

**Red2Green**



# Adult Autism Development Project Launch

**Wednesday May 19<sup>th</sup> 2010  
4:00 p.m. – 6:00 p.m.**

The Meadows Community Centre  
St. Catharine's Road  
Cambridge  
CB4 3XJ

Maria Cooper Development Officer for Adults with ASD  
June 2010

## Introduction.

### Autism

Autism (Autistic Spectrum Disorders, ASD, Autistic Spectrum Conditions, ASC) are complex lifelong developmental conditions that affect approximately 1%<sup>i</sup> of the population. People with the condition have difficulties in three main areas: social communication, social interaction and social imagination. They may also display rigid stereotyped behaviours and can often have sensory difficulties.

It is believed approximately 20%<sup>ii</sup> of people with Autism also have a learning disability and many have other co-occurring medical conditions such as epilepsy, depression and anxiety. People with Autism and learning disability are usually eligible for support from learning disability services (Learning Disability Partnership - LDP) health and /or social care professionals. Those people with Autism who do not have a learning disability may not meet adult social care eligibility criteria but some may. It is often unclear if they do need support if they will be supported by learning disability or mental health services. Currently the LDP undertake social care assessments for vulnerable adults. Many others who may not be eligible still experience significant difficulties that impede their daily lives and independence.

### Legislation.

There have been a number of legislative and policy developments recently that have highlighted the gaps in services for people with Autism. The Autism Act 2009 and the newly published National Strategy for Autism places new obligations on NHS and local authorities to meet the needs of all people with Autism.

### Adult Autism Development Project

Cambridgeshire Learning Disability Partnership acknowledged the need for dedicated resources to improve access to support, before any of this legislation was implemented. A Multi-agency Adult Autism Consortium was formed and an Action Plan was drawn up to improve the lives of those with Autism. One key element, was the need for a development project and together with NAS (National Autistic Society), Red2Green were awarded funding for 2 years to work in partnership with Cambridgeshire County Council and NHS Cambridgeshire. The key purpose of the project is to bring

about positive change in outcomes for people on the Autistic Spectrum. The project is now able to champion the cause, identify best practice, map and document existing provision across the county and highlight gaps in provision. The project also covers those young people going through transition from children's to adult services and links to Children and Young People's services developments.

## Project Launch.

The Development Officer had been in post for 6 months before the launch.

### Aims

Careful consideration was taken into the objectives of the launch of the project and the following aims were drawn up.

- To increase awareness of the project throughout Cambridgeshire.
- To give a clear overview of the role and aims of the project.
- To provide an opportunity for those with Autism, their parent/carers and professionals to meet together.
- To provide an opportunity for people with Autism, their parent/carers and professionals to comment on current services and issues and identify how they would like them to be in the future.
- To encourage active participation by those with Autism and their parent/carers
- To introduce the Development Officer for Adults with Autism Spectrum Disorders

### Invitees

Invitations went out to statutory, third sector, service providers, parent/carers, people with Autism and those with an interest.

