss parental concerns – with young person consent • Parents to attend PACE Programme Level 1 or 2

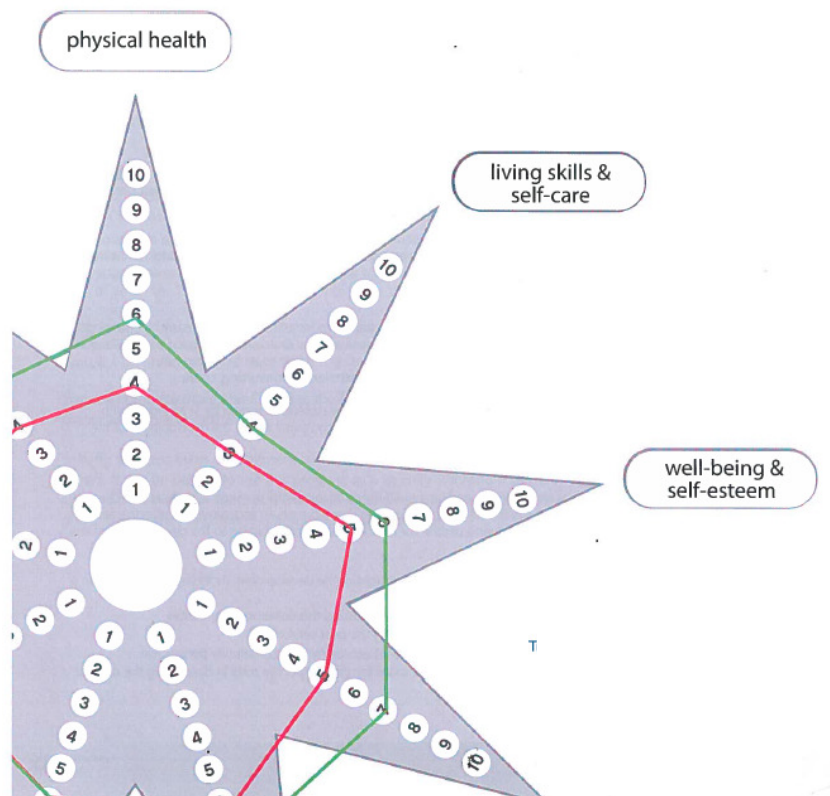
		<ul style="list-style-type: none">• Onward referral to another service (with parental consent) <ol style="list-style-type: none">9. Allow for any questions from the young person or parent.10. Close session.
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Appendix 8: Booklet for Parents/Carers to continue using the Star Assessment



Northern Health
and Social Care Trust

Paediatric Autism Spectrum Disorder (ASD) Service



Spectrum Star
Reviewing the Star with your Young Person

It is important to continue to monitor how your young person is getting on using the *Spectrum Star*.

Use the Star completed by the Paediatric ASD Service as a base line to begin with.

There are 2 steps in using the Star:

1. Selecting a Score
2. Creating an Action Plan

STEP 1: Selecting a Score

Every month or every other month, get the star out and ask your young person:

- How they are getting overall since the last star
- What number do they score themselves in each area, using the category descriptors below as a guide
- Why did they choose that number

Mark on your laminated star where they are now.

You may want to keep a record in a notebook to show change over time.

REMEMBER: This Star belongs to the young person and the score is allocated by them to show where they think they are not parents scoring where they think the young person is!

The Spectrum Star covers the following 9 areas. The table below provides descriptions of what to consider when scoring on the area.

Star Area	Description of Area
Physical Health	<ul style="list-style-type: none"> • Going to the doctors • Attending for any medical treatment • Eating healthy meals • Getting exercise • Sleep routines
Living Skills and Self-care	<ul style="list-style-type: none"> • Cooking • Cleaning • Laundry • Shopping • Money • Washing and dressing
Well-being and Self-esteem	<ul style="list-style-type: none"> • Feeling content • Confidence • Feeling ok about yourself
Sensory Differences	<ul style="list-style-type: none"> • Too noisy/too quiet • Too bright/too dark • Too many people • Not enough stimulation
Communication	<ul style="list-style-type: none"> • How you communicate with others • Understanding what other people say • Following instructions

	<ul style="list-style-type: none"> • Getting your needs met
Social skills	<ul style="list-style-type: none"> • Dealing with people • Knowing your boundaries • Knowing who's who • Behaving appropriately • Getting around in the community
Relationships	<ul style="list-style-type: none"> • Satisfaction with relationships • Relationships with your: <ul style="list-style-type: none"> ○ Friends ○ Family ○ Girlfriend/Boyfriend
Socially Responsible Behaviour	<ul style="list-style-type: none"> • The expectations of society and where you live • The law – drinking, smoking etc • Knowing your limits • Managing impulses e.g. controlling outbursts
Time and Activities	<ul style="list-style-type: none"> • Balancing interests and other activities • Work/School • Learning – homework, revision

Each area is scored on number between 1 and 10. This corresponds to the descriptions below as to how much support the young person requires.

1 – 2	<p>Autism/Asperger’s Syndrome is a major barrier</p> <ul style="list-style-type: none"> • At this stage the young person may be feeling overwhelmed, frightened or confused. • The young person will need help and support to improve things in this area. • This may involve seeking help from professionals such as Occupational Therapy, Child and Adolescent Mental Health Service (CAMHS), GP, Educational Professionals. • It is important that steps in the action plan are small at this stage in order to achieve success.
3 – 4	<p>Accepting some support</p> <ul style="list-style-type: none"> • The young person may need help organising things or advice on what to do to make life less stressful. • The young person will require support them in this area, this may be parents providing support or health/educational professionals
5 – 6	<p>Stable</p> <ul style="list-style-type: none"> • The young person’s basic everyday needs are being met, but they still require help in making decisions and to become more independent.
7 – 8	<p>Learning for yourself</p> <ul style="list-style-type: none"> • The young person is becoming more

	<p>independent.</p> <ul style="list-style-type: none"> • At this stage, they can start to set goals for themselves, with guidance only from parents. • They are trying new things but are aware what areas they still need support with.
9 – 10	<p>Choice and self-reliance</p> <ul style="list-style-type: none"> • The young person has good understanding, awareness and skills to manage as independently as would be expected for their age. • They may still require occasional support and reminders from parents.

STEP 2: Creating an Action Plan

Firstly, review the action plan from the last time.

- Were all the actions completed?
- If not, why not?



Remember to praise the young person for any actions that were completed.

Secondly, create a new action plan (laminated copy). Aim to have 3-5 actions per plan. Even if you have several areas that are scoring low, it is best to choose only 3-5 actions, then work on different areas the next time you review the Star.



SMART Actions

When creating actions, they should be ‘SMART’ as detailed below.



S = Specific

 Build relationship with brother	<i>Too vague – doesn't say how this will be achieved</i>
VS	
 Buy brother bar or chocolate once a week as a treat	<i>Specific steps as to how to build the relationship</i>



M = Measurable

 Get fit	<i>Can't measure how fit you are</i>
VS	
 Walk on the treadmill	<i>Can measure if this has been done</i>



A = Achievable

 Make dinner for family	<i>Young person may not be able to accomplish this by themselves</i>
VS	
 Help mum to make the dinner for the family	<i>Mum can give tasks that are achievable</i>

R = Realistic

 Tidy room every day	<i>Not realistic for any teenager</i>
VS	
 Tidy room once a week	<i>Realistic goal to achieve</i>

T = Timed

 Go out with friends to cinema	<i>Indefinite time scale</i>
VS	
 In the next month, go out with friends to the cinema	<i>The young person knows when they have to do this by</i>

Always ask... Are the actions SMART?

Examples of Actions in Each Star Area

Below is a list of some 'SMART' actions to give you some ideas how to get started with your action plan.

Physical Health

1. Go for a 10 minute walk around the housing development, 3 times per week and write 'Walk' on the calendar when complete to keep a record.
2. Make an appointment with the dentist to go for a check-up and put reminder in my phone for appointment.

Living Skills and Self-care

1. Set the table for dinner, including cutlery, glasses and drinks, every Tuesday and Thursday night.
2. I will clean my room on a Saturday for 15 minutes, to include vacuuming and dusting. Mum will show me how to use the vacuum.

Well-being and Self-esteem

1. Write down in a notebook, one thing everyday that I am good at or that I like about myself. Dad will help me if I get stuck.
2. Go to one place a month that I am not familiar/comfortable with e.g. concert, cinema or town and remember to focus on why I am there. Write down in a notebook where I went and how I felt during the trip and afterwards when I get home.

Sensory Differences

1. Make a poster to put on my bedroom wall to remind myself to keep calm, take deep breaths, count to 10, leave the room and put my music on when the house becomes too loud.
2. Mum and I will go to the GP to get a referral to Occupational Therapy to help me manage my sensory differences.

Communication

1. Ask my brother the score of Chelsea's football match each weekend and who they were playing.
2. I will make a worry box from an old shoe box. I will then write down any worries or concerns I have each day and post them in the worry box. Mum or dad will check the box each evening and talk to me about the worries I have written down.

Relationships

1. Have a movie night with my family every other Friday night. Everyone will take turns to choose a film to watch, starting with the youngest person and moving to the oldest person.
2. Go for a walk with my cousin and their dog 2 times each month. Write in the calendar when I have done this.

Socially Responsible Behaviour

1. If a teacher challenges me, I will ask to speak to them outside the room rather than shout in class and I will try to explain why I am not doing what they have asked me to do. Mum will speak to my head of year in school to let the teachers know that I will be doing this.
2. I will go to the website www.wethinksafe.com and do the internet safety quiz to learn about being responsible on the internet.

Time and Activities

1. I will find out what afterschool clubs there are in school and tell dad.
2. I will pack my school bag each night for the next day. I will make a checklist to make sure I have:
 - All the books I need for the next day
 - All homework completed
 - Homework diary
 - Any additional items e.g. P.E. kit, H.E. ingredients

ACTION PLAN example

Priority Area from the star	Current Score	Next Steps	By Who?	By When? (date)	Complete (date)
Physical Health	5	Go for a 20 minute run on the treadmill once a week. Use my 'Nike Fitness' app to record when I do this.	Young Person (name)	2 months time (date)	
Communication	4	Mum and dad to attend Paediatric ASD Service 'What is ASD?' Information session to help them understand more about Asperger's Syndrome to help us communicate better.	Mum and dad	3 months time (date)	
Sensory Differences	6	Buy a squeeze stress ball from the Supermarket to use when I am feeling stressed with loud noises in school. I will squeeze it under my desk 10 times to calm down.	Young person (name)	1 month (date)	
Relationships	5	I will tell mum and granny 'thank you' for all the help and support they regularly give to me.	Young person (name)	Next week (date)	

Contact Details:

Paediatric ASD Service

The Cottage

5 Greenmount Avenue

Ballymena

Co. Antrim

BT43 6DA

Tel: 028 2563 3777

Appendix 9: Northern Adult Autism Advice Service leaflet



The Braid is situated at the junction of Linenhall Street and Bridge Street beside the Town Hall.

By Road

From Belfast

Take the M2 motorway from Belfast and follow until the M2 becomes the M22. Take exit (J1) for Antrim/Ballymena/Coleraine (A26). At the roundabout follow signs for Ballymena (A26). At the Seven Towers (Ballee) roundabout follow the signs for The Braid.

From the North (Coleraine, Portrush)

Join the A26 following signs for Ballymena. Once the A26 becomes the M2 just outside Ballymena directions to The Braid are clearly signposted.

By Rail/Bus

Ulsterbus and Northern Ireland Railways offer regular daily services to and from Ballymena, please check their website for times-- www.translink.co.uk or phone 028 9066 6630.

The Braid is a 10-minute walk from Ballymena Railway Station and Bus Depot. Upon leaving the station turn left along Galgorm Road. At the end of the Galgorm Road at the major road junction cross the Galgorm Road, then the North Road. Follow the North Road until it ends. Turn right and cross the Linenhall Road. The entrance to The Braid is located along Bridge Street.

Contact details

The Braid Ballymena Town Hall,
Museum & Arts Centre
1 - 29 Bridge Street
Ballymena
BT43 5EJ

Tuesdays 1.30pm - 4.30pm

Tel: 028 2766 1335
Email: AdultAutismService@northerntrust.hscni.net

This service is provided in partnership with:

The Department of Employment and Learning (DEL)

The Northern Regional Colleges

Improving Benefits Uptake, Social Security Agency

Citizens Advice Bureau

National Autistic Society

 Northern Health
and Social Care Trust



Northern Adult Autism Advice Service

Information Leaflet

Email: info@northerntrust.hscni.net
Web: www.northerntrust.hscni.net

This document is available, on request,
in accessible formats, including Braille, CD,
audio cassette and minority languages.

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The Northern Adult Autism Service is made up of a small multiagency team providing a service to adults with Autism and those who support them.

The key aims are:

- To help individuals with Autism access a range of appropriate main-stream services, for example, employment, further education;
- to offer individuals with Autism one to one support for specific problems;
- to offer post-diagnostic support;
- to provide a safe place where individuals with Autism can share their experiences.

(Individuals may be supported by their carer/ advocate to attend)

Who is the service for?

The service is for individuals aged 16yrs+ who have a diagnosis of Autism, who reside in the Northern Trust Area.

The service operates an open/self referral system and offers advice and support.

One to one sessions

What are these for?

These sessions aim to help you with specific problems. For example:

- Support to manage difficult emotions;
- problem-solving for specific difficulties;
- support around education;
- support around employment and career progression;
- help to deal with housing and benefit issues;
- advice about difficulties in relating to other people;
- gain more understanding about Autism.

We ask that you come to the one to one session with a specific issue in mind, which we can focus on during the session.

To book an appointment, please contact Rikki on 028 2766 1335 or email: AdultAutismService@northerntrust.hscni.net

Occasionally there will be some available appointments on the day. Please check with a member of staff at the Advice Service as they may be able to book you an appointment for that afternoon.

Post-diagnostic support

Group sessions

Northern Adult Autism Advice Service offers you the opportunity to attend this group after you have received a diagnosis of Autism. The aims of this group are to enable you to:-

- Learn about Autism;
- learn about how Autism affects you;
- discuss the experience of receiving a diagnosis;
- discuss telling people about your diagnosis;
- learn about what further support is available to you.

How do you book a place:

If you have received your diagnosis through the Northern Health & Social Care Trust you will have been asked if you would like to be added to the waiting list for this group and will be informed when the next group is available.

Otherwise please contact:-

Rikki : 028 2766 1335

AdultAutismService@northerntrust.hscni.net