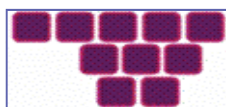


# AUTISM GM

## NEWSLETTER



Greater Manchester  
Autism Consortium

[www.autismgm.org.uk](http://www.autismgm.org.uk)

### SPRING EDITION 2011

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Hello and welcome to the Spring 2011 edition of the Autism GM newsletter.

This edition contains lots of proposed new policy from the coalition government which we realise will be causing some anxiety to people on the spectrum and their families. More than ever, it is vital that individuals and carers know their rights and exercise them in order to get the help and support they need. Locally you can ring us on 0161 998 4667 Monday to Friday for advice about all issues related to autism spectrum disorders, benefits and services. There is also a lot of information on the National Autistic Society's website [www.autism.org.uk](http://www.autism.org.uk) and opportunity to get involved and have your say regarding some of these proposals via our Policy and Campaigns team.

On our own Greater Manchester website [www.autismgm.org.uk](http://www.autismgm.org.uk) you can now read and download full editions of '**AS Inform**' for young people and adults, and our new '**AS Inform**' for children. These contain lots of useful advice and contacts for people with Asperger Syndrome and their families living within the Greater Manchester Area. This has been compiled by our Information Officer, John Davies. We hope you find it useful. Professionals are very welcome to forward the documents to families they are working with too.

Wishing everyone a safe and happy Spring. Do let us know if anyone would like to review a book or DVD for future editions of this newsletter.

All the best  
Debbie Waters  
Editor and Project Officer



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# IMPLEMENTING FULFILLING AND REWARDING LIVES: the strategy for adults with autism in England

## The NAS briefing



### SUMMARY

The Autism Act 2009 put two key duties on the Government.

The first was to produce a strategy on services for adults with autism. This was published in March 2010.

The second was that statutory guidance for local authorities and local health bodies had to be published by the Secretary of State for Health by the end of 2010. The Act stated that the aim of this guidance was to secure implementation of the strategy.

On 17 December 2010 the statutory guidance was published. This guidance sends a clear message that local authorities and the NHS must improve:

- ♦ training for their staff
- ♦ identification and diagnosis of autism in adults
- ♦ planning of services for people with autism, including the transition from child services to adult services
- ♦ local leadership

As this guidance is statutory, it is to be treated as if it were issued under section 7 of the Local Authority Social Services Act 1970. Therefore, local authorities and NHS bodies must follow the guidance when it is relevant to them and, unless a good reason can be given, can be challenged through the courts.

This brief explains in more detail exactly what is in the guidance but, if you would like more information – or to see a copy of this guidance please visit [www.autism.org.uk/autismstrategy](http://www.autism.org.uk/autismstrategy)

### TRAINING FOR STAFF

In the first draft of the guidance, training was a particular area of concern. However, in the final draft the training section has been significantly improved. Stating very clearly that:-

- ♦ general autism awareness training should be available for everyone working in health and social care
- ♦ key staff – such as GPs and those responsible for conducting community care assessments – should have specialist training

These two measures will not only help raise awareness but also mean that, within each area, there will be some staff that have clear expertise in autism.

The guidance also says that adults with autism and their parents/carers should, where possible, be included in training programmes at a local level.

### IDENTIFICATION AND DIAGNOSIS OF AUTISM AND APPROPRIATE SUPPORT FOR ADULTS

Central to the Government's vision for improving services for people with autism lies in improving **diagnosis and access** to support in each area. This section of the guidance reconfirms that a community care assessment cannot be denied on the grounds of a person's IQ. It also makes it clear that on receiving a diagnosis of autism the newly diagnosed adult should be able to access a

*(Continued on page 3)*

(Continued from page 2)

Community Care Assessment and any carers should access a carers assessment. Furthermore, the guidance states that each area should put in place a clear route through which a person can receive a diagnosis and, from initial referral, get a Community Care Assessment.

## TRANSITION

It has long been recognised that **transition** can be a particularly complex time for children with autism. Therefore, transition is a key area that needed to be covered by the statutory guidance. This guidance seeks to make sure that the whole transition process works better for people with autism.

Also, following the success of our *You Need To Know campaign*, the guidance also sets out that NHS bodies, including Foundation Trusts, should make sure that there are agreements in place in every local area for the **transition of clinical mental health care for children with autism in receipt of Child and Adolescent Mental Health Services (CAMHS)**.

## PLANNING

This section of guidance focuses on how local authorities can better identify need and make decisions based on adequate population data.

The guidance gives two key actions that should be taken to improve this:-

- ◆ Local authorities should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area.

- ◆ Commissioning should be based on accurate population figures and, as such, local authorities must improve the data they collect on autism. One of the best ways to do this is to include autism in the Joint Strategic Needs Assessment (JSNA).

## LEADERSHIP

The guidance also sets out the importance of local Autism Partnership Boards and local Autism Teams in the improvement of services at a local level.

## WHAT ARE WE DOING AND HOW YOU CAN HELP

Finally, each local authority should appoint a **lead professional in autism** who is responsible for delivering these improvements and planning in relation to the provision of services to people with autism as they move from being children to adults.

To help local authorities and the NHS to deliver this change, the NAS has been commissioned by the Department of Health to develop a central online resource for information regarding the autism strategy. This resource has been developed to support health and social care professionals in the implementation of the strategy and can be found at [www.autism.org.uk/autismstrategy](http://www.autism.org.uk/autismstrategy)

Secondly, because we need to make sure all local authorities are implementing the statutory guidance, the NAS is continuing the campaign at a local level.