### Speakers and Talk Content

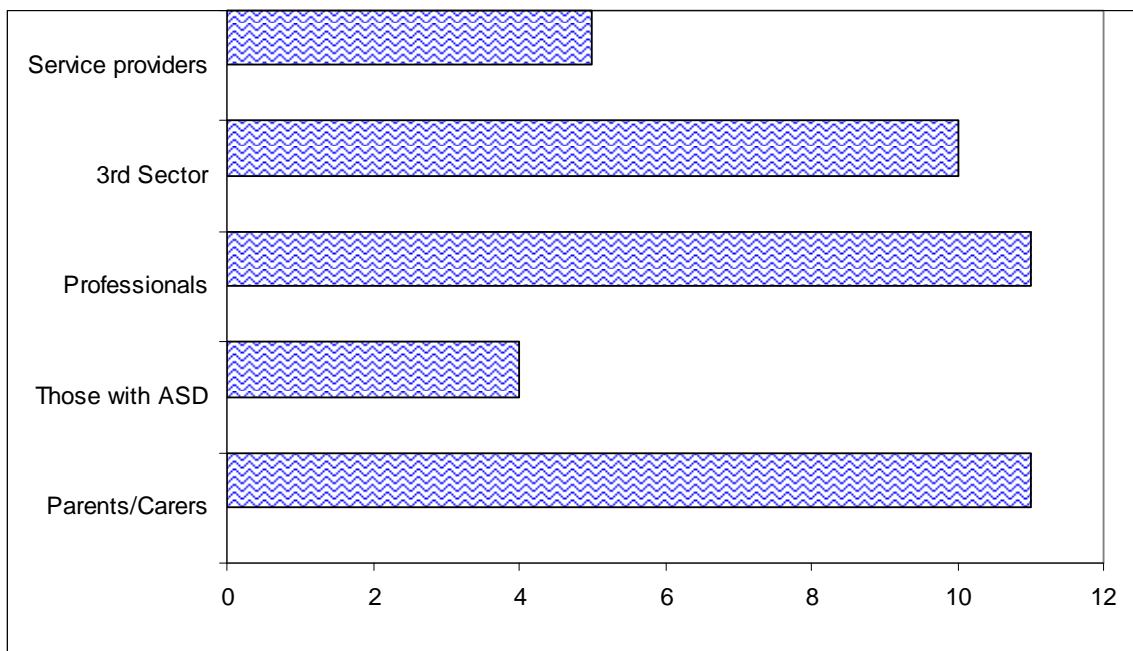
- Claire Bruin Service Director Adult Support Services - Chair Cambridgeshire County Council involvement and partnership working
- Maria Cooper Development Officer for Adults with ASD- role and aims

- Carol Povey NAS Director of The Centre of Autism - The Autism Strategy
- Joanna Hastwell\* Aspergers Syndrome Project Offer, Disability Resource Centre, The University of Cambridge- Aspergers Syndrome and University
- Ruth Rogers Chief Ex Red2Green Closing address

\*Joanna Hastwell kindly offered to talk after Professor Simon Baron-Cohen (and most of the ARC team) sent his apologies due to the fact he was flying out to Philadelphia that day , for IMFAR,(International Meeting for Autism Research).

Attendees.

41 people signed in, 10 people sent their apologies that day, and 4 people were unable to attend. A good cross-section attended.



## Table-top Discussions

Attendees sat at three tables for parent/carers and those with ASD or for a mixture of 3<sup>rd</sup> sector, service providers, professionals, and parents.

Facilitators:

- Sam Sizer                      Parent and NAS Cambridge Co-Branch Officer
- Joseph Simon                Parent and NAS Cambridge Co-Branch Officer
- Susan Owen                 Aspirations manager Red2Green.
- Bev Price                     Regional Officer National Autistic Society.

The groups were asked to work on 2 key aspects.

First discussion point    (20 minutes to discuss and record)

***What do services look like now?***

- Diagnosis
- Services and Support
- Information received.

Second discussion point    (20 minutes to discuss and record)

***What would we like services to look like?***

- Diagnosis
- Services and Support
- Information needed

Facilitators provided a brief feed-back.

A list of the key points is enclosed.

