THE ASC
GOOD PRACTICE GUIDE

St. Nicholas Academy for Autism Trust
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WELCOME TO THE ASC GOOD PRACTICE GUIDE

Welcome to the eighth issue of *The ASC Good Practice Guide*, a free monthly resource for individuals with an autistic spectrum condition, professionals, and parents.

Which organisation does this Guide come from?

The Guide is written under the banner of the St. Nicholas Academy for Autism Trust, a non-denominational North-London based ASC and special needs charity.

Who writes and edits the Guide?

The Guide is written by Christine Haugh, and edited by Chris Mitchell.

Christine Haugh's two sons are diagnosed with autistic spectrum conditions. She works at Middlesex University as Disability Development Officer for Aimhigher London North Partnership, a DfES-funded organisation. Her duties include Project Management of the Partnership's activities for learners with special educational needs, including autistic spectrum conditions. Christine is currently completing her MEd Autism (Distance-Learning) at University of Birmingham.

Chris Mitchell was diagnosed with Asperger Syndrome at University, at the age of twenty. For the first twenty years of his life, Chris felt that he was someone who didn't exist, trying to fit into a social environment he couldn't understand. However, once diagnosed, he found a reason for who he was and his self-confidence returned. Since his diagnosis, Chris has completed his MA (Hons) in Information and Library Management at the University of Northumbria. He has also become an advocate for Asperger Syndrome. Most recently, he has published the autobiography *Glass Half-Empty, Glass Half-Full*. Currently, he works as a clerical assistant with Durham County Council's Special Educational Needs Department. He also speaks about his experiences of Asperger Syndrome at various events and conferences throughout the UK, including the 2005 Aimhigher "Transition to University" Summerschool for students with autistic spectrum conditions, where Chris and Christine met, and at an annual lecture at the University of Northumbria. Additionally, Chris coordinates training workshops for professionals who work with ASC.

To enquire if Chris is available to become involved as a trainer or a speaker at your event, please visit his new website, at www.chrismitchell.org.uk, or contact him at ChrisMitchell@mitchell17.wanadoo.co.uk

To ensure accuracy and relevance, prior to its publication, the Guide was read and feedback was contributed by a range of individuals including relevant education and health professionals from a number of different Boroughs, individuals with autistic spectrum conditions, and parents. Each issue of the Guide will continue to be "proof-read" in this way.

What is the purpose of the Guide? The purpose of this Guide is to provide practical support in the form of a one-stop-shop of information on existing good practice in the field of Autistic Spectrum Conditions, in relation especially to Transitions. "Transitions" is a broad term, encompassing phase transfer to nursery, primary, or secondary schools, as well as to further and higher education and even adult learning opportunities. "Transitions" also covers the area of transition between types of placement, for instance from specialist to mainstream, or from home education to school-based provision. Information provided in this guide will come from a range of reputable, identifiable sources, such as the DfES. Whenever possible, links to relevant websites will be included alongside the information provided. Always, the intention is to empower the audience by keeping them informed of existing good practice.

How can you subscribe to the Guide? **To receive the free monthly Guide, simply email ahaughc@aol.com with the words "Subscribe to Guide" as the subject! If you would like the Guide posted rather than sent via email, simply include name and postal address in your email.**

How can you help this Guide? Any reader, whether a professional, an individual diagnosed with an autistic spectrum condition or a parent, who is aware of any existing best practice relating to autistic spectrum conditions and who would like to share this information with others, is welcomed to contribute an article to this Guide! Please email Christine on ahaughc@aol.com if you would like to contribute an article. Also feel free to email if you wish to get involved with the Guide in another way, such as helping to reformat or distribute it! All help is greatly appreciated!

RECOMMENDED ASC READING AND RESOURCES

MY FUTURE CHOICES- THE MAGAZINE OF THE TRANSITION INFORMATION NETWORK

Published by the Transition Information Network, *My Future Choices* is a quarterly magazine featuring opportunities for disabled people throughout the United Kingdom. Relevant articles from young people and professionals are welcomed by the Editors.

In its own words, the Transition Information Network (TIN) is:
"*an alliance of organisations and individuals who came together with a common aim: to improve the experience of disabled young people's transition to adulthood*."

The information in *My Future Choices* has relevance to young people with ASC who are in the process of making the transition to adulthood, as well as to their parents/carers and professionals working in the area of transitions and ASC.

To find out more about *My Future Choices* and TIN and to receive free copies of *My Future Choices* as well as updates from TIN, please register at www.myfuturechoices.org.uk or www.transitioninformationnetwork.org.uk, or contact:

Transition Information Network
8 Wakley Street
London EC1V 7QE
(0207)843-6006

The ASC Good Practice Guide warmly thanks TIN's Lucia Winters and Jo Marriott for providing this information. Please refer to the Conference/Seminar section of this Guide for information on a forthcoming **FREE** TIN Seminar taking place in Birmingham on 25th October.

CHILDREN'S AND YOUTH SERVICES

FILM EDUCATION- NATIONAL SCHOOLS FILM WEEK

Film Education is showing over 1000 films across the nation during National Schools Films Week. In England, Wales, and Northern Ireland, the week runs from 16th-20th October. In Scotland, the week runs from 30th October-3rd November. The screenings need to be booked in advance and are **free** for **schools** and **home educators** to attend! Certain cinemas are running special screenings specifically for children with ASC, for instance the Barnet Odeon is running a special screening of *Finding Nemo* specifically for children with ASC at 10am on Tuesday 17th October! Film Education has both a Primary Programme and a Secondary Programme, including some scheduled special events such as screenings incorporating storytellers. For further details, please visit www.nsfw.org or call (0207)439-4880.

The ASC Good Practice Guide warmly thanks Stephanie Moriarty for contributing this information.

"TRACKER" (BARNET, NORTH LONDON)

What is Tracker?

Tracker is a short-term pilot, early intervention project funded by the Early Years Development and Childcare Partnership in the London Borough of Barnet. It started in the Autumn term 2003. This initiative is multi-disciplinary, with Teachers, a Speech and Language Therapist, Educational Psychologists and a Family Support Worker all involved.

Who is Tracker For?

Tracker is aimed at children under three years who are presenting with developmental delays/difficulties in at least two of the following areas: social interaction, language and play skills.

What Are The Aims?

- To provide a more immediate service to a range of professionals
- To provide a home visiting service
- To provide practical ideas to help develop the child's skills
- To provide carers with ongoing support and skills to support their child
- To provide a language and communication group that meets the needs of the children
- To support with transitions into pre-school settings

What Does It Entail?

- The team, together with parents/carers, set up an individual plan for the child
- Families are visited weekly for 6 weeks by 1 or 2 members of their team to carry out ongoing assessment, teach, give advice and make appropriate changes to the plan
- The Family Support worker guides the family with the programmes set, e.g. Picture Exchange Communication System (PECS), as well as helping the family implement behaviour strategies.
- Parents and children are invited to the weekly speech and language group

How Are Referrals Made?

Tracker has an open referral system. This is the same for any pre-school Barnet child identified as having special educational needs. The suitability of the project will then be discussed with the family by the Tracker team.

How Can I Access Further Information on Tracker?

For further information, please contact: Tracker Team, c/o Oakleigh School, Oakleigh Road North, Whetstone, London N20.

The ASC Good Practice Guide warmly thanks Tracker's Fiona Mitchell for contributing this information about Tracker.

For a first-hand account on Tracker's impact on family life, please turn to this Edition's "Reader Feature", written by Tracker parent Katey Ross.

OPPORTUNITIES FOR UNIVERSITY STUDENTSWITH ASC

THIS-ABILITY STUDENT AMBASSADOR SCHEME- AIMHIGHER LONDON NORTH/LONDON EAST THAMES GATEWAY, IN PARTNERSHIP WITH NAS PROSPECTS

This academic year, Aimhigher London North in association with Aimhigher London East Thames Gateway is launching the "This-Ability" Student Ambassador Scheme, for University students with disabilities including ASC. Our partner for work involving ASC This-Ability Student Ambassadors is NAS Prospects, who are engaged in a Transitions Project specifically for College/University students with an ASC.

What does this Scheme consist of?

The Ambassadors have two primary roles in the Partnership:

1. To participate as an Aimhigher representative and deliver presentations to schools and colleges throughout 10 different Boroughs based in North and East London. Presentations will be delivered to a mixture of staff, parents, and students, according to the school/College visited. Content of presentations will partially focus on personal experiences, partially on specific areas such as: applying to University, the DSA and its assessment, managing successful transition into University. This-Ability Student Ambassadors will be promoting a Social as opposed to a Medical model of disability, considering changes in educational environments rather than in their condition which might be addressed in order for ASC students to successfully manage the transition to University.

2. To participate in our "HEI Policy Focus Group", which will meet once a term. This group is partially comprised of "This-Ability" Student Ambassadors and partially comprised of Policy makers working in the field of disability/education. The Focus Group has been established in order to provide This-Ability Student Ambassadors with an opportunity to engage in direct dialogue with Policy-makers on those issues the Ambassadors feel need to be addressed.

Are This-Ability Student Ambassadors paid for their work?

Yes they are paid for their work- this is an employment rather than a volunteering opportunity.

How many hours and where exactly would the Ambassadors work?

Obviously Ambassadors will need to fit their work around their studies, and as such the Ambassador work is part-time.

The hours Ambassadors work and the times they work are flexbile- there are both morning and evening events Ambassadors will be able to participate in, according to their individual preferences.

Ambassadors are invited to participate in events throughout North and East London, and in all cases they are free to decide which events they will participate in, and which they will not. Ambassadors will be supported by Aimhigher on an on-going basis.

Who is eligible to join the Scheme?

The Scheme is open to University Students with disabilities, who have completed a minimum of at least their first year of studies. Postgraduate students and recent graduates are also most welcome to apply. Students with ASC are most welcome to apply.

Please note: all applicants are required to undertake one day's paid training and to obtain CRB clearance prior to the commencement of their duties. Training will include content and delivery of presentations.

