

January 2007

A message from Dot..

Dear All

You may remember me from contacts made over the last two years, either directly or through the mail. I have been working in several different roles over the last four years and I am aware this may have caused some confusion. I felt it may be helpful to share some of the work that I and my colleagues have been involved in, and introduce you to some future proposals which may be of interest. Many of you have contributed information and situations to me and this letter is an attempt to keep you updated with the areas I know about.

1. Autism and Asperger Action Group

You may recall that I have worked, and continue to work, with several parents/carers in a voluntary group – **Autism and Asperger Action Group** (for families with young people (14+) in transition, and adults). You may have met us at the Open Day we held in 2004 at Offington Park Methodist Church in Worthing when Chris Jacobsen presented her report about Autistic Spectrum Disorder (ASD) in West Sussex, together with a ‘meet and greet’ session with various agencies. The Autism and Asperger Action Group continues to lobby and work with local services, statutory and voluntary, to raise awareness of the needs of people with an ASD. Our membership has varied, but remains persistent! An outline of what we do (varying from local meetings to a visit to Parliament!), plus details of the aims and objectives of the group can be found at our website (www.aaaction.ukf.net).

2. Sussex Autistic Community Trust.

Between September 2004-November 2005, I was fortunate enough to work for Sussex Autistic Community Trust (SACT) as **Asperger Advice and Liaison Worker**. This was a role developed by SACT following funding from learning difficulty and mental health commissioning agencies. The aim was to respond to the problems of accessing services and fragmented information. Some of the outcomes of this role included:

- Developing a database (you probably sent me your details). SACT have kindly distributed this letter for me through that database. This has been done to conform to the Data Protection Act guidelines that govern the information you originally gave and the commitment of SACT not to share that information without seeking your permission first;
- Providing support for complex family situations which needed help with accessing services;
- Raising awareness of the challenges facing adults with an autistic spectrum disorder at significant meetings with statutory and voluntary agencies;
- Contributions to the Working Group for the Development of Services for People with ASD (including Asperger Syndrome) in West Sussex (see below);
- Supporting professionals in understanding the needs of adults with AS;
- In partnership with Adult Education, we developed a successful pilot course for young people with Asperger Syndrome, teaching social skills;
- In partnership with voluntary agencies (Learning Links and SASBAH), we developed a pilot ‘buddy’ scheme – Buddylinks – for three young people with AS. The pilot has now finished and due to lack of funding has not been continued although links developed through the pilot have been maintained;
- Acting as a resource for advice and information around AS.

In addition to their previous services, you may be interested to know that during the last two years SACT has also developed:

- Resource base in Battle, East Sussex, providing day care, training, information, etc
- Base in Bognor in the last year, providing day care and group work (including adults with AS)
- Outreach support service to support individuals in their own home with social skills and care
- Residential facility for 6 young people with autism in Bognor
- Training courses throughout the year for families and professionals
- Sheltered housing complex for 12 adults in Hastings, East Sussex with a plan to develop a similar facility in West Sussex. The residents have their own self-contained accommodation, and staff available 24 hours/day if required, although they may also be in employment and/or day activities/education.
- Worked in partnership with educational organisations to develop living skills for adults with ASD.

For further details regarding any of these developments issues please contact **Tricia Stubbs, Senior Administrator at SACT (see details above).**

3. Working Group for the Development of Services for People with Autistic Spectrum Disorder (including Asperger Syndrome)

This group, composed of senior management representatives from adult services, mental health, learning difficulty, and representation from the AAAGroup (see above), has been working over the last two years as a response to some of difficulties faced by adults and young people in transition with an ASD.

Its development arose out of a varied context: the problems identified in Chris Jacobsen's report; local families' experience; raised awareness to problems; and, the frustrations of professionals as they find difficulty meeting need due to issues such as eligibility criteria and limited/fragmented resources. This context is added to by the increasing national awareness of the needs of children and adults with ASD and the projected increasing numbers being diagnosed. The group was seen to be a major step forward and has, over the last two years, facilitated the development of a pilot Assessment and Diagnostic Clinic, commissioned and supported project work by Helen Knowles to develop a workable plan forward, and have secured funding for development of that plan.

The initial focus of this plan is to appoint a specialist manager. Peter Joyce has just been appointed and his role includes the following:

- provide a clear process to access services i.e addressing the problems around eligibility criteria,
- map services and clients in order to coordinate services effectively,
- develop a network of professionals with a specialist interest in ASD who are easily accessible by the community teams, e.g. social workers and mental health workers, who are supporting families on a day to day basis.
- implement a training strategy for professionals

Also the plan includes:

- Continuation of the Assessment and Diagnostic Clinic
- Further development - (1) provided the outcomes set are realised within the first year, it is hoped that specialist services can then be developed and added to the current provision (which will be readily identifiable through the mapping process).
- (2) the recent merger with East Sussex health and learning difficulty services, provides the opportunity to use this initial year as a pilot

which, if successful, can be extended to East Sussex, while the second phase of the project continues in West Sussex.

There has been much work achieved, but as you read this, I am sure you will agree that there is still much to be done. I firmly believe that progress will only continue as long as voluntary and statutory bodies work together (as they have done in the past) with families. It remains important for parent/carer groups and groups/individuals with autistic spectrum disorders to continue to raise awareness about their needs for support to enable individual potential to be met.