## Points Raised

### 1. Diagnosis

Present	What it needs to be like
<ul style="list-style-type: none"> <li>• Fortunate to have CLAASS but expect parental input for childhood experience.</li> <li>• CLAASS - good but:</li> <li>• GP's have had pay £1,000</li> <li>• 3 - 15yrs</li> <li>• Diagnosis requires living relative present</li> <li>• If also has learning disability still able to get diagnosis.</li> <li>• with Aspergers/ High functioning diagnosis can be longer</li> <li>• sometimes almost accidental</li> <li>• Can be very slow with a delay in clarifying the condition.</li> <li>• some are unsure where to go or who you talk to.</li> <li>• varies at different ages</li> <li>• can have to fight to get it.</li> <li>• takes a long time - long wait.</li> <li>• sometimes its a bit vague.</li> <li>• GP lack of clarity</li> <li>• some restrictions around diagnosis (LD)</li> <li>• Psychiatrists - unclear/ patchy / inconsistent</li> <li>• ?need ld to get referral to Psychology.</li> <li>• RELATE</li> <li>• A lack / Gap</li> <li>• timescale for assessment</li> <li>• refer for other reason then diagnosis made</li> </ul>	<ul style="list-style-type: none"> <li>• Clear consistent pathway</li> <li>• not having to pay for diagnosis as reliant on GP being prepared to pay for it.</li> <li>• freely accessible</li> <li>• follow up appointments</li> <li>• post diagnosis support to include - info pack / follow up appointments</li> <li>• Better links to information</li> <li>• acceptance of siblings view of childhood experience</li> <li>• diagnosis without 3<sup>rd</sup> party childhood experience</li> <li>• carers / family's views taken into account</li> <li>• adequate time / information from others taken into account</li> <li>• needs to lead to information, advice, signposting that is consistent with diagnosis.</li> <li>• Need an accessible easy service with good follow up support.</li> <li>• wider availability</li> <li>• Diagnostic pathway including care management</li> <li>• Awareness needs to be widespread</li> <li>• Awareness can also lead to better and earlier diagnosis</li> <li>• Carers being informed and helped to access diagnosis if appropriate</li> <li>• a pathway model not crisis response.</li> </ul>

## 2 Services, Support and Awareness

Present	What it needs to be like
<p style="text-align: center;"><u>General</u></p> <ul style="list-style-type: none"> <li>• varies where you are and where you lie.</li> <li>• Some UNI's brilliant others not.</li> <li>• What happens post diagnosis?</li> <li>• diagnosis can sometimes lead to a service / statement etc</li> <li>• gaps/ Slips between education, health and social support</li> <li>• Benefit issues</li> <li>• Rural isolation</li> <li>• Lack of training for staff in services</li> <li>• Speaking Up /Next Steps new project in Oct 10</li> <li>• Advocacy across county</li> <li>• Psychotherapy</li> <li>• Social care if LD- Community LDP support people with Id and ASD</li> <li>• Gap for people with higher functioning ASD</li> <li>• no needs led</li> <li>• Mencap / other providers</li> <li>• NAS Cambridge Branch</li> <li>• Funding crisis</li> <li>• Particular gaps in Fenland</li> </ul>	<ul style="list-style-type: none"> <li>• ASD awareness amongst frontline professionals</li> <li>• socialisation / sport activities</li> <li>• Need to be responsive , listening and adaptable.</li> <li>• are influenced by family experience</li> <li>• non patronising.</li> <li>• recognise adults</li> <li>• value positives yet take account of specific needs.</li> <li>• mainstream taking account of ASD needs.</li> <li>• support based on need and not diagnosis.</li> <li>• Much more awareness over all services.</li> <li>• A one stop shop - but remembering one size does not fit all.</li> <li>• Geographically accessible and in all other ways</li> <li>• Aim to develop relationships</li> <li>• Working with people with ASD / families / partners / parents+ carers</li> <li>• Sees parents / carers / people with ASD as experts.</li> </ul>
<p style="text-align: center;"><u>Transitions</u></p> <ul style="list-style-type: none"> <li>• Aspergers + High Functioning AS do not get the same level of support into adult services. No social work support,</li> </ul>	<ul style="list-style-type: none"> <li>• schools should be better informed especially around transitions</li> <li>• support in everyday life</li> <li>• after school mentoring into work</li> </ul>