We have launched a survey that we are asking Adult Social Care Leads to fill in.

(Continued on page 4)

(Continued from page 3)

**Please take action now to ask your local authority what progress they are making in implementing the adult autism strategy and how they will meet their new legal duties.**

Find out more about:-

- ◆ Read the full statutory guidance.
- ◆ Read our guide on what the changes will mean to you.
- ◆ Read a summary of the guidance (PDF).



By visiting the NAS website at:-



[www.autism.org.uk/working-with/autism-strategy/the-autism-strategy-an-overview.aspx](http://www.autism.org.uk/working-with/autism-strategy/the-autism-strategy-an-overview.aspx)



## AUTISM ONLINE TRAINING RESOURCES

**T**he Adult Autism Strategy for England, published last year, committed the Government to increase understanding of autism and improve autism awareness training.

As part of this, the Department of Health invested £500,000 in the development of training materials for health and social care staff. The Department of Health has now produced a document with links to many of these training materials. It coincides with the publication of new 'tools' to monitor progress on the implementation of the Adult Autism Strategy for England. The new training materials include:

**The Social Care Institute for Excellence** has put together two videos for social care professionals. One looks at how professionals can better support people with autism, and the other documents the experiences of two people with autism. [www.scie.org.uk/socialcare](http://www.scie.org.uk/socialcare)

**The Royal College of Psychiatrists** has also produced video footage, specifically of assessments of people with autism, to be used as part of training into how to diagnose autism in adults. [www.rcpsych.ac.uk/training](http://www.rcpsych.ac.uk/training)

**The British Psychological Society** has taken

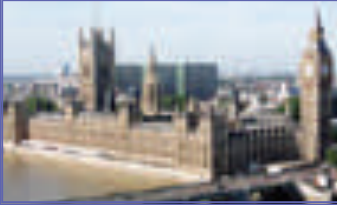
a slightly different approach by developing three e-learning modules. Two of these modules will be freely available, while the third is aimed principally at psychologists. [www.bps.org.uk/cpd](http://www.bps.org.uk/cpd)

**The Royal College of General Practitioners** has also produced an e-learning guide aimed at improving professional standards relating to the care of people with autism and their families. [www.elearning.rcgp.org.uk](http://www.elearning.rcgp.org.uk)

**Oxford University** has built on its previous research to produce a more comprehensive resource on experiences of living with autism. [www.healthtalkonline.org/Autism/](http://www.healthtalkonline.org/Autism/)

**The National Autistic Society (NAS)** was commissioned by the Department of Health via Skills for Health and Skills for Care, to provide a framework to guide the training of generic/mainstream health and social care staff. To find out more, contact Steven Owens; Tel: 0141 221 8090 or email: [training@nas.org.uk](mailto:training@nas.org.uk)

**The Royal College of Nursing** took on two projects. For the first they produced a poster with ten main points to consider when dealing with people with autism; the second project, soon to be published, is an education guide for nurses on the autism strategy. [www.rcn.org.uk](http://www.rcn.org.uk)



**DWP** Department for  
Work and Pensions

# GOVERNMENT CONFIRMS DISABILITY LIVING ALLOWANCE (DLA) TO BE REPLACED IN 2013/ 2014

**T**he Government has confirmed that **Disability Living Allowance (DLA) is to be abolished and replaced by a new benefit called Personal Independence Payment (PIP) in 2013/14.**

Details were announced in a document published by the Department of Work & Pensions and although some details are still to be worked out, there will no further public consultation.

## What's staying the same?

- Many aspects of PIP are the same, or similar, to DLA.
- Like DLA, PIP will have two components, a mobility and a daily living (care) component.
- It won't be means-tested or taxed and won't depend on National Insurance contributions.
- You can claim in or out of work.
- It will be a cash payment.
- It will be payable to children and adults who claim before they reach 65 and can continue in payment beyond that age.
- There will still be 'special rules' claims for people who are terminally ill.
- Motability will still be 'supported' under PIP.

## What's changing?

- Applicants will need to show they have met the criteria for six months and are likely to meet them for a further six months before payment can be made. For DLA the qualifying period is three months in the past and six months in the future.
- There will be no more automatic entitlement for specific conditions or impairments. This means that the automatic entitlement to higher rate

mobility for some people agreed in March 2009 and due to come into force in April 2011, will be very short-lived indeed.

- There will only be two rates for the daily living component, compared to the three rates for the care component of DLA. The PIP mobility component will have two rates as well.
- There will be new criteria for qualifying for the mobility and daily living component. Activities that are likely to be considered when assessing eligibility will include:
  - **Getting around**
  - **Interacting with others**
  - **Managing personal care and treatment needs**
  - **Accessing food and drink**
  - **Possibly, planning and making a journey, and understanding and communicating with others.**

## New Assessment System

There will be a new assessment system for PIP. Most people will have to have a face-to-face assessment with a health professional from Atos, the private sector healthcare company contracted by the government to carry out the assessment. This seems likely to be an assessment on very similar lines to the work capability assessment for employment and support allowance (ESA), quite probably

*(Continued on page 6)*

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with some of the activities overlapping so that one medical will cover both benefits for some claimants.

More account will be taken of aids and adaptations. The document gives the example of considering an individual's ability to get about in a wheelchair rather than just their ability to walk.

There will be a periodic review of all PIP awards, unlike the current DLA system which allows for indefinite awards with spot checks on just a small proportion.

