

Autistic Adults

Did you
know?

Information on local services for **Autistic Adults** - 2015 edition

by Caroline Henthorne

Autistic Lambeth resident

Useful Contacts

National Autistic Society Autism Helpline 0808 800 4104

(free to call from landlines and most mobiles)

www.autism.org.uk

Lambeth Autism Group

(the Lambeth branch of the NAS)

lambeth@nas.org.uk

Introduction

Who This Guide Is For

This guide has been written by a local autistic adult for local autistic adults.

The guide is one of a pair. This guide covers services for autistic adults who can engage with services for themselves (with a little encouragement).

If you picked up this guide because, as well as being an autistic adult, you care for an autistic child or learning disabled autistic adult, then you also need to read the partner guide to this one, which offers information on local services for carers and for autistic people who cannot seek their own support. It has been produced by the Lambeth Autism Group and is simply called 'Did You Know?'

Using This Guide

1. Each section describes services for a particular area of life
2. Use the contents page to find the sections you need
3. Each section begins with a tip on how to engage with the services listed
4. The services available change all the time, and 2015 is an election year. For the most up-to-date information email the Lambeth branch of the NAS at lambeth@nas.org.uk
5. Unlike the partner guide, this guide does not list useful books or websites. There are simply too many from which to choose. This guide is not everything you need to know about autism. It is your starting point to finding what you need in Lambeth

Who Produced This Guide

The author has tried to ensure that the information in this guide is up-to-date, and accurate, at the time of publication. She does not recommend any therapies, approaches, or services, or endorse any products. This guide exists to help you make up your own mind.

This guide lists the services of which the author has heard. It could be better. If you know of other services which you would recommend email caroline.henthorne@icloud.com.

Introducing The National Autistic Society

The National Autistic Society is the UK's leading autism organisation. The NAS provides a range of information and services as well as campaigning for a more autism-friendly society. The NAS is for all people living with autism, both those of us on the autistic spectrum and those who care for us. Membership is offered to both groups. When you join you can have your say at a national level and in the Lambeth branch: one membership covers both. The NAS head office can offer you membership (www.autism.org.uk). Enter 'Lambeth' on the form, where asked which branch you would like to fund, unless you wish all of your membership fee to go towards national services.

Introducing Lambeth Autism Group

LAG is for all Lambeth residents who live with autism, either because they themselves are autistic or because they care for someone who is autistic. Membership is open to all local autistic adults and adult carers (adults being people aged 18 or over). You do not have to be a member of the NAS nationally to join the local branch. The branch aims to be inclusive of those who need support to make their voice heard. Non-verbal and learning disabled people can be members in their own right: while LAG listens to local autistic children (aged those 0-15) and young people (those aged 16+17) through the membership of the adults who care for them.

LAG is your local voice for autism: join their email list to receive regular news on local events and issues, come to their information and support meetings, come to their AGM and campaign for better local services and policies, get involved.

If you have just reached adulthood and are starting to manage your life as an autistic person for yourself join the branch and make your voice heard. The branch needs to know what concerns young adults in Lambeth.

If you are not so young, join the branch anyway. Whatever you want to discuss: whether its access to training, workplace support, mental health services or leisure activities the branch wants to know what concerns you.

To get involved and add your voice to LAG, email: lambeth@nas.org.uk

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Section One - Information on Autism

TIP - This section is about finding out about autism and staying up-to-date on developments in the autism field. It lists national sources of information that give a voice to autistic adults, not just to experts.

Autonomy

An on-line inter-disciplinary journal made up of articles written by autistic academics. Great if you'd like to know what is happening in autism research from the autistic point of view.

<http://www.larry-arnold.net/Autonomy/index.php/autonomy>

The Centre for Research in Autism and Education

A partnership between Ambitious about Autism (a children's charity focusing on education) and the Institute of Education at the University of London, CRAE is a research group with aims which extend beyond the narrow education remit.

CRAE host regular evening events at their base near Russell Square with presenters including autistic speakers. Topics have included the changes to the new definition of autism in the latest edition of the DSM manual, and the need for more research into the lives of autistic adults. CRAE have screened films about the lives of autistic people including on-line performances. Sign up to the mailing list.

ioe.ac.uk/crae twitter.com/CRAE_IOE crae@ioe.ac.uk

Section Two - Connecting with the Autistic Community

TIP - This section takes you beyond meeting other autistic individuals to connecting with the national community of autistic adults.

- * This community can help you find a positive autistic identity.
- * The community also push for the change we need in society.
(Which is not what the experts think we need)

Asperger United

A quarterly magazine edited by an autistic man 'The Goth' and made up of items sent in by autistic people – find a pen pal, write about your life experience, share coping strategies, send in your art work, review a book on autism that has helped you, talk about accessing support services. The magazine is printed by the NAS and is free. To have your name added to the mailing list use this link.

<http://www.autism.org.uk/about-autism/our-publications/asperger-united.aspx>

Autscape

Autscape is a fun annual conference on all things autism, run by and for autistic people. To find out how to attend or even how to run a workshop see

<http://www.autscape.org>

Autscape Chat

Can't wait to attend the Autscape conference? Try the on-line chat list. Autistic adults from all over the UK, and even other parts of Europe, chat daily on-line on all topics from accessing useful psychotherapy to tending their allotments. Chat is sympathetic, light hearted and intelligent.

<http://www.autscape.org>

Section Three - Diagnosis

TIP - This section

- * Explains why diagnosis matters
- * Explains the different assessments you will need (and warns you about the pitfalls)
- * Puts you in control of the process
- * Tells you where to seek advice
- * Tells you where to look for support after diagnosis

Why Diagnosis Matters

1. Your autism is as much a part of who you are as your gender. Diagnosis helps us make sense of ourselves. Not knowing whether you are autistic is about as helpful as not knowing whether you are male or female
2. Diagnosis helps us explain a hidden condition to others. We can be clear about who we are and what we need
3. Diagnosis of autism is diagnosis of a recognized disability so it opens the door to the support services we need to reach our potential and live full lives in a world designed for non-autistic people
4. Autism is a hidden condition of which society has only been aware in recent years. So the true number of autistic people is unknown. The shortage of support services for autistic people reflects this. Services for adults are especially poor. Being diagnosed helps raise the profile of autism
5. You have a right to a diagnosis. Autism is not a nasty label, it's a factual description of who someone is, like the words 'man' or 'woman'

The Assessments You Will Need

Your diagnosis is not something medical experts do to you to determine whether you are a defective version of a normal person. Your diagnosis is the first step to being empowered as an autistic person. It's about you and you have a right to make informed choices every step of the way.

1. Diagnosis

- