

# GREATER MANCHESTER AUTISM CONSORTIUM

## STEERING GROUP MEETING

To be held on Wednesday 2<sup>nd</sup> December 2009

1pm – 3pm

The Link Centre

140 Union Street

Oldham

OL1 1DZ

## FAMILY SERVICES DEVELOPMENT PROJECT REPORT

### DISTRIBUTION OF REFERRALS

(As from 1<sup>st</sup> September – 20th November 2009)

Local Authority	Total referrals	Male referrals			Female referrals		
		All ages	Under-19	Under-5	All ages	Under-19	Under-5
Bolton	170	134	57	0	36	10	0
Bury	145	123	61	2	22	13	0
Manchester	493	441	260	4	52	33	0
Oldham	99	82	43	3	17	7	0
Rochdale	132	109	53	1	23	12	1
Salford	184	154	82	1	30	15	0
Stockport	312	257	146	3	55	33	0
Tameside	124	106	64	2	18	6	1
Trafford	210	175	97	2	35	17	0
Wigan	103	89	41	1	14	6	0
Left GMA	25	20	7	0	5	3	0
Closed Cases	17	13	4	0	4	2	0
	<b>2014</b>	<b>1703</b>	<b>915</b>	<b>19</b>	<b>311</b>	<b>157</b>	<b>2</b>

There have been 25 new referrals during this quarter.

## ANALYSIS OF STATISTICS

(Period covered 1<sup>st</sup> September – 20<sup>th</sup> November 2009)

AUTHORITY	NO OF FAMILY/ INDIVIDUAL CALLS	NO OF PROF CALLS	TOTAL TIME PER AUTHORITY		ISSUES RAISED										
			HRS	MINS	1	2	3	4	5	6	7	8	9	10	11
BOLTON	7	1	1	58	2	3	4	0	1	1	0	0	3	0	0
BURY	4	4	1	33	0	0	3	2	0	0	0	0	3	1	0
MANCHESTER	35	10	12	37	3	3	13	14	0	2	0	1	18	2	0
OLDHAM	3	1	1	58	0	1	2	0	0	0	0	0	1	0	1
ROCHDALE	6	2	1	50	0	1	5	1	3	0	0	0	0	0	1
SALFORD	2	1	0	44	0	1	2	0	0	0	1	0	1	0	0
STOCKPORT	17	1	4	57	1	4	6	5	0	0	0	0	8	1	1
TAMESIDE	4	0	1	33	2	0	1	2	0	1	0	0	0	0	0
TRAFFORD	9	5	3	48	0	1	7	2	2	1	0	1	5	0	1
WIGAN	12	3	4	28	2	1	5	7	0	0	4	2	2	2	1
OTHER	5	1	2	25	0	0	3	2	0	0	0	0	0	0	0
<b>TOTAL</b>	<b>104</b>	<b>29</b>	<b>37</b>	<b>51</b>	<b>10</b>	<b>15</b>	<b>49</b>	<b>37</b>	<b>3</b>	<b>8</b>	<b>5</b>	<b>4</b>	<b>41</b>	<b>5</b>	<b>4</b>

### KEY TO ISSUES RAISED

1. Issues around diagnosis
2. Behaviour management
3. Family support
4. Support for adult with ASD
5. Respite (overnight accommodation)/ Residential care
6. Benefits
7. Leisure
8. Transition (14yrs-19yrs)
9. Education
10. Mental Health – Children
11. Mental Health – Adults

### Other issues raised during this quarter:

Housing  
 Criminal Justice x 3  
 Counselling  
 Employment x 3  
 Further Education x 3  
 Sex education  
 Fundraising x3  
 Training x 3  
 Siblings  
 Bullying  
 Bus Pass  
 Airport  
 Christmas

## **AUTISM SERVICES DEVELOPMENT GROUPS**

### **BOLTON**

Children's Group: Following discussion about the Manchester Children's Hospital event in September, the group decided they would like to do some work developing simple person centred plans or passports that could be used in health settings. This could be one of a set of three (health, education, social/general) one or two page profiles that professionals and parents could fill in together containing essential information about a child with ASD.

As part of the Aiming High initiative, Bolton has signed up to the Me Too! kitemark scheme where young people with disabilities train in and then rate the inclusiveness of community services.

The SENIAS team, along with the local authority, are looking at ways to target extra support to those children with ASD in mainstream primary schools who may otherwise be at risk of exclusion. Different models are being explored and will be consulted upon.

Adults group: – The Adult group met on Tues 16<sup>th</sup> September and decided to hold a planning event in November to look at the professionals in Bolton who offer support to adults with an ASD. The day will look at individual services, how they support people with an ASD at the moment, the challenges they face and how they could provide better services and support. Following on from this will be Bolton's plan to better support people with autism after using the information day as a platform.

### **BURY**

ASD Brokerage service is now up and running and there was a Family Information day about self-directed support on November 20<sup>th</sup>. The day was well attended and there were talks about Community Care assessments, Person Centred Plans and Individual/Personal Budgets. Service providers will be at the information sharing day on Dec 9<sup>th</sup> at the Met, Market Street, Bury 10am -6:30pm.

At the moment Sarah Crookdake is still gathering information about available services but she has started to support a few adults. Issues with these young people have focused on the lack of knowledge of specific needs of young people with an ASD in further education.

Autism Services Development Group: Met on the 21<sup>st</sup> September. Aiming High money has been used to start play schemes for children with an ASD and complex health needs. Karen Ross was wary of the lack of staff and their knowledge at one of the schemes. There is a new ASD support group run by Bury Carers.

### **MANCHESTER**

Children's group: The NAS do not sit on this group, as explained by Mari, as we are seen as a service provider. No sub-group activity has taken place since the last meeting. Mari has written to the LDP Board to clarify our role re development and is awaiting a reply. There has been a new education strategy published by the Local Authority – this includes the autism specific schools for South, Central and North

Manchester and the mainstream autism specialist. Gavin continues to attend post-diagnostic groups.

The new children's hospital in Manchester is trying to develop a care pathway for children with planned and unplanned admission. Gavin sits on the working group and the plan is to produce a health passport for visits and also a protocol for families and professionals which would begin before the visit. There will be a review of nurses' knowledge of ASD, their training and experience; the director of nurse training sits on group.

Adult Group- The group met in September to pull together their Autism Strategy response. There were good and bad practice examples included. The consultation events gave a good mix of responses and thoughts from people on the spectrum and parents and carers. They met again on October 28<sup>th</sup> and set an agenda for 2010 – re response to Act/Strategy, review membership, training audit for professionals and diagnosis.

## **OLDHAM**

Children: The training group continues to review and develop its training strategy. The train the trainer has been a success (people with autism). The NAS has started a "Buddying" scheme in Oldham (October 2009 - October 2010) and Trafford (November 2009 - March 2010). We are working with Oldham council and Trafford CPS and the projects are funded by the governments aiming higher scheme. We will be matching volunteers aged 16 to 19 years old to young people aged 11-16 with an ASD on a 1:1 basis. The aim is to enable young people with an ASD to fit in with others of a similar age by accessing mainstream activities in their area such as youth groups and sports clubs as well as doing other every day activities such as going to the cinema, meeting for lunch or going bowling.

Adults: The Way Forward meeting was held on 24<sup>th</sup> September. The group is very well attended but wants to have a more focused direction around the themes of the meeting.

## **ROCHDALE**

The group has been re-established and will be meeting on Friday 30<sup>th</sup> Nov.

## **SALFORD**

Children's Group: The group are looking at ways of supporting the Aiming High initiatives via multi agency training, as it is felt that universal services could provide for some children with ASD with additional training and support. An area needs assessment has been completed, although consultation with parents and local groups is ongoing.

A more standardised care pathway is being looked at by a small task group. A student is currently auditing parents' experiences of diagnosis via the local Child Development Team.

There is some uncertainty about secondary education ASD developments anticipated under the new schools for the future programme.