<ul style="list-style-type: none"> <li>• Its only crisis management.</li> <li>• Less support from adult teams /</li> </ul>	<ul style="list-style-type: none"> <li>• better transitions - proactive and not reactive.</li> <li>•</li> </ul>
<p><u>Support into Employment</u></p> <ul style="list-style-type: none"> <li>• Connexions little understanding of ASD</li> <li>• no real help</li> <li>• no awareness at employment services</li> <li>• DWP no understanding of support needs</li> <li>• Limited employment advice / lack of understanding</li> <li>• Limited information about support,</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• more people in paid jobs</li> <li>• access to advice and support after school and UNI</li> <li>• DEA / Job centre aware of needs</li> <li>• Job clubs/ support / job coaching for ASD</li> <li>• Increased use of Access to work initiatives.</li> <li>• Better into work support</li> <li>• Support at different stages</li> <li>•</li> </ul>
<p><u>Housing + support to live independently</u></p> <ul style="list-style-type: none"> <li>• Have been trying to arrange a special housing for 5 years</li> <li>• access very difficult</li> <li>• Very difficult</li> <li>• Communication problem</li> <li>• No overall plan</li> <li>• Some visiting support via housing (Supporting People floating) agencies</li> <li>• Limited ongoing support</li> <li>• Lack of / critical need for supported living</li> </ul>	<ul style="list-style-type: none"> <li>• support to live independently</li> <li>• continuity make sure that if the family is not able to support any more somebody can continue</li> <li>• Preventative not crisis management</li> <li>• small ASD communities</li> <li>• access to specialist accommodation / support locally not out of county</li> <li>• person centred planning - shared</li> </ul>

### 3. Information

Present	What it needs to be like
<ul style="list-style-type: none"> <li>• Care manager with relevant experience can provide info.</li> <li>• No info in general</li> <li>• Red2Green / Aspirations</li> <li>• Got adequate info on benefit</li> </ul>	<ul style="list-style-type: none"> <li>• Solicitor , legal advice on all sorts of things / wills / trust funds</li> <li>• Life after parents die.</li> <li>• Need a listening ear / someone</li> </ul>

<p>entitlement but only because of parents.</p> <ul style="list-style-type: none"> <li>• Lack of guidance as to where you go for what</li> <li>• Fight for your rights</li> <li>• You "trip over" information</li> <li>• its variable depends who you link with</li> <li>• Some signposting</li> <li>• Limited information - needs more</li> <li>• Links to others</li> <li>• NAS Cambridge + website</li> <li>• National websites</li> <li>• No one place for parents / carers / professionals</li> <li>• Generic carers groups not appropriate</li> <li>• Carer workers in each locality</li> <li>• CCC website / Contact centre</li> <li>• Speaking Up + advocacy</li> </ul>	<p>to talk too / not just written or web information</p> <ul style="list-style-type: none"> <li>• Information needed about employment options</li> <li>• Drop in opportunity</li> <li>• a person on the end of a phone</li> <li>• Easy to understand</li> <li>• Seen as a service in its own right</li> <li>• Libraries used as a resource with staff that are aware.</li> <li>• Range of internet and written materials and A-Z.</li> <li>• Champion what we do have,</li> <li>• funding and support opportunities</li> <li>• local strategy - all working together</li> <li>• close the gap - lots of people with ASD don't meet social care eligibility criteria but still need support, advice and information</li> <li>• what is available and where - and what's not</li> <li>• ASD county wide events</li> </ul>
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### Feedback.

All facilitators briefly fed back the points raised during consultation, to all attendees.

Those present were informed the project would produce regular up-dates in the form of newsletters.

### Participation

One person asked for a follow-up event, preferably to newsletter. Which was agreed.

Those on the spectrum were contacted and consulted after the launch and asked, how could any future events could be made more accessible and comfortable.

## Outcomes

A follow-up event will be arranged for 6months time.

Points raised during table-top discussions were then circulated and discussed at the next Adult Autism Multi-agency Consortium and relevant actions included in the action plan.

## Recommendations

- To hold follow-up event
- To send out agendas to those on the spectrum before the event
- To have larger a venue, to allow more free space
- To establish if anyone has additional needs
- To encourage additional engagement from Health
- To ensure everyone signs in

## Conclusions

The event was well received, and well attended from a good cross section. Feedback from attendees was very positive. The event achieved the original aims.

## Acknowledgements

Thanks go to all the speakers, and those who helped during the event and a special thanks goes to Adam for giving permission in the reading of his piece at the launch and to allowing it to be printed (appendix 2).