### What's undecided?

No decision has yet been made on whether to apply some or all of the new system to children aged under 16yrs.

Also no decision has been made on whether the age limit for initial claims for PIP should rise in line with the increase in the state pension age once it is the same for men and women in 2018.

No decision yet on relating entitlements to Warm Front grants and the Blue Badge scheme as happens with DLA.

How PIP assessment will work in with revised tougher assessment for ESA (Employment Support Allowance)

### Who is most likely to lose out?

The government's aim is to cut the cost of DLA by at least 20% through these 'reforms'. So there will be many losers when all current working age DLA claimants are forced to be re-assessed starting in 2013/14.

With the daily living component being reduced to two rates, it seems likely that many people who receive the lower rate of the care component will be at risk. This is strongly hinted at in the consultation document. Others will be assessed at lower mobility and care rates than with DLA.



Further detail can be found on the DWP website

[www.dwp.gov.uk/docs/dla-reform-consultation.pdf](http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf)

John Davies  
Information Officer



## REFORMS TO BLUE BADGE PARKING SCHEME



The government recently announced some changes to the Blue Badge scheme. As you'll see below, these are mainly administrative changes, but do include extending the scheme to more disabled children under 3 years.

The changes include:

- ◆ Providing local authorities with an on-the-spot power to recover badges that have been cancelled and misused
- ◆ Shared administration between authorities – including an on-line application facility – resulting in faster renewals, reduced abuse and operational efficiency
- ◆ Transferring assessments for Blue Badges from the NHS to Local Authorities. With wider use of independent mobility assessments to determine eligibility, including where previously that assessment was carried out by a GP.
- ◆ The replacement of handwritten badges with standard electronic ones which are harder to alter and forge

- ◆ Extending the scheme to more disabled children under three years of age, to provide consistency with assessment guidelines for children of 3 and over
- ◆ Administrative improvements for severely disabled Armed Forces personnel and veterans
- ◆ Increasing the fee that local authorities can charge for a successful application from £2 to £10

It is hoped these changes make the assessment process more consistent and fairer between different local authorities and cut down fraudulent use of Blue Badges.

The changes will start to be introduced from this April.

Full details of the changes can be found on the Department of Transport website at:



[www.dft.gov.uk](http://www.dft.gov.uk)

# NICE (NATIONAL INSTITUTE FOR HEALTH & CLINICAL EXCELLENCE) CALLS FOR MORE CROSS-SECTOR WORKING TO IMPROVE AUTISM SERVICES FOR UNDER 18s



**T**he NHS must improve its autism services for children and young people if it is to cope with the increasing demand on them, according to the National Institute for Health and Clinical Excellence (NICE).

The health body calls for better joint working between healthcare professionals and more engagement with schools and the social care and voluntary sectors in its latest draft guidance, **Autism Spectrum Disorder: Recognition, Referral and Diagnosis in Children and Young People**.

The NICE report emphasises that while autism spectrum disorder (ASD) affects at least one in every 100 children under the age of three, correct diagnosis can be difficult due to the range of possible signs and symptoms, and other conditions with similar features. Analysis has also shown that levels of understanding of ASD among healthcare professionals vary greatly across the UK.

**Among its proposals, NICE recommends that:**

- **Local ASD strategy groups are set up, with representation from child health and mental health services, education, social care, the voluntary sector and parents or carers of children with ASD**
- **A multi-professional team should lead the referral and diagnosis of children and young people with possible ASD, including a paediatrician, a child and adolescent psychiatrist, a speech and language therapist and a clinical or educational psychologist**
- **Every child or young person who is to undergo a diagnostic assessment of ASD should have an appointed case co-ordinator from the ASD team who will be their**

**single point of contact and signpost them, and their parents or carers, to appropriate services and support.**

**Dr Fergus Macbeth, Director of the Centre for Clinical Practice at NICE**, said: *"A correct diagnosis of autism can bring a profound sense of relief to some children and young people from what can be an intense feeling of isolation from the rest of the world. It can also help them and their families or carers to get support from education, health services and voluntary organisations and make contact with others with similar experiences."*

**Mark Lever, chief executive of the National Autistic Society**, said: *"Too often we hear from families who are sent from pillar to post while seeking a diagnosis, or who find themselves outlining their experiences over and over again to different professionals. The longer they have to wait, the longer it takes for them to get the right support in place. Once published, I hope that the final clinical guideline will bring about a more consistent approach to referral and diagnosis and recommend comprehensive training for professionals involved. This is something families have long been calling for."*

**Consultation on the NICE draft guidance ended on 25 March with the final guidelines due for publication in September.**

**The guidelines can be viewed at:-**



**[www.nice.org.uk/nicemedia/live/11826/52736/52736.pdf](http://www.nice.org.uk/nicemedia/live/11826/52736/52736.pdf)**

**John Davies  
Information Officer**



# SOS: SAVE OUR SERVICES

## How to challenge cuts to Autism services in your area



**T**he National Autistic Society has produced an online guide called '**S.O.S Save Our Services**' to help challenge proposals to cuts in services. This is in response to the many people who have contacted the NAS with concerns about proposals to make cuts to services for people with autism in their area.

As we are all aware, over the next few years local authorities will receive less funding from central government than they have in the past. Local authorities currently provide, or fund other organisations to provide, a wide range of services that are a vital lifeline for people with autism and their families. This might be support in education, social care services like short breaks, help with daily living or residential care, or health services.