Adult Group: The group organised a planning day on the 13<sup>th</sup> November to plan for the future. This was attended by around 20 professionals from Salford as well as Gavin. The various outcomes from the day included a new round of person centred reviews, joint assessment between LD and MH teams (a working group has been set up), user involvement day, review of number of adults with autism and the use of current transition information. Adult services are also trying to set up a pilot befriending scheme but did not get funding from Salford University. They will try alternative funding streams.

## **STOCKPORT**

Children's Group- As part of the care pathways work, the group are looking at ways of making post diagnostic interventions more equitable and clarify which services should be involved at what point and with whom. It is felt that currently there can be a postcode lottery for services received, particularly centred on school placement. Services are being audited to ascertain which groups they work with, in what way, what training is provided etc to ensure the most effective use of resources in the future by identifying gaps and avoiding duplication.

Adult Group- No group has met recently but there is work ongoing regarding the AS Service. The Employment Support Officer is now in post at Pure Innovations as is the new social worker, Dawn Price, and Gavin is meeting her next week to discuss the consortium and her role. There hasn't been announcement yet about the service provider.

## **TAMESIDE**

The pilot of the Social Care training took place on 18<sup>th</sup> September. There were 12-15 social workers and the training was led by Dan Redfearn. Feedback was very positive and the pilot sessions will now be rolled out in Trafford in the New Year.

Dan submitted a comprehensive response to the autism strategy and the Autism Strategic Planning Group is following the headings from the strategy with the sub-groups. There will be a more focused theme to the meetings in future – the December meeting will be around transition. Dan also had a stall at the World Mental Health Day Event on 9<sup>th</sup> October.

Dan has submitted a diagnosis service proposal to NHS Tameside and Glossop and to aid this Gavin has asked the PCT how many out-of-areas diagnostic assessments they have funded within the last 3 years and the costs involved?

TASCA had a planning meeting for World Autism Day next year.

## **TRAFFORD**

There will be training sessions for 32 social workers around assessing adults with an ASD in early Jan 2010.

LD services are now provided by Cheshire and Wirral Partnership NHS Foundation Trust.

## **WIGAN**

A response to the autism strategy was sent by Mari and parents of adults in Wigan. This was then sent onto Andy Burnham, Secretary of State for Health and MP for Leigh. He agreed to meet the parents. This meeting was on 9<sup>th</sup> October and the parents raised their concerns about the lack of provision in Wigan for adults with an ASD. Examples were given of other local authorities who have AS/ASD specific services. He has set up a cross agency meeting for 29<sup>th</sup> January 2010.

On 14<sup>th</sup> September there was a Wigan One Stop Shop event for people with ASD. This event had awareness-raising at the start of the day and a chance for appointments with individual organisations in the afternoon, including the NAS. The event led to an increase in calls to the project.

An Autism Strategy Group Meeting was held on 5<sup>th</sup> November. During the adult services review over the next 12 months there will also be an audit of the number of people with an ASD.

Helen Madden, Educational Psychologist, is trialling the diagnostic pathway at the moment and there will be a multi-disciplinary team for child diagnosis. Gavin has sent the IDA material that was launched by NHS North West (see below).

## **NW IDENTIFICATION, DIAGNOSIS AND ASSESSMENT OF AUTISM GROUP (NHS NORTH WEST):**

This group held its fourth annual event publicising regional work designed to improve the identification and diagnostic processes for children with autism and their families. This year the steering group used the event to launch a basic toolkit of materials that PCTs and local authorities might find useful in both creating and improving their own ASD care pathways. This included some template leaflets for families explaining processes and diagnoses. These can be adapted according to local circumstances, and contains space for local contact details.

At this event two North West localities shared their pathway journey so far, a Clinical Psychologist spoke about explaining their diagnosis to young people and what it means, and a parent explained the impact of waiting years for a diagnosis.

We can send copies of all the toolkit materials via email to anyone who would like them.

## **TRAINING STRATEGY GROUP**

The children's group have met once since the last CSG. The group started to pull together materials and an outline for the 'growing up and relationships' work. A pool of material has been put together and two professionals who already deliver this training to children (including children with ASD) have been invited to the next meeting.

