

**Autism Workshop : Building Bridges from Adolescence to  
Adulthood**

**13<sup>th</sup> March 2013**

**Summary Report**

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**(Photo: Autism Workshop – Belfast Central Mission, March 2013)**

## 1. Introduction and Purpose of the Workshop

A workshop for Parents and Carers of Young People with a diagnosis of Autism was held in Belfast Central Mission, Glengall Street, Belfast on the 13<sup>th</sup> March 2013. Eithne Darragh, Social Care Commissioner in the Health and Social Care Board, led the workshop.

The main aims of this workshop were:

- to provide parents and carers with information on services in Northern Ireland to support transitions for young people with autism
- to share best practice across the region and provide a networking opportunity for parents and carers
- to hear service users experiences, and give parents and carers the opportunity to identify concerns and raise issues for commissioners
- to consider particular case scenarios, identifying resources and share learning.

Representatives from a wide range of sectors were invited to present their services to the workshop, including input from statutory health care services, the education sector and the voluntary sector. There were also personal contributions from individuals who had direct experience with the system in Northern Ireland.

The workshop had an ambitious schedule, with the goal of providing attendees with as much information as possible in the half day session. There were 8 presentations delivered to the audience, with breaks in-between for some reflection on what had been heard and for questions from attendees.

**(Photo: L McKerr addresses the workshop)**

The workshop participants were then asked to do some group work, led by Karen Buchanan. Groups were asked to consider a number of case scenarios and provide suggestions to answer the questions that had been set. A brief synopsis of discussions held around the scenarios was delivered to the workshop, and this summary of suggestions can be found later in the report.

Before the workshop closed, attendees were invited to complete an evaluation form that had been provided. The purpose of this was to discover to what extent attendees had found the workshop useful, to determine any areas for improvement, and to collect ideas and recommendations for topics of any future workshops that may be held. The findings from the evaluation forms can be found later in the report.



## 2. Presentations

There were 8 presentations in total delivered at the workshop. A copy of these presentations can be found on the website alongside this report. The table below outlines a brief summary of the presentations, in the order that they were delivered.

	<u>Presenter</u>	<u>Role/Organisation</u>	<u>Topic</u>
1	<b>Iolo Eilian</b>  <i>Contact Details:</i>  <a href="mailto:iolo.eilian@hscni.net">iolo.eilian@hscni.net</a> <a href="tel:02837414451">Tel:- 02837 414451</a>	Lead Commissioner for Learning Disabilities and Mental Health, HSCB	<ul style="list-style-type: none"> <li>• Integrated Planning and Commissioning for Children and Young People – Transitions Group</li> <li>• CYPSP – Children and Young People Strategic Partnership</li> </ul>
2	<b>Frances Beagon</b>	Autism Lead, Belfast Health and Social Care Trust	<ul style="list-style-type: none"> <li>• ASD – The Teenage Transition (Belfast Trust)</li> </ul>
3	<b>Lesley Waugh and Marie Louise Hughes</b>	Autism Services Co-ordinator, Southern Health and Social Care Trust <u>and</u> Senior Educational Psychologist/Manager of Autism Services <a href="#">Transition Officer</a> , SELB	<ul style="list-style-type: none"> <li>• Southern Trust Transition Services</li> <li>• Partnership between SHSCT and SELB</li> <li>• Transition and Education</li> </ul>
4	<b>Louise Potts</b>	Project Manager, Co-operation and Working Together (CAWT) Project	<ul style="list-style-type: none"> <li>• Turning the Curve – EU Project</li> <li>• Improving the lives of children and young people with autism and their families and carers</li> </ul>
5	<b>Elvin Simpson</b>	Expert by Experience	<ul style="list-style-type: none"> <li>• Transition – undiagnosed Asperger's</li> <li>• Personal experience from service user</li> </ul>
6	<b>Lynn McKerr</b>	Parent	<ul style="list-style-type: none"> <li>• Growing up, bridging the gaps and moving on</li> <li>• Personal experience of a parent</li> </ul>
7	<b>Carrie Ann Rainey and Caroline McAteer</b>	Deputy Manager, Cedar Foundation <u>and</u> Right 4 U Project Officer, Cedar Foundation	<ul style="list-style-type: none"> <li>• Right 4 U ☺ Service</li> <li>• Case Study examples of how the service is beneficial</li> </ul>
8	<b>Theresa Hazzard</b>	Employment and Personal Development Sector Manager, Mencap	<ul style="list-style-type: none"> <li>• Employment Services and assistance offered by Mencap</li> </ul>