Enquiries regarding further information or requests for application forms should be directed to Christine Haugh, Aimhigher London North's Disability Development Officer, on (0208)411-6308 or via email to C.Haugh@mdx.ac.uk

SERVICES FOR ADULTS

NEWHAM-BASED ASPERGER SYNDROME/HIGH-FUNCTIONING AUTISM SERVICES (NEWHAM, LONDON)

Newham Adult Services, in partnership with ELCMHT (East London & City Mental Health Trust), have launched a project to coordinate the delivery of services for adults with Asperger Syndrome or High Functioning Autism. An initial report from the partnership found that people who receive a diagnosis of AS/ HFA were generally receiving ineffective and costly services, such as crisis management because there were no specific services for this group. Demographics for Newham suggest that over 650 adults would meet the diagnostic criteria, however, only a small number are known to services. In developing a service Newham will enable those people to access appropriate support.

The new service aims to:

- Provide easier access to assessment;
- Provide individual assessments to those who meet the criteria to determine the impact of AS/ HFA;
- Signpost to provider agencies, services and advice;
- Provide a specialist service to support the most complex needs of some individuals.

The project also offers training to partnership agencies, including colleges, voluntary groups and community groups to raise awareness of AS/ HFA. It aims to improve the accessibility of community services to adults who have AS/ HFA, which will hopefully include education and employment opportunities. The project plans ongoing development work with involvement from service users and carers and will be consulting on a long-term strategy to ensure that the needs of this group are properly recognised and supported.
Partnerships are an integral part of the way independent and voluntary sector works in Newham. There has been close consultation with the National Autistic Society throughout the period.

What follows is (a smaller-print version of) the Service's flyer.

Do you have Asperger Syndrome or High Functioning Autism?
Do you care for someone who has been told that they have Asperger Syndrome or High Functioning Autism?

- ☐ **Are you worried or confused by the diagnosis?**

- ☐ **Would you like more information or support?**

- ☐ **Do you want to know services that can help with:**
  - **Benefits**
  - **Housing**
  - **Training and Education**
  - **Employment**
  - **Making Friends/ Leisure Activities**
  - **Health/ Your feelings**

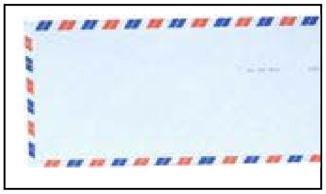
- ☐ **Would you like to meet other people who have Asperger Syndrome or High Functioning Autism?**

If you said yes, you are 16 years old or older, and you live in Newham, contact the Asperger Service:

By telephone

020 8221 7600

By Post



Asperger Service,
Rehabilitation & Recovery Team
1st Floor Warton House,
150 Stratford High Street,
London, E15 2NE

The ASC Good Practice Guide warmly thanks Asperger Specialist Care Coordinator Melissa Balik, from the Rehabilitation and Recovery Team of the East London and The City Mental Health NHS Trust, for contributing this information. **To receive copies of the flyer or assessment referral forms, please contact the Rehabilitation and Recovery Team.**

ASC PARTNERS' GROUP (LONDON)

In the September Edition of *The ASC Good Practice Guide*, readers were asked if they were aware of a Group running specifically for the Partners of persons diagnosed with an ASC. Although no readers were aware of such a London-based group, one of our readers has taken the initiative of launching a London-based Partner's Group.
The groundwork for the Group is currently underway, with a venue being sought for monthly meetings.
For further information, or to assist with the process of launching the group, please contact either The ASC Good Practice Guide at ahaughc@aol.com or the group founder, Delyth, on delyth@daviesbolt.com.

ADULTS- IMPORTANT POLICY INFORMATION

NATIONAL CENTRE FOR INDEPENDENT LIVING- A BRIEFING ON THE DISABLED PERSONS (INDEPENDENT LIVING) BILL

The ASC Good Practice Guide warmly thanks The National Centre for Independent Living's David Morris for contributing this article he has written, explaining the significance and positive role of the Disabled Persons (Independent Living) Bill. David Morris is also Senior Policy Advisor (Disability) to the Mayor of London.

"NCIL is the national organisation providing information, training, expertise and policy development on all aspects of direct payments and independent living.

Our aim is to enable disabled people to have self-determination, choice and control, equal access to economic, social and cultural life.

NCIL's core objectives are:

- to promote independent living;

- to set up a forum for discussion of independent living;

- to contribute to national policy development relating to independent living;

- to promote and support the use of direct payments to enable independent living;

- to ensure that the options of independent living and direct payments are available to all who want them, on a basis of equality.

The National Centre for Independent Living has campaigned for a long time for a legal framework to protect disabled people, who wish to live autonomous lives in their own communities. NCIL has worked closely with the British Council of Disabled People and with the Disability Rights Commission in helping to deliver a credible independent living bill, which will give appropriate rights and entitlements to disabled people based on the key principles of control and choice allowing real freedom and dignity.

The bill was introduced in the House of Lords on 8 June 2006 and the second reading was on 14 July. This briefing explains why NCIL believes that the bill is necessary and what will be achieved for disabled people and the wider community generally.