The adult group have decided to focus on issues re safeguarding and ASD as their next topic.

## **CRIMINAL JUSTICE ISSUES**

The Criminal Justice Forum (NW) met on the 17<sup>th</sup> September, with a very high turn out from a range of different organisations and professions (police, forensic nurses, mental health social worker, clinical psychologists). Terms of reference for the group have now been circulated as the membership has been transient at times. The next meeting is 3<sup>rd</sup> December 2009.

Gavin has met with James Gibbs, the regional co-ordinator for Greater Manchester Voice UK who is doing a lot of good work including their national helpline and training for adults with a learning disability who have been victims of crime. They also cover safeguarding issues. There may be a link with Voice UK's training around safeguarding to see if it can be adapted to an ASD audience. James and Gavin also spoke about the CJ Forum and he will, hopefully, attend the next meeting.

Gavin and John Davies have delivered training to GMP and this will be a rolling programme. Gavin has also carried out training to the Greater Manchester West Mental Health Trust Engagement and Diversity team.

## **HELP! PROGRAMMES 2009**

Programmes delivered between September – November 2009:

- Oldham 1 day programme attended by 20 families
- Tameside help! 2 programme (“siblings” 16 families and “managing anger” 18 families)
- Macclesfield- 3 day programme (this generally draws a lot of people from Stockport area) 7 families
- Cheshire help! 2 “toileting” (opened up to families in Greater Manchester) 11 families

Upcoming programmes:

Salford 3 day programme in January 2010

North Manchester 1 day programme in January 2010

Bury help! 2 in March 2010

Stockport help! 2 (sensory and toileting) in March 2010

## **CONFERENCES**

Mari Saeki and Andrew Powell, co-authors of the *Social Care: Assessment of need for adults with an ASD* guide on ASD spoke at a joint NAS and British Association of Social Work Conference in Birmingham on 10<sup>th</sup> September. The subject was ‘Assessment and ASD’ and they received a very good audience response and requests for the booklet are still high.

Gavin attended an Information Sharing day for the voluntary and public sector in Trafford. As part of the process the project's information sharing process will be

audited to see how effective we are at passing on information to professionals, families, parents, carers and people with an ASD.

## **NEWSLETTER**

The AutismGM newsletter (autumn/winter edition) has been produced and is being distributed.

## **AUTISM ACT AND STRATEGY**

The Autism Act passed its final stage in the Lords on 22<sup>nd</sup> Oct and obtained Royal Assent in November. This makes it the first ever disability specific law. The Act, which will come into force in Jan next year, means that the Adult Autism Strategy is legally enforceable and the Strategy will be published in April 2010 and implemented by Oct 2010 with guidance issued by Dec 2010. Guidance will be used to establish case law.

Guidance will include:

- Provision of relevant services for the purpose of diagnosing ASDs in adults
- Identification of adults with an ASD
- Assessment of the needs of adults with an ASD and provision of relevant services
- Planning of relevant services as move from children's services to adult services
- Planning of relevant services for adults
- Training of staff who provide these services
- Lead member of staff responsible for these actions

From April to Sep 2009 Department of Health (DH) consulted on the Autism Strategy and they are also considering the recommendations and findings of the National Audit Office report *Supporting People with Autism through Adulthood* published July 2009

The DH is now asking interested parties ie. Local Authorities and Primary Care Trusts a series of questions:

- How do we commission, design and develop services on the basis of scant information?
- Are there identified gaps in service provision where improved information would deliver benefits?
- What are the barriers within current services (mainstream and specialist)?
- How can we best support integrated working across health and social care to meet needs of adults with an ASD?
- How do we establish "pooled budget" arrangements
- How do we develop training programmes to widen understanding and awareness
- Establishing commissioning competencies/standards for services
- How best to deliver strategy locally?

## **GREATER MANCHESTER CONVENTION**

The convention has been booked for the **11<sup>th</sup> May 2010** at Best Western Hotel, "Smokies Park", Ashton Rd, Bardsley, Oldham.

Gavin Owen and Debbie Waters  
Project Officers – Family Services Development Project