**The NAS is concerned that cutting the services that people affected by autism rely on will push families to crisis point, and this is likely to cost local authorities and health services more when they are left to pick up the pieces.**



'**SOS Save Our Services**' is an online document to help challenge proposed service cuts. It is available at [www.autism.org.uk](http://www.autism.org.uk). And includes sections on:-

- **Getting the facts: what to ask before you start your campaign**
- **Gathering evidence: demonstrating the potential impact of cuts**
- **Rights and duties: what the law says about cuts**
- **How to campaign against cuts and who to contact**
- **Further information and resources about challenging cuts**

If you would like further information or advice, please contact the **NAS Campaigns Team** by:

Emailing: [campaign@nas.org.uk](mailto:campaign@nas.org.uk)

OR

Telephoning: 020 7923 5799

OR

writing to them at:

393 City Road, London, EC1V 1NG.

**NB**

**Please also let the Campaign Team know about how your campaigning is going, and if you have any success stories to share.**

# The Hardest Hit Defending disabled people's futures

**UKDPC**

United Kingdom  
Disabled People's Council

**DBC**



**O**n Wednesday May 11th thousands of disabled people, their families and supporters from all over the country will come together to protest with one voice outside the Houses of Parliament and make their feelings known about the impact of spending cuts on disabled people.

The day of protest, organised by UKDPC and major disability organisations, will send a strong and powerful message to the Government.

The National Autistic Society is taking part in the protest march and know that it can be difficult for people with autism to take part in a noisy protest. For this reason the NAS has booked some quieter rooms in Parliament for those who want to meet their MP in a calmer environment. Please contact the Campaigns Team on [hardest.hit@nas.org.uk](mailto:hardest.hit@nas.org.uk) or Tel: **020 7923 5799** if you wish to arrange to use a quiet room.

As well as the London protest there will also be an Online Protest. Numbers count, so it's really important that you get involved in any way you can. You can take part in the online protest by sending a photo or video in support of the campaign and writing to your MP.

## Why are we marching?

We're marching to make sure that the Government hears disabled people's voices. Cuts to vital benefits and services will have a massive impact on disabled people's independence and could push people into poverty – the Government must act now to make sure that disabled people are not the Hardest Hit.

## How do I take part on May 11th?

We're expecting thousands of disabled people to descend on London and join us on the day, so we're asking everyone to sign up to let us know their coming and tell us which parts of the day you'll be joining us for – The March, lobby or the whole day of action.

## The Rally

From 11.30am there will be a rally on the Embankment to hear from disabled people about the deep unfairness of the cuts for their lives and futures. Politicians from the main political parties will be invited to speak and asked how they plan to uphold the rights, equality and participation of disabled people. The speeches will take place between 12pm and 12.30pm.

## The March

The march will start from the Embankment by Horseguards Avenue at 12.30pm, and will end in Westminster at around 13.30pm, going past the Houses of Parliament to ensure that MPs and Peers hear our collective voice and understand our message.

## The Lobby

After the march, many people will be lobbying their MPs inside Westminster between 13.30pm and 17.30pm. If you want to take part in the lobby it is important to ask your MP for an appointment in advance, so that they will be able to meet you at some point during the lobby. When you sign up on the Hardest Hit website you will be taken to a form which makes it easy to invite your MP to meet you.

**Please visit the website for further details**



**[www.hardest.hit@nas.org.uk](http://www.hardest.hit@nas.org.uk)**

# NAS RECOMMENDED LINKS



## Choice and Control

The Office for Disability Issues (ODI) has launched a new area of its website, Choice and Control. Aimed at frontline health and social care professionals, the resource has been created to champion choice and control for people with disabilities. The website contains resources on personalisation, planning, and advocacy. There are also real life stories, answers to common questions, and the option to sign up for an e-newsletter.

[www:/odi.dwp.gov.uk](http://www:/odi.dwp.gov.uk)



## Is that discrimination?

Is that discrimination? provides information on the Equality Act, and how to recognise and challenge discrimination.

**www:**  
[Isthatdiscrimination.org.uk](http://Isthatdiscrimination.org.uk)



## Law Staff

The Children's Legal Centre is an independent national charity concerned with law and policy affecting children and young people. Last year they launched an exciting and innovative new website, Law Staff. The website contains information on the rights of young people and the laws that affect all aspects of their lives—education, healthcare, discrimination, policing, age-based laws, leaving home and more. The information on the website is presented in an accessible, interactive way, through questions and answers, a 'mythbusters' tool and case studies. The content, functionality and features of the website will be added to throughout the year, including through the addition of podcasts. The Children's Legal Centre hope that young people will make use of the website and feel empowered to learn about their legal rights and entitlements.

[www.lawstuff.org.uk](http://www.lawstuff.org.uk)



## NAS online Community

The new online Community is a place where people can visit to share their experiences, thoughts and questions around autism. The service is open to

people on the autism spectrum, their parents, carers and friends. We also hope the Community will be used by professionals and other people with an interest in autism. The only restriction we have is that the service isn't open to people under 16 years old. We aim to provide a safe, welcoming space for people to discuss whatever is on their minds. If you feel people you work with would benefit from sharing their experiences with other people, in a public online environment, then please suggest they visit the Community.