The future beckons.....

AAAction Group

Group for Parents/Carer support - At a recent AAAction Group meeting, one of our members suggested that carers/parents may be interested in meeting others in the same situation in their own area. You will recall that the original database set up in the SACT (Asperger Advice and Liaison) role, did ask for addresses and thus there is a record of where families live and in theory it would be possible for them to get together provided information could be shared. This information only relates to adults with AS and/or their carers. It does not relate to adults with autism. The suggestion was that the links could initially be made via e-mail/phone and then progress to a group meeting. **This would be a group or link for Carers/Parents only.**

If you are interested in being put in touch with other families in your area would you be kind enough to complete the information below to release your details to AAAction Group, in order to comply with Data Protection Act guidelines. This information would not be shared with individual families but it is hoped that either an e-mail forum would be established, or a venue sought to which individual families would be invited and they could then decide if they want to develop the group/links further. Additionally they could also decide if they would like to be involved with future meetings of the AAAction Group.

I am aware that several adults with AS are keen to attend a social group of their own.

Groups for adults with Asperger Syndrome are currently being developed by SACT in Worthing and Bognor. Details of these can be obtained from Hilary Bishop on 01243 870109 and Hilary is based at Sussex Autistic Community Trust Resource Centre, First Floor, r/o United Reform Church, Linden Road, Bognor Regis, PO21 2AP.

Working Group for the Development of Services for People with Autistic Spectrum Disorder (including Asperger Syndrome)

It would be prudent to save asking everybody for their contact details repeatedly to transfer details direct from those given to me whilst I worked for SACT. Therefore if you are happy for your details to be given to Peter Joyce, the new Integrated Team Manager who is developing the services for adults with an ASD on behalf of the statutory services, please would you complete the authority below and return it to me via SACT. I will be happy to transfer them to the new service manager. This would enable you to be kept up-to-date with developments as they happen and allow you to participate with your views if desired.

This letter has mainly focused on families, but some of you receiving it will be professionals who I have had contact with in my role at SACT. If you would also like your details (as an interested party) passed on to the new Specialist Service being developed, please sign the authority below.

I hope this letter has been helpful in trying to offer some feedback about progress within the County. I'm sure I will meet some of you again in the future. In summary:

Contacts:

AAA Group

I, and my fellow group members, can be contacted via the **AAAction website:** www.aaaction.ukf.net, or via my e-mail at: raedot@aol.com. Details about the new Specialist Service Manager in relation to the Working Group will be put on the web site as soon as available.

Written correspondence can be forwarded to me by kind permission of SACT if clearly marked 'for the attention of Dot Rae'. Please be aware that I am only able to devote a limited amount of time to AAA group activities as I am a parent/carer myself, and thus there may be some delay in response. Any urgent enquiries about care for families and adults with ASD can be taken to the GP or appropriate keyworker involved e.g. social worker, mental health team. (The National Autistic Society also offer a helpline service 0845 070 4004 Mon-Fri 10-4pm).

Sussex Autistic Community Trust

Social Groups for adults with an autistic spectrum disorder: Hilary Bishop on 01243 870109 ; address - Sussex Autistic Community Trust Resource Centre, First Floor, r/o United Reform Church, Linden Road, Bognor Regis, PO21 2AP.

Service development via Sussex Autistic Community Trust: via SACT on tel: 0124 773366, e-mail enquiries@sact.org.uk, or SACT, Sussex House, Tills Courtyard, 19 High Street, BATTLE, East Sussex TN33 0AE.

Working Party for Development of Services for Adults with ASD,

New Manager - Peter Joyce can be contacted via e-mail:

Peter.Joyce@sussexpartnership.nhs.uk, or at Meadowfield, Sussex Partnership NHS Trust, Swandean, Arundel Road, WORTHING, West Sussex BN13 3EP.

With very best wishes

Dot Rae

Authority for information held on the database at SACT, as collected by Dot Rae, to be shared as detailed below:

1. AAAction Group and proposed Carer Groups

I would like my details (name, address, tel no/e-mail only) to be shared with the AAAGroup in order for me to be made aware of other carers/parents and families in my area. This group will be for parents/carers only.

Signature

Name (capital letters please)

Address

.....

..... Postcode

Tel No E-mail

Date

2. Working Group for the Development of Services for People with Autistic Spectrum Disorder (including Asperger Syndrome)

I would like my details (name, status e.g. parent/professional/adult with AS, address, tel no/e-mail) to be shared with the new Specialist Manager in order to help plan future services, and for me to be made aware of future developments. For reasons of confidentiality, the authority must be signed by the individual with an ASD if his/her details are to be shared. No details will be shared without their signature. If you want to be contacted as a parent or professional about general developments, please indicate your status below.

Signature

Name (capital letters please)

Status (parent/professional/adult with ASD).....

Address

.....

..... Postcode

Tel No E-mail

Date

Please return this form to: For the attention of Dot Rae, 'Database update', Sussex Autistic Community Trust, Sussex House, Tills Courtyard, 19 High Street, BATTLE, East Sussex TN33 0AE.