### **3. Issue Log**

As a part of the Information Pack supplied at the beginning of the workshop, attendees were provided with a number of blank post-it notes and encouraged to write any issues or comments that they had in relation to Autism Services that they felt needed to be addressed. These notes were collected on two boards throughout the workshop, and some of the main themes to come from this exercise are listed below:

- One of the most common comments gathered through the issue log was the apparent variation of services available depending on which Trust you are from
- A number of comments were received regarding the limited availability of services in the Northern Trust in particular
- Despite the many initiatives and services that were discussed at the workshop, some people felt that the presentations were not reflective of the services that they had been in contact with
- What services are being provided for young people with more complex needs? e.g. child with severe learning disability, parents with impairments etc.
- Communication issues were raised in relation to people receiving relevant information on services in their area, and how they could actually access these services
- Issues were raised regarding the clarity of criteria for different services – age, diagnosis etc.

#### **4. Scenarios – Summary of Group Activity**

Three different scenarios were distributed among the tables at the workshop. Each group was asked to spend 30 minutes considering two questions, noting any suggestions on their flipchart. Once this was completed, the answers to each scenario were summarised and presented to the entire workshop.

##### **Scenario 1: Higher Education**

Robert is 19 years old. He lives with his mum Patricia. He has a diagnosis of Asperger's Syndrome. He has just finished grammar school with very good grades. He wants to attend Queen's University to study computer programming. Robert has always relied on his mum to help him. Robert and his mum both live in Newry. He will have to travel to university on his own each day on the bus. Patricia is employed full-time and cannot accompany Robert on the bus. Robert needs help navigating his way around new situations and surroundings. He also has frequent anxiety and panic attacks. He is worried he won't know where, or how to find his new classes or how to get home if he gets lost in Belfast.

***Question 1: What planning and strategies should already have been implemented for Robert prior to his decision to go to university?***

- Student Support at QUB
- Halls of residence at QUB
- Access to and liaison with transition services
- Consideration of travel routes, arrangements, money
- Independence training and life skills – cooking/cleaning/washing etc.
- Contact QUB Peer mentoring services
- Consideration of any implications on family members – parents, siblings etc.
- Methods for dealing with anxiety – prepare for unfamiliar environment
- UCAS application and support
- Support system in the local area
- Social Skills training
- Time table in advance
- Preparation for moving from a school environment to university
- Well established communication links
- Introducing Robert to the university area for familiarity

***Question 2: Which organisations and services are available to help Robert succeed at university?***

- Help from student disability services – support and assistance
- Meet student counsellor
- Establish a 'safe place' in case of panic attacks
- Peer mentoring
- Transition planning
- Time management training
- Mencap
- Autism Support Groups
- Mentor (academic)
- DSA – for equipment
- Talk to teaching staff about issues
- Awareness of social groups he may be interested in
- Students union
- SENAC
- National Autistic Society

## **Scenario 2: Adolescence**

Sophie is a bright 14 year-old twin who attends a local grammar school. She was diagnosed with Asperger's Syndrome when she was seven. She moved to secondary education with a Statement of Special Educational Needs.

Over recent months she has become withdrawn, and stays in her room. She is limiting her food intake. She does not want to talk to her sister, mum, or friends. Her parents Rachel and David are finding it increasingly difficult to cope with her worsening mental health. Her mum also has a diagnosis of Asperger's Syndrome. CAMHS has refused to help Sophie and her parents have not received help from their Health Trust, or any voluntaries either. They live in an isolated area of Northern Ireland. There is no ASD social worker available.

Sophie's main Transition Interview is coming up at school. The principal has indicated that it is up to Sophie's parents to sort out any on-going medical problems that are interfering with school attendance.