[www.autism.org.uk/community](http://www.autism.org.uk/community)



## Mutual Caring Project

You may come across people with autism who live with their elderly parents and have to care for them, while also receiving support from them as lifelong carers. Mutual Caring is a project designed to promote recognition of good practice and develop improved service provision for older families where the balance of the caring relationship between the long-term family carer (often a parent) and the person with learning disabilities (normally an adult son or daughter) has changed. The project website provides access to a wealth of resources

[www.learningdisabilities.org.uk/mutual-caring](http://www.learningdisabilities.org.uk/mutual-caring)



# BRITISH AUTISM STUDY OF INFANT SIBLINGS

## Volunteers Needed For Phase 2!



Isabella and her mum Rachel

A year ago, we mentioned in the newsletter the I-BASIS project run by the BASIS network. It involves working with parents to maximise social communication opportunities for baby siblings of children with autism. The project has been running successfully for a year and is about to start Phase 2. The team running it are now looking for further volunteers.

The first phase of the I-BASIS programme ran in the Manchester area for 12 months and is now nearing completion. A total of seven families have taken part so far including baby Isabella and her mum Rachel, pictured above. Those that have taken part to date have reported that they found the project enjoyable

and helpful in terms of understanding their babies' communication better.

**Now the second phase of the project is about to start.** This will involve a full randomised controlled trial and as such, the I-Basis team are now looking to work with a larger group of families. If you would like to

BASIS  
The Babylab  
Centre for Brain and Cognitive Development  
Tel: 020 7079 0761  
Email: [basis@bbk.ac.uk](mailto:basis@bbk.ac.uk)

[www.basisnetwork.org](http://www.basisnetwork.org)



PAWS (Parents Autism Workshops and Support) has been set up under the wing of Dogs for the Disabled with funding by The National Lottery and a number of trusts and donors, to bring together the parents and carers of children with autism to share experiences and to explore the helping potential that a pet dog might have within their family. The project is supported by the National Autistic Society and Lincoln University who are undertaking research in this area to increase our knowledge of the relationship between dogs and humans. The results are already encouraging; a child who refused to clean his teeth will now do so happily if the family dog has his teeth brushed at the same time; a young lad who had real problems with his school uniform now sets off to school happy and proud and appropriately dressed, providing the dog goes with them, wearing a school tie too!

There is a PAWS Workshops delivered over 3 one-day sessions over a period of 3 months taking place in the North West in May, June and July at the Dogs Trust Rehoming Centre in Liverpool. The cost is £30. Through practical demonstrations, discussions, hands on learning and course handouts, the workshops will cover a variety of topics, from practical ways in which the dog can help the child's development, to selecting the right dog for the family.



For more information visit the website  
[www.paws.dogsforthedisabled.org](http://www.paws.dogsforthedisabled.org)

or  
Tel: 01295 759836



# NAS INFORMATION SHEETS

**T**he following Information Sheets have been updated or are new:--

- ◆ Adolescents and adults with autism spectrum disorders: resources for parents and professionals
- ◆ Education and autism: a selective guide to resources
- ◆ Partners of people with Asperger syndrome: a guide
- ◆ Resources for adults with Asperger syndrome (**NEW**)
- ◆ Auditory Integration Training (AIT)
- ◆ Employment at the NAS: opportunities for a career
- ◆ Lovaas
- ◆ Picture symbols: for professionals and students
- ◆ Autism: information for school and college students studying the condition
- ◆ Social services: getting help for your child (England and Wales)
- ◆ Asperger syndrome: a selective guide to books and other resources
- ◆ Community care: a guide for adults with autism spectrum disorders and their carers (England)
- ◆ Home improvements and equipment: funding
- ◆ Information sheets and leaflets available from the Autism Helpline

**All the above Information Sheets are available on the NAS website:-**

**[www.autism.org.uk/infosheets](http://www.autism.org.uk/infosheets)**



# SELF ADVOCACY BOOKLET



**T**he NAS Advocacy and Project Manager, Patrick Simms, who is based in the Nottingham Office, has been working with a group of adults with autism to produce a pioneering booklet that will enable people with autism to communicate and express themselves in all types of social situation.

**The Self Advocacy Booklet** was launched last week and is the first of its kind to help people to bypass their difficulties with verbal communications by writing them down. There are separate sections within the booklet relating to the different problems that people with autism might experience, such as social interaction, body space and smell. People can then fill in how each individual difficulty affects

them and the measures that need to be put in place to help them with these issues.

To obtain a copy of the booklet which is free please ring the **Autism Helpline**

Tel: 0845 070 4004  
Mon-Fri 10am—4pm  
Minicom: 08045 070 4003  
Email: [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)

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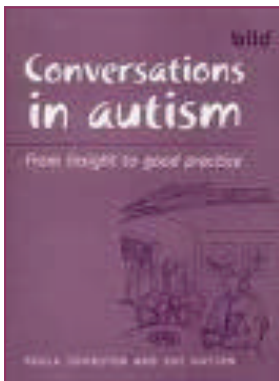


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# CONVERSATIONS IN AUTISM

## From insight to good practice

**Paula Johnston and Sue Hatton**  
**BILD Publications 2003 £10.00**



This is a very intelligently written and easily readable book. Once started there is little effort needed to continue to the end. This is entirely due to the quality and depth of Paula Johnston's own insight into her unique way of perceiving the world, relationships and her and her autism's place within these. It wasn't until I had finished the book that I read on the back cover that Paula was not diagnosed with an ASD until she was 46 years old. Having just read all about her difficulties understanding social cues and demands, her exhausting need to know and perfect every detail of each new consuming interest, and her sometimes violent response to needing solitude and space, it was hard to imagine how she coped at all without the internal and external understanding a diagnosis brings.