Independent Living

Disabled people, who need support in day-to-day living have for many years been campaigning for services that allow us to be equal citizens, Many innovatory and flexible approaches have been developed by disabled people and their organisations. The Independent Living Fund and Direct Payments have shown that freedom and choice is possible for a wide range of people, who have been traditionally labelled as dependent and who have been provided inappropriate services or no service at all. Independent Living as a concept has been developed by disabled people meaning support and practical assistance to participate in society as equal citizens. This is counter to a medical based definition, which explains independent living as the physical capacity to live alone. Centres for Independent Living controlled by disabled people incorporating personal assistance support services have developed as a key local resource to deliver appropriate services to facilitate equal citizenship for disabled people who require support in daily living.

A right to independent living is an issue to the broad community of disabled people, who use support in different ways and includes a wide range of people, who can benefit including people with learning difficulties and people using mental health services, older and younger disabled people and people with hidden impairments.

Why is there a need for a right to independent living?

Although a lot of progress has been made over the last few years in relation to statutory rights for disabled people there is no existing legislative right for disabled people to chose to live in their own communities as equal citizens with appropriate support.

Even with the commitment to an approach based on citizenship and the social model, which underpins the Government’s strategy contained within *Improving the Life Chances of Disabled People* the current system is underpinned by services which focus on disabled people as being dependent individuals, who need “caring for” rather than empowering services allowing choice and control. Disabled people are still treated as vulnerable adults at risk. This is not acceptable and not necessary.

There continue to be a number of barriers for individuals who wish to access services to meet their independent living needs. These include

- Strict interpretation of criteria for services by local authorities, which only provide services to people who are assessed with the very highest needs
- Inadequate services, which only provide a minimum physical existence creating a new generation of disabled people being institutionalised in their own homes
- Increasing numbers of disabled people being institutionalised against their wishes, particularly people with learning difficulties and people with mental health needs
- The lack of support and advocacy services for disabled people
- No right to communication support meaning that many people's choices are simply not hurt
- A postcode lottery in relation to provision meaning that disabled people find it almost impossible to move to a new local authority area
- Inappropriate and inadequate services for people using mental health services
- Inadequate housing provision and the crisis in the provision of accessible housing

What the bill will do

Part one a rights based framework for Independent living

Part one of the bill establishes principles as a foundation for the delivery of independent living by service providers involved in the lives of disabled people. The bill would mean that services we use would have to –

- Deliver freedom, choice, control and participation
- Ensure that disabled people have a right to determine the support we need to manage our lives
- Ensure positive action to counter discrimination and disadvantage within independent living services
- Ensure that disabled people have access to a family life and dignity in living
- Ensure that people supporting disabled people have appropriate protection in relation to their health and well-being

Part two independent living

Part 2 of the Bill establishes a number of fundamental things to ensure local authorities develop and deliver real choice for disabled people. Key aspects include:

- The establishment of effective strategic planning including resourcing, training and meeting unmet need. This includes the active involvement of all disabled people, people providing support to disabled people and people running independent living services.
- The establishment of a duty on local authorities to promote independent living
- Ensuring that local authorities provide communication support, independent advocacy, support and equipment for daily living, advice and information, flexible housing support services and employment support.
- Ensuring that agencies involved in delivery of services for example local authorities, Primary Care Trust and Access to Work together and pool funding in relation to individual budgets.
- Requiring local authorities to ensure the support of user-led organisations, including Centres for Independent Living.
- Introducing a right for all disabled people to have a self-directed and comprehensive review of their needs for personal assistance and support along with any health requirements they may have.
- Introducing the right to be told what level of resources will be provided and offers a choice of delivery in the form of an individual budget, a delegated budget or services provided by an authority. Such services are available equally for disabled children and their families and include support for parenting.
- Giving disabled people the right to advocacy and communication support in relation to the process of determining resources.

Part three Residential Provision

Part 3 of the Bill sets out rights for disabled people living in residential care.

- Residential support providers will be required to show how they meet individual's requirements for choice, freedom, control and dignity.
- Provides people with mental health problems with rights to assessment, treatment and support for the first time
- Amends the Mental Health Act to ensure – among other things - that independent living options are investigated and applied before the authorities resort to sectioning.
- The framework for complaints set out in the 2003 Health and Social Care Act is amended to ensure a stronger focus on urgent remedies for cases especially those raising issues under the Human Rights Act and stronger advocacy rights.

- Given that the question of coverage of private and voluntary sector care homes and agencies under the Human Rights Act remains to be resolved the Bill will bring those care establishments within the definition of public authority under the Act.
- Draws the line against any further extension of means testing, puts disability benefits outside of any financial assessment, enables regulations to exclude earned income and occupational assessments
- Ensures that charging regulations must include a disability equality impact assessment

Part four Housing and Planning

Part 4 of the Bill considers accessible and affordable housing and includes:

- A duty on local housing authorities to set up a disability housing register to enable people to choose houses which match their needs
- Stronger duties on local housing authorities to allocate suitable housing in the community and to plan to meet the needs of disabled people in their localities
- Making the Lifetime Homes standard mandatory by incorporating them into Building Regulations and making them a requirement for all new homes

The Bill would change current policy and practice and encourage local authorities and their partners to intervene earlier and to provide services beyond basic personal care and in particular giving people rights to remain in the community rather than being moved to residential care. This Bill will go a long way towards delivering the policy shift set out in the Department of Health White Paper and *Improving the Life Chances of Disabled People* published by the Prime Minister's Strategy Unit in January 2005 as well as other recent policy documents, amongst them the cross government publication *Opportunity Age: a Strategy for an ageing society* 2005 and the Social Exclusion Report *A sure start to later life 2006."*

CONFERENCES, LECTURES, SEMINARS AND SESSIONS

ACTION FOR ASD- SOCIAL STORIES WORKSHOP

Action for ASD has arranged a workshop produced by Carol Gray's Social Stories Team and presented by Team member Eileen Arnold.
An all-day event, the Workshop consists of lectures, discussions, and practice in writing social stories.