**Appendix 1. List of attendees who signed in**

Sallyanne Broughton	Community LD Nurse	CCC
Helen Brown	Chief Exec	Crossroads
Pauline Brown	R2G Trustee	Red2Green
Jean Clark	Commissioning Manager	CCC
Margaret Drew		Parent
Graham Fitzgerald	Project Manager Next-Steps	Speaking-up
Marie Gilmartin	Social Worker	CCC
Sara Halliwell	Learning Support	Hills Rd 6 <sup>th</sup> Form
Christine Hannington		Parent
George Hoskin		Service User
Richard Holland	Aiming High Commissioning	CCC
Frances Johnson	Adult Tutor	Independent
Annika Lewry		Service user
Phyl Lewry		Parent
Sheila Link	Support Officer	Cambridge Housing Society
Gordon MacKenzie	Support Officer	Cambridge Housing Society
David Moat	Psychotherapist	ASD Therapy
Geoff Morris		Parent
Jan Morris		Parent
Natalie Murzina		Parent
Anne Necus	Clinical Psychologist	CCC
Jonathan Ramsden		Service User
Peter Ramsden		Parent

Suan Rowland	R2G Trustee	
Joseph Simon	NAS Branch Officer	& Parent
Sam Sizer	NAS Branch Officer	& Parent
Cheryl Smith	LD Nurse	CCC
Tracy Smith	Transitions Social Worker	CCC
Ben Steven		Service User
Mark Steven		Parent
Fiona Whelan		Parent
Bob Turner	Marketing Manager	Brookdale Care
Paul Williams	Equality and Diversity Officer	South Cambs District Council
Claire Bruin	Service Director	CCC
Sharon Burrows		R2G
Maria Cooper	Development Officer	R2G
Joanna Hastwell	AS Project Officer	Disability Resource Centre University of Cambridge
Susan Owen	Learning Programme Manager	R2G
Carol Povey	Director of Centre of Autism	National Autistic Society
Bev Price	Regional Officer	National Autistic Society
Ruth Rogers	Chief Exec	R2G

## **Appendix 2**

### **Autism and Me as read by Ruth Rogers**

My name is Adam

Adam highly probable has Autism

Adam gets overload when too much happens

A room with too much different items is hard to take in so Adam usually looks at the floor.

Adam find it hard to understand people are saying because there are lots of other things happening like smells and sounds and more.

Adam find it hard to know what to do first.

Adam has to work everything out because Adam can't do it automatically.

Adam sometimes need to do things different way.

Adam shut down sometimes if there is too much information. Adam needs information slow down.

Adam sometimes sits in the room with the blue roller and big ball for quite.

Adam find it hard to make friends because Adam doesn't know what to say or do.

Adam sometimes works better on own and sometime in group.

Adam sometimes rocks or twist in a circle or move hands or rub face when things are bad.

Adam has strong senses.

Adam find certain smells (like vinegar), sounds (like singing birthday candle), tastes (like too much different flavours example lasagne), touch (some clothes) and sight (too much going on in one room) hard.

Adam find touching difficult but unexpected touching is even worse.

Sometimes things rush in to Adam head but other information comes before Adam can say it.

Sometimes Adam takes long time to think of something but sometimes it is good when it comes.

Things upset Adam usually a different thing each time.

Adam has a sense of humour.

Adam doesn't mind being like Adam (most of the time).

### Appendix 3

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<sup>i</sup> No prevalence studies of adults have been carried out. 1 in 100 is the best estimate of prevalence in children from the most recent studies. This figure is accepted by the National Autistic Society and the NHS.

<sup>ii</sup> At present it is not possible to give an accurate figure of those with autistic spectrum disorders and a learning disability (IQ less than 70). Using the accepted projections based on recent studies and the 2001 census, the tables (NAS) below show a combined estimate of 535,000 have autistic spectrum disorders in the UK

People with Learning Disabilities		
	Kanner's	Other Spectrum Disorders
Children	6,700	20,000
Adults	22,700	68,200
All Ages	29,400	88,200
<b>Total</b>	<b>117,600</b>	

People with Average or High Ability (IQ 70 or above)		
	Asperger Syndrome	Other Spectrum Disorders
Children	48,100	46,700
Adults	163,600	159,000
All Ages	211,700	205,700
<b>Total</b>	<b>417,400</b>	