The book is not written as an autobiographical account – a format that people with ASD struggle with – but more as a collection of 'think pieces' by Paula Johnston about those subjects that interest and confuse her, and how she has managed and adapted to having autism in a predominantly non-autistic world. Sometimes these verge on the surreal, as in the account of how harelips could be reduced in rural Pakistan, but more often they illustrate and inspire by highlighting the sheer effort and resilience that people with autism show in their endless attempts to make sense and find some solid ground in a very confusing and intimidating social world. The 'think pieces' are interrupted and woven together by a commentary in a different typeset by Sue Hatton, a training co-ordinator for autism. I did

find myself wanting to skip these sections at times, and get back to the fascinating insights into Paula's world, but actually they are necessary to provide some coherent structure and to draw the readers attention to implications for practice when supporting others with ASDs. On occasion, Sue is able to provide some more information about something Paula has written about – for instance, she is able to relay how caring Paula has been to her husband while he was sick – which balances the sometimes self-critical bias Paula shows. Paula's account of how she came to be married is as follows;

*'I am married to a man 18 years older than me with ASD traits – he collects egg cartons, yoghurt cartons, empty washing powder boxes etc, and becomes distressed at attempts to remove them. .. He was a special interest of mine for about nine months, during which time we got married. Unfortunately he is no longer a special interest.'* (p 18)

I would recommend this book to parents and professionals as a very readable and insightful account, with clear links to best practice in supporting people with similar difficulties. It is however far too short! Many questions about Paula and her life go unanswered (inevitably perhaps as the content was determined by what interested Paula herself), and at £10 for 70 pages it may not be as accessible as it should be which is a shame.

**Debbie Waters**  
Project Officer





## GOVERNMENT PUBLISHES PROPOSALS FOR REFORMS TO SPECIAL EDUCATION NEEDS PROVISION

**S**arah Teather, the Children's Minister (pictured above) has published a 'Green Paper' setting out the government's proposals for reforming the education system for children with special educational needs (SEN).

A key proposal is the replacement of statements of SEN with '**education, health and care plans**', which would be determined through a single assessment and included in an overall package of support. This should get rid of current confusion and delay about responsibility for delivery of services included in the statement.

The Government has said that these plans will provide the same legal protection to parents as statements and that these plans will be for children with SEN or a disability from birth until the age of 25yrs.

Other proposals include:

- ◆ Work to improve early identification of children with special needs.
- ◆ Support from the Government to develop local networks of schools to develop teachers with specialist skills and knowledge who can be deployed across local clusters of schools.
- ◆ Ensuring parents have a real choice over the type of school their child goes to.
- ◆ The option of a 'personal budget' by 2014 for all families with children with a statement of SEN or a new 'education, health and care plan' to give parents greater choice over the services their child receives. This is to be piloted first.
- ◆ More teachers to spend time in special schools as part of their initial teacher training.

### The National Autistic Society Response

The ambitions in the Green Paper are welcomed by the National Autistic Society who emphasise the need for the proposals to be properly implemented and funded to achieve their aim. The NAS is particularly keen to ensure early identification of children actually happens, and that specialist autism teachers are accessible to every school to help teachers to properly support children with autism in their class.

The NAS will be looking carefully at the proposals and consulting with its members and others to respond. It plans to produce a report in the summer on how the planned SEN system should work for children with autism.

The Government's Green Paper is titled

**Support and aspiration: a new approach to special educational needs and disability.**

It is available on-line at



[www:education.gov.uk](http://www:education.gov.uk)

**John Davies**  
Information Officer





# THE NEW EQUALITY ACT 2010 AND YOU

advice now

**I**t's upsetting and humiliating to be singled out for worse treatment because you or a member of your family or friend has autism. For example, if a shop refuses to serve you, or you are made redundant from your job.

You have a right not to be discriminated against. It's completely unfair and, in many cases, against the law.

The law in this area has recently been tightened and clarified in the Equality Act 2010.

## What do we mean by discrimination?

- Being treated worse than others because of who you are
- Being harassed because of who you are
- Being subject to unnecessary rules and ways of doing things that put you, and people like you, at a disadvantage
- Being punished for complaining about discrimination
- When someone doesn't make a reasonable adjustment for your disability
- Being treated unfairly because of something to do with your disability (New right in Equality Act 2010)

## This discrimination could be by:

- Your employer
- An education or training provider
- A public service provider (for example transport company, local authority, medical services)
- Someone selling, letting or managing property
- A shop or other service provider (for example pubs, restaurants)



Discrimination against a person's friends, family and work colleagues due to their association with the person also counts as discrimination! If you are being discriminated against by someone such as a neighbour or even complete strangers, your rights will differ. These people could be interfering with your human rights or committing a criminal offence. You might be able to take them to court to claim compensation or put a stop to it. If you feel physically threatened in any way or someone damages your property, call the police.



The new Equality Act prevents employers asking job candidates about their health or any disabilities before offering them work. However, note that it's not discrimination for an employer to look at your skills, knowledge and experience when they decide whether or not to offer you a job or promotion, send you on training or decide on your terms and conditions of work (such as how much they're going to pay you). This isn't treating you worse because of who you are. This is treating you appropriately because of what you can do for them. Nor is it discrimination for an employer to require you to tone down brightly dyed hair or remove an eyebrow ring – self-expression is not covered by anti-discrimination laws.

*(Continued on page 16)*

(Continued from page 15)

## How To Deal With Discrimination

If someone has broken the law by discriminating against you, you don't have to put up with it. What should you do?