WHERE: NorthBridge House, Elm Street Business Park, Burnley, Lancashire, BB10 1PD
WHEN: Wednesday 31st January 2007, 9:30am-4:30pm (tbc, registration from 9am)
COST: Parent Members-£40/Parent Non-Members-£50/Professional Members-£90/Professional Non-Members-£100/Members with ASD-£40/Non-Members with ASD-£50
Payment is by invoice, BACS, or cheque made payable to "Action for A.S.D." (please send cheques to the NorthBridge House address listed above)
For further information, please contact Action for ASD by calling (01282)714-218, emailing info@actionasd.org.uk or visiting the website www.actionasd.org.uk

The ASC Good Practice Guide warmly thanks Action for ASD's Gemma Sampford and Hanna Ingleby for contributing this information.

THE ASPERGER SYNDROME FOUNDATION SEMINAR SERIES PRESENTS PRACTICAL STRATEGIES FOR DIFFICULT MOMENTS: "TRANSITION TO COLLEGE/UNIVERSITY FOR AS STUDENTS- SHARING GOOD PRACTICE"(CENTRAL LONDON)

"Transition to College/University for AS Students- Sharing Good Practice" is a one-day Seminar aimed at parents, carers, professionals, and of course individuals who themselves have ASC.

Speakers: Christine Haugh and Chris Mitchell. Christine Haugh will be sharing some of the many examples of best practice taking place at the schools, Colleges, and Universities she works with, and Chris Mitchell will be sharing his own personal experiences and lessons on best practice he has experienced in College and University as a student with Asperger Syndrome.

WHERE: The Royal Institute of British Architects (RIBA), 66 Portland Place, London W1B 1AD
WHEN: Monday 20th November 2006, 10am-3:30pm (registration from 9:30am)
COST: £25 professionals, £15 parent/carers, free for individuals with Asperger Syndrome (please make cheques payable to the "Asperger Syndrome Foundation")
Sandwich lunches and refreshments are included in the cost.

Please email seminars@aspergerfoundation.org.uk to download a booking form from the Asperger Syndrome Foundation website. This form needs to be returned to the Asperger Syndrome Foundation along with cheque payment, to reserve a place at the Seminar. The Foundation's address is:

Asperger Syndrome Foundation
The Kensington Charity Centre
4th Floor, Charles House
375 Kensington High Street
London W14 8QH

The ASC Good Practice Guide warmly thanks Asperger Syndrome Foundation's Founder, Beatrice Buisseret, for contributing this information.

BROMLEY AUTISTIC TRUST: TEACCH IN THE HOME/ANGER AND ASD

BROMLEY AUTISTIC TRUST presents
TEACCH in the Home, Managing Autism at Home
Date: Friday 3rd November 2006
Time: 10am-3pm
Venue: Bromley Town Church, 2 Ethlebert Road
Presenter: Marie Doyle, SEN Advisor and ASD Development Worker

Division TEACCH's structured teaching approaches have been used worldwide and were developed from an understanding of the unique thinking and learning needs of people with autistic spectrum disorder.

TEACCH uses visual systems to organize routine and the environment and is used throughout the UK, particularly in classroom settings.

The course will look at how the principles can be practically used at **home** or out in the community.

The course aims:

- To increase our understanding of ASD thinking and learning
- To learn the key principals of using TEACCH
- To be able to adapt supportive strategies for managing daily home life

Costs for parents/carers/individuals with ASD	**£25**
Costs for professionals	**£40**

BROMLEY AUTISTIC TRUST presents
ANGER and ASD
Date: Thursday 30th November 2006
Time: 9:30am-4:30pm

Venue: Oakley House, Bromley, Kent
Speakers: Jenny Ronayne, Dr. Katingo Giannoulis, Luke Beardon, Genevieve Edmonds
What is Anger and ASD? It is a one day conference to look at the needs of young people with Asperger Syndrome and High Functioning ASD

The Conference is aimed at parents, carers, professionals and young people with Asperger Syndrome and ASD.

The day will explore what living with AS and ASD can be like, the challenge of daily life, what anxieties are faced, and why anger can often manifest as a result.

Our speakers will offer practical strategies from a personal, professional, and academic perspective on how we can help the young person to reduce anxiety, manage their anger, and seek more productive ways of coping with the rigors of everyday life.