### ***Question 1: What services and support should already have been in place for Sophie AND for her parents?***

- Education plan and teacher awareness
- SENCO
- GP advice and guidance
- CAMHS Referral
- Voluntary Agencies
- SENAC
- Mentorships
- Home Support
- EWO – for support
- Access to ASD Intervention Service
- Educational Psychologist
- Family Support  
Transition Officer and Review
- Paediatrician – to signpost crucial services
- Social Worker
- Partnership between Trust and Education
- Dietician
- Classroom assistant support

### ***Question 2: What difference would be made to the lives of Sophie and her parents if they had the support they needed?***

- Reduced anxiety for Sophie and Parents
- Prevent Mental Health issues - anorexia
- Feel more supported and less isolated
- Proper educational support means a happier child, and therefore happier parents
- Enable support for child and family
- Parents more positive and optimistic about child's future
- Learning social and life skills for future

### **Scenario 3: Moving into Adulthood**

John is 17, and left secondary school at age 16 with no qualifications. He had been excluded on a number of occasions, due to his “disruptive behaviour”. He has been attending a part-time sound recording course at the Tech, but is finding staff are not helpful, and do not understand his perspective on life. His mum Maria is a single parent and she is unemployed. She now has to drive him daily, as the free transport finished after the first year.

Maria believes his challenged behaviour may be due to Asperger’s Syndrome. She has asked for a formal assessment, and has been told her Trust does not offer adult diagnosis.

John would like a career in music. He also wants to live independently. However, his limited benefit income and poor social skills means he has no choice but to stay at home with his mum. His Trust has not offered any opportunities for social involvement, or learning. Maria feels very isolated, and worn down from battling to get support from the system.

#### ***Question 1: How can Maria obtain a timely referral for formal diagnosis for her son?***

- Approach Trust AST – Autism Spectrum Team
- Look into information in local Trust area
- Contact other agencies – Mencap, CAB, Autism NI
- Is 17 adult services? Find out!
- Needs to develop own knowledge
- Approach GP for advice and guidance
- Request referral for Autism Assessment
- Ask for written reason why Trust has refused diagnosis
- Area ASD Co-Ordinator

#### ***Question 2: What do you think might happen to John in the future, if he does not get the help he needs?***

- More excluded/socially isolated
- Remain unemployed
- Poor self-esteem/self-worth
- Significant impact on relationship with mum
- Might leave home and fall into vulnerable or homeless situation
- Fewer life chances
- Poor emotional wellbeing – Mental Health issues?  
Without diagnosis - no access to services, opportunities, support and advice
- Educational isolation
- Won’t receive benefits he is entitled to

## **5. Evaluation Analysis and Recommendations**

69 completed evaluation forms were returned by the end of the workshop. After reviewing these, 58 (84%) found that the workshop was useful or somewhat useful, and 11 (16%) found that the workshop was not useful to them. It was clear from all of the Evaluation Forms that attendees would like further information that is more specific to their own personal situation, and in relation to their Trust area.

There are a number of key points noted that attendees found useful:

- Attendees found that they had learned a lot more about the services available in Northern Ireland
- A large proportion of responses indicated that the information provided through presentations and hand-outs gave them a better understanding of ASD
- The opportunity to network and meet other people with similar issues proved useful to many
- Several responses stated that presentations from E Simpson and L McKerr offered a beneficial insight into the real life experiences of a service user and a parent.

There are a number of key points that were identified as areas for improvement for future workshops:

- Some found that the day was too rushed and that more time for question and discussions would be beneficial
- Attendees found that some of the information was quite specific to individual Trusts and did not apply to them, and stated that input from all 5 Trusts would have been better
- It was noted that physical hand-outs of the presentations being delivered would have been useful
- Although many people found that the information on services was very useful, it was noted that more specific information on what services are available in each Trust area and how to access these services would be appreciated.

The Evaluation Forms also requested suggestions for topics for future workshops. Many suggestions were received, and some of the most popular are listed below:

- ASD Workshops for individual Trusts
- Information and guidance regarding available Benefits
- Advice for parents - young people, puberty and sexuality
- Workshops for young people with ASD – puberty and sexual education
- Information for parents in relation to young people, social interaction, self-esteem and motivation
- Advice in relation to severe learning disability and ASD transitions
- Individual workshops on different life options for young people with ASD – education, further education, employment