### Employment Discrimination

If it's an employment problem you could:

- Have a word informally with your manager or, if it's your manager who is the problem, someone more senior or someone in HR.
- Make a formal complaint to your employer (called, 'a grievance').

If that doesn't resolve the problem you could take the matter further using ACAS (the Advisory, Conciliation and Arbitration Service) to help you and your employer find a solution you're both happy with. If this fails, you could bring a claim in an employment tribunal, or ask to be moved to a different team or a different site.



### Discrimination by shops and services

You can vote with your feet by not using that shop or service provider again, but, this won't always be possible. If you were discriminated against by your GP surgery, for example, and there isn't another surgery in your area that will take you. Anyway, there is no reason why you should have to avoid places because of someone else's behaviour. You could:

- Complain informally to the person that dealt with you
- If that doesn't work: make a formal complaint to the organisation in writing, following their complaints procedure, if they have one. If you don't get a reply, or you're not satisfied with the reply:

- Complain to someone else responsible for upholding the standards of the service (for example, a regulatory body, membership organisation or an ombudsman), or, as a last resort:
- take the organisation to court

### Be prepared!

Whatever action you decide to take, the better prepared you are, the more likely it is that you will get what you want. There are a number of simple steps you can take to improve your case:

- Keep a discrimination diary. Write down the date, time, what happened, who was involved and whether there were any witnesses. If you think they'll be sympathetic, ask the witnesses to make a note of these details.
- Keep a copy of any emails, memos or text messages that show what's been happening.
- If an employment issue, try to find a copy of your employment contract, and any employment policies and procedures of your organisation, particularly the grievance procedure (these might be set out in a staff handbook).
- In an ideal world, you should get legal advice about your rights and options, and legal help with whatever course of action you decide to take. If you end up bringing a claim, you should also get someone to represent you at the tribunal.

For further information visit

[www.isthatdiscrimination.org.uk](http://www.isthatdiscrimination.org.uk)

*'Is that fair?'*

*'You don't have to put up with it  
How to recognise discrimination'*

These are two excellent guides produced by Advice Now which are available on this website.

**John Davies**  
Information Officer





# CELEBRATING 10 YEARS OF PROVIDING EDUCATION RIGHTS ADVICE



The NAS Education Rights Service (formerly the Advocacy for Education Service) recently celebrated ten years of providing information, advice and support to families of children with autism.

The Education Rights Services is the only autism-specific service of its kind in the UK. Over the last ten years it has helped over 16,000 families concerned about their child's education to understand their rights and entitlements.

The Education Rights Service aims to empower and encourage parents to be confident partners in their child's education, enabling them to them to successfully negotiate with their education authority or child's school.

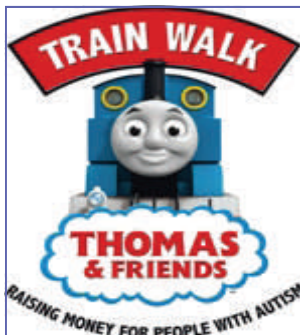
The advice lines help with a wide range of topics, from assessments to school transport, education plans to reviews. The Tribunal Support Scheme helps parents who have a right of appeal to tribunal in England and Wales.

**To contact the service call**

**Tel: 0845 070 4002**



**[www.autism.org.uk/educationrights](http://www.autism.org.uk/educationrights)**



## PEEP PEEP!

## THE FAT CONTROLLER NEEDS YOU!

Train Walk is The National Autistic Society's Thomas-themed family sponsored walk, raising vital funds for our work in the North of England. Why not jump aboard and enjoy a family day out whilst supporting the work of the National Autistic Society. Find details of your nearest Train Walk at [www.trainwalk.org.uk](http://www.trainwalk.org.uk)

Hannah Taylor Our Regional Fundraising Manager– North would be pleased to hear from you if your group is interested in organising such an event. Give her a ring on Tel: 0161 292 1710 or Mobile: 07799 658837.



## THE ENGINE SHED TRAIN CLUB FOR CHILDREN WITH ASD

The Engine Shed is a new, free monthly train club aimed at children on the autistic spectrum who love trains. Their families are also welcome. At the club there will be:

- ◆ Large Hornby layouts, kindly supplied by local model railway enthusiasts, for children to enjoy. (Thanks to the Cheshire Railway Modellers for their very kind help!)
- ◆ Train sets of all kinds, for all ages and abilities to play with (including wooden Thomas sets, plastic Tomy, Hornby and lots more).
- ◆ Train books, craft activities and puzzles and other hands on trains activities.
- ◆ Free refreshments for everyone.
- ◆ The chance for parents to relax and chat while the children play!

The club is held on the last Saturday of every month at

Chorley Village Hall  
Mobberley Road  
Knutsford

For further information please contact Liz Syed on:

**Tel:** 01565 872 010

**Email:** [liz\\_syed@yahoo.com](mailto:liz_syed@yahoo.com)

**Web:** [www.engineshedcheshire.com](http://www.engineshedcheshire.com)



## DONKEY RIDING FOR CHILDREN WITH DISABILITIES

Children with special needs and disabilities are welcome to benefit from donkey riding therapy at the Elisabeth Svendsen Trust riding centre in Debdale Park, Manchester.

Many families go along to family days and have a great time. These are usually held once a month.