Costs for parents/carers/individuals with ASD £45
Costs for professionals £80

For Seminar/Conference outline, agenda and booking form, please log onto:
www.bromleyautistictrust.co.uk

The ASC Good Practice Guide warmly thanks Bromley Autistic Trust's Jo Walsh and Jo Parker for contributing the information on the above Seminar and Conference.

PARADIGM CONFERENCE: "NO REASON TO LEAVE US OUT"

What is Paradigm?
Paradigm is one of Europe's leading human service consultancy and development agencies.

When/Where is the Conference?
21st November 2006, 9:15am-4:45pm, in London

What is the theme?
This one day conference focuses on the impact of existing policy in relation to individuals with an autistic spectrum condition. In particular, the conference highlights current best practice in terms of policy implementation, and gives a strong voice to individuals with an autistic spectrum condition.

Who will be speaking?
Speakers include: Louise Appleby, National Clinical Director for Mental Health; Rob Greig, National Director for Learning Disabilities; Trish Bugg, Learning and Skills Council; Genevieve Edmonds, AS Advocate, Author and Consultant.

Who is the Conference aimed at?
The conference is aimed at ASC Service Providers, Social Services and NHS managers, transitions staff, parents/carers, and individuals with an autistic spectrum condition.

What Specific Topics will be covered in the day's talks and workshops?
Topics covered include: national policy and its application to people with an ASC; person-centred approaches; best practice in commissioning and provision; statutory responsibilities.

What are the Conference costs?
Costs per person: £275 + VAT (total £323.13)
Costs for minimum of three bookings: £225 per person + VAT (total £264.38 per person)
Please Note: For every three places booked, Paradigm offers a complimentary 4th place
Free places available for individuals with learning difficulties and for family carers

How do I book a place at the Conference?
Return a completed application form along with payment. Forms can be downloaded from www.paradigm-uk.org and emailed back to admin@paradigm-uk.org

Registration by email and payment by BACs secures a small discount. Bacs payment information is as follows:

Account name: Paradigm **Account #**40187240 **Sort code** 205036 **Ref**: Conf-NR

How can I contact Paradigm for further information?

Paradigm's contact details are as follows:
Paradigm
8 Brandon Street
Birkenhead, CH41 5HN
(0870)010-4933
www.paradigm-uk.org
admin@paradigm-uk.org

The ASC Good Practice Guide warmly thanks Genevieve Edmonds and also Paradigm's Daniel Kirkham for contributing this information.

TRANSITION INFORMATION NETWORK- FREE SEMINAR

The Transition Information Network (TIN) is running a FREE Seminar for young people, parents and professionals, on the issues relating to transition to adulthood for young persons with disabilities.

Date: Wednesday 25th October 2006
Time: 10:45am-3pm
Venue: BVSC.138 Digbeth, Birmingham, B5 6DR
Workshops include:

- **Young People's Aspirations: What are they and why?**- facilitated by Dr. Sonali Shah, Research Fellow, School of Sociology and Social Policy, University of Nottingham
- **Voluntary and Work Opportunities**- facilitated by Lynne Whyley, Birmingham Mencap
- **Every Disabled Child Matters**- facilitated by Kate Williams, the Every Disabled Child Matters Campaign

To find out more or to book a place, please email TIN@ncb.org.uk stating the number of places you require, names of delegates, and whether you are a young person, parent/carer, or professional. Please also inform TIN of any special requirements.

The ASC Good Practice Guide warmly thanks TIN's Jo Marriott and Lucia Winters for contributing this information.

READER FEATURE! PARENT KATEY ROSS SHARES HER EXPERIENCES OF "TRACKER"(DESCRIBED IN THIS GUIDE, UNDER "CHILDREN'S SERVICES"

The ASC Good Practice Guide warmly thanks parent Katey Ross for sharing her experiences of "Tracker" and the tremendous, positive impact the Tracker initiative has had on her family. (Please note: The professionals mentioned in this article have given permission for their names to be used).

Katey writes:

"Late last year, our (then) two year old son Jos was referred to the Pre-school Education Team by a Paediatrician from Barnet's Child Development Team. The Paediatrician felt it was possible that Jos may have an autistic spectrum disorder - he also had very little speech and language, and other social communication and behavioural difficulties.

We were really struggling at home to understand and cope with Jos's difficult behaviour and rages; he had very few words, and his attempts at communication were extremely physical and involved a lot of screaming and throwing things. Jos was frequently violent, and at times he seemed to be obsessed with carrying out rituals - lining up cars and jigsaw pieces and flying into a rage if anyone moved the objects out of line. He was also regularly smearing his faeces over our furniture and toys, and any attempts I had made to take him to pre-school play groups had been disastrous - he simply couldn't seem to cope at all with 'circle times' or any form of structure. He particularly hated the singing at these groups and would start to run madly around pushing, hitting and knocking over other children as soon as it started. Trying to take him to anything where there were other children present would be a miserable experience – I would battle to control him, feeling more and more upset as the session went on. Coming out of a ‘Tumbletots’ session with a split lip from where he had head butted me was a particularly low point!

Despite having two other children (aged 7 and 12) my husband and I were feeling very confused about how to help Jos develop language – all the things we had done with our other children; talking to them all the time and looking at pictures and books together, were having no effect, and we were finding his violent outbursts extremely difficult to deal with. He seemed strangely detached one minute, and angry and frustrated the next, and didn’t seem to enjoy playing with us in the ways that our other children had. Our problems with Jos were all consuming, and left virtually no time at all for our other children. This left me in particular with a real feeling of failure, guilt and confusion – I’d had two other older children and had done this before – why was it so hard this time? Our days were a constant battle; to try to get Jos to sit and eat breakfast, to somehow get him into the car for the school run with him screaming and kicking me. It was awful for all of us, and really upsetting to watch our other children so desperately wanting to play the role of big sister/brother to Jos; and yet being constantly screamed at and often physically hurt by him. I was always exhausted, absolutely stretched to my limits and felt helpless about knowing what to do to make things better.

Following the referral, we were visited at home by Fiona Mitchell, from the Pre-school Teaching team. Fiona gave us information, leaflets, and contact details of organisations which we might find useful, and we decided to take part in the ‘Tracker’ project. Fiona explained how Tracker would work, what types of professionals were on the team, when they would visit us, and what sorts of things she as our link worker would be able to do. A few days after her visit she sent us a summary of the things we had discussed, and again this also helped us to be really clear about what would happen next. It was a real relief that the visits from the team took place in our home, as we were always exhausted from coping with Jos’s behaviour, so the prospect of having to attend appointments elsewhere and cope with Jos in waiting rooms would not have worked well for us. It also meant that when the team gave advice about helping Jos at home, they had a feel for what his daily routine was like, and could therefore tailor their advice to suit our lives.

Fiona arranged to visit us at home each week for the following six weeks; it was an immense relief to know that she would be coming to visit us so frequently. Prior to this the only real opportunity we’d had to discuss our concerns about Jos was very occasionally with our health visitor, and once with the paediatrician who had referred us to the team. Each week Fiona arrived armed with a big bag of toys and puzzles, and at first Jos spent much of the visit running around the room, hiding in the cupboard or disappearing upstairs. Fiona reassured me that there was no need for me to keep trying to bring him back down stairs or coax him out of the cupboard, which made me feel much more relaxed.

Gradually each week, Jos became more and more interested in Fiona and her visits, and managed to stay sitting on a little chair whilst doing activities for short periods of time, which was a major breakthrough. Even in the early stages Fiona would point out that he had sat for five minutes this week instead of the two he managed the week before – I probably wouldn’t even noticed this progression, but having it pointed out made me feel more positive. Fiona used a visual timetable so that Jos could see which activities he was going to do and what was coming next, and this seemed to really ease his frustrations - I had never seen or heard of a ‘visual timetable’ before, and I was amazed at how knowing what was going to happen next was so important to Jos, and the way in which it seemed to reduce his anxiety.

Jos gradually started to accept taking turns with Fiona, and waiting during activities until it was his go. This wasn’t always easy, but I learnt so much by watching the techniques she used and the way in which she reduced her language when she spoke to him. I was then able to do the same, and pretty soon all our family was talking to Jos in what came to be known as ‘Fiona’ language! We were able to use the same techniques at home in between her visits, and in other situations: when we were out, at mealtimes or visiting Jos’s grandparents. By the end of the first six week block Jos was able to sit and concentrate on puzzles and games for up to 20 minutes at a time – something that I could never have imagined before!

Prior to Tracker one of the biggest difficulties I had was the amount of time it took me to fill out forms and make phone calls; to firstly find out what help was available for Jos, and then to access the appropriate services. The very nature of Jos's difficulties meant that it was difficult to take my attention away from him - even to make a simple phone call – as this could result in him behaving in a very destructive way. Knowing that Fiona was able to provide information about the support available, take over making some of the phone calls, and help chase up reports made accessing support for Jos from other services so much easier. Fiona also came to one of Jos's review appointments with our paediatrician, and as well as giving information about his progress, she was also able to help me manage Jos's behaviour during the appointment. This was a huge help as I was able to relax and think about the questions I wanted to ask, and listen properly to the advice given. At our previous appointment I had spent most of the time trying to stop Jos jumping on an expensive looking treatment couch, and throwing toys around the room. It's incredibly difficult to relax, under those circumstances, and appointments with paediatricians can be so infrequent that it is really upsetting if you feel one has been wasted!

In just a matter of weeks the Tracker team helped us with a huge range of issues, including: arranging one to one help for Jos at nursery; visiting his nursery to observe his behaviour and providing support for the staff; helping me to fill out claim forms for Disability Living Allowance, and giving us huge amounts of advice and practical support to help develop Jos's language and social skills. They also made us aware that we were entitled to free nappies, and ensured that we knew who to contact about getting them; developed strategies with us to help Jos to stop undressing all the time and smearing; and introduced us to other support services, such as Parent Partnership, and the new 'Early Support' scheme. Fiona also took us to visit the Acorn Assessment Nursery at Oakleigh School in Whetstone, which Jos now attends and absolutely loves. Throughout Tracker the members of the team were always contactable by phone or e-mail if I needed advice from them in between visits. Feeling that my husband and I were no longer alone in dealing with Jos's problems was an enormous relief to us both, and having such regular contact with the team enabled us to ask as many questions as we needed to, and seek help immediately if difficulties arose.