For more information, dates and times please contact:

**Tel:** 0161 301 4051

**Email:** [estmanchester@btconnect.com](mailto:estmanchester@btconnect.com)

**Web:** [elisabethsvendsentrust.org.uk](http://elisabethsvendsentrust.org.uk)

Elisabeth Svendsen Trust  
Green Fold  
Abbey Hey  
Manchester M18 8RJ

# FORTHCOMING EVENTS IN THE REGION

## **Transition to High School Planning a successful transfer for children with an autism spectrum condition (ASC)**

**Wednesday 11th May 2011  
9.30am—12.30pm**

Presented by Sheila Stubbs—Specialist  
Teacher

Venue: Inscape Centre  
Schools Hill, SK8 1JE

Cost: Professionals £45 Parents £15

For further information please contact:

Inscape Centre  
Tel: 0161 283 4761  
Email: [inca@togethertrust.org](mailto:inca@togethertrust.org)

## **The 5th International Conference**

### **Communication: The Key to Success Addressing Autism/Asperger's syndrome**

**Friday 20th May 2011**

Keynote Speaker: Professor Tony Attwood

Venue: Edge Hill University, St Helens Road,  
Ormskirk, Lancashire, L39 4QP

Cost: Professionals £180 (inclusive of VAT)  
People with ASD and parents of young  
people with ASD £75 (inclusive of VAT)

Online booking is available at:  
[www.edgehill.ac.uk/keytosuccess](http://www.edgehill.ac.uk/keytosuccess)

Tel: 01695 650738  
Email: [weatherp@edgehill.ac.uk](mailto:weatherp@edgehill.ac.uk)

## **My Town Tiggers Annual Autism Conference: 'Research, Reality & Rock N Roll'**

**27th May 2011  
9.00am—4.30pm**

Keynote Speakers:

Professor Simon Baron-Cohen, Dr Glenys  
Jones, Professor Jonathan Green and John  
Clements

Venue: Hilton Hotel, Blackpool

Cost: £159 (including lunch) for  
Professionals, practitioners and those in  
employment  
£59 (including lunch) for parents/carers and  
people with ASD

For further information contact:  
Blackpool Children's Workforce Development  
Unit

Blackpool Council, Progress House, Clifton  
Road, Blackpool, FY4 4US  
OR

Tel: 01253 476533 (for enquiries)  
Email: [cwdu@blackpool.gov.uk](mailto:cwdu@blackpool.gov.uk)  
Internet: [www.mytowntiggers.co.uk/](http://www.mytowntiggers.co.uk/)



# ASD PARENT SUPPORT GROUPS

## BOLTON

**Hyperactivity And Neuro Developmental Family Unity Link (H.a.n.d.f.u.l.)**  
Tel: 01204 794979  
Contact: Michelle Daubney  
Email: handfulehelp@yahoo.co.uk

## BURY

**Bury Autism Parent Society**  
Tel: 761 0132  
Contacts: Joanne and Tony Moran  
Email: mail@baps-online.org  
(Telephone support only)

**Bury Autism/Asperger syndrome Support Group**  
Contact: Chris Parkinson  
Tel: 0161 763 4867  
Email: burycarers@yahoo.co.uk

## MANCHESTER

**Spectrum Assist**  
Tel: 07866 643241  
Contact: Sue Broadhurst  
Email: spectrumassist@live.co.uk

## OLDHAM

**OSCA**  
Tel: 07913672175  
Contact: Cathy Williams, or Maria Aspin  
Email: osca@bigfoot.com  
Website: www.fdk.org.uk/osca.html

## **Oldham ASPACE (Asperger's support for Parents/Carers)**

Tel: 01706 847455  
Valerie Foster, Chair  
Pam Butler, Secretary  
Tel: 01706 847455

## ROCHDALE

## **RAGS (Rochdale Autism Group Support)**

Tel: 01706 374525  
Contact: Margaret Littleborough Autism, Aspergers syndrome and ADHD Support Triangle (L.A.A.A.S.T.)  
Tel: 07980 983872  
Contact: Liesl Beckles  
(Telephone support only)

## **Rochdale Jigsaw**

Tel: 07534828764  
Contact: Sharon

## SALFORD

**Salford Action for Autism (SAFA)**  
Tel: 0161 607 1695  
Carol Gray or Barbara Berry

## STOCKPORT

**Living with Autism**  
Tel: 0161 283 4750  
Contact: Sue Allison

## **Stockport ASD Partnership Project Support Group**

Offering monthly sessions with invited speakers.  
Tel: 249 4474  
Contact: Cheryl Salt  
cheryl.salt@stockport.gov.uk

## TAMESIDE

## **TASCA (Tameside Action for social communication & Autism support group)**

Tel: 07931 466417  
Contact: Valerie Bayley  
Email: tasca4u@ntlworld.com  
Website: www.tasca.org.uk

## **Tameside Asperger's syndrome Support Group**

Tel: 604 3600  
Contact: Julie Scrymgeour

## TRAFFORD

## **ADHD/ASD Family Support Group**

Tel: 07969 459523 (Jess)

## WIGAN

## **Landgate Parent Support Group**

Tel: 01942 730134  
Contact: Caren  
Email: landgatesupport@aol.com

## OTHER SUPPORT GROUPS IN GREATER MANCHESTER

### **The Autistic Society Greater Manchester Area (ASGMA)**

A group for parents of children and adults with Asperger's syndrome.

For further information regarding dates and times please contact the ASGMA Information Officer

Tel: 0161 866 8583  
Email: information@asgma.org.uk

### **Cygnat Springside ASD Support Group**

Organises events for parents, carers and individuals affected by ASC. Professionals are also welcome.

Contact: Amy Stanion  
Tel: 0161 443 4060