During Tracker Jos learnt to use PECS (the Picture Exchange Communication System). This led to a marked reduction in the amount of frustration Jos felt when trying to communicate, and dramatically reduced the episodes of throwing things, tantrums, and frustrated rages We were taught how to use PECS with Jos by Liz Elms, who visited us weekly at home, and she also made regular visits to the nursery Jos was attending to teach the staff there how to use the system. Using PECS has been extremely effective in helping Jos to form words and basic sentences, and I really don't think we would have managed to use PECS so successfully with Jos without the support we had from Liz through Tracker. The fact that she taught the nursery staff to use PECS with Jos was great; using PECS was so new to us that I certainly don't think we would have been able to teach it to anyone else at that stage.

Liz also had some helpful strategies to deal with Jos's difficult behaviours such as his smearing, and screaming when I was out shopping with him. Because he seemed to be responding really well to visual supports, Liz devised a 'pictorial shopping list'. The first time we used it Fiona and Liz came to the supermarket to observe us, carefully hiding behind the aisles as not to distract Jos. It proved to be a great device for getting Jos involved in finding items in the supermarket; prevented him from screaming, and was much envied by other shoppers! Liz also provided us with countless pictures to use on Jos's visual timetable, in his PECS book, and on a portable key ring for when we were out. She made communicating so much fun for Jos, and the relief he felt from having a way to express himself, and subsequent change in his behaviour was amazing, and gave us the confidence to try taking him to places that would previously have been impossible.

Liz also continually provided us with written plans to support the advice she has given us. These were a great help, and enabled me to communicate her advice to my husband and other family members so we could all be consistent. They also provide a constant source of reference for us to look back at if we found we were unsure about anything. One of the effects of Jos's difficulties on me as a parent was that I felt constantly under stress, and often didn't retain information that well; so it was really helpful to have everything written down so clearly.

During Tracker I also took Jos to the weekly language group sessions at Edgware Hospital, run by Speech and Language therapist Pam Czerniewska, who also visited us at home. This enabled me to meet parents of other children with similar difficulties to Jos. Previously, attending any sort of group with other children had been virtually impossible for us; Jos couldn't cope with trying to participate in group activities such as singing and action rhymes, and would run around frantically, often lashing out. I had really wanted to take Jos to pre-school groups where he could meet other children of his own age, and through Tracker's language group I was able to comfortably do this for the first time, as I knew his behaviour would be understood by both the staff and the other parents.

Each week the group would start by sitting in a circle and going through the same simple routine of songs and activities. Pam assured me that most of the children found this really hard at first, and told me that my job was simply to sit and participate in the songs and activities and to leave running around after Jos to the members of the team. This sounded great to me, because if nothing else I would get a rest! During the first session Jos was literally bouncing off the walls, but as the weeks went by he began to show more interested in what was happening in the circle and would gradually spend longer and longer periods of time sitting. Because the activities and songs were exactly the same each week I was able to clearly see how much Jos was progressing with his language; his ability to pay attention to what was going on; and the way he was interacting socially with the other children. One of the best moments for me was when he tried to sing for the first time! Jos began to use more and more language in the group as the weeks went by, and through watching the way Pam and the other members of staff spoke and interacted with the children, I picked up many ideas about how to engage him in similar activities and songs at home.

We feel incredibly lucky to have had access to Tracker. It's a fantastic service which offered exactly what our family needed – great support and regular access to a team of professionals, all with different expertise, who communicated really well with each other, and were very sensitive to our needs, and the difficulties we were having. Without meaning to sound clichéd, Tracker really did change all of our lives, and the help and support we have had has made it so much easier to cope with having a child with complex communication and behavioural difficulties. The Tracker team not only helped Jos directly, but they also educated our whole family, and made us realise that the parenting techniques we had successfully used with our other children just weren't going to work with Jos, and that we needed to learn a whole new approach. We now see that he has a real need for things to be done extremely slowly, simply and clearly, and understand that knowing exactly what is going to happen during our day is so important to him, and helps stop him from becoming anxious and distressed. We had to be very organised when we were getting used to a whole new way of talking to him, carrying around PECS books and visual timetables, but the benefits have been enormous. We were able to work out exactly which techniques were effective for Jos and, because we were able to form a close relationship with the team, if a strategy wasn't working we could get advice straight away and, if necessary, try another approach.

The support we received through Tracker has also greatly improved Jos's relationship with his siblings; showing them a new way of understanding, playing and communicating with him. This has made it much easier for them to cope with having a little brother who is often hard to live with. Jos's language, speech and social skills have improved dramatically, and continue to do so. His behaviour can still be difficult at times; the big difference now is that we have strategies to manage and deal with this, and as a result feel much more in control of our lives. He is noticeably happier, calmer and more playful, and this has enabled us to see a side of him that was previously masked by his anger and frustrations. Jos still doesn't have a clear diagnosis, but thanks to Tracker he now has a family who understand his needs, and can enjoy him so much more." from Katey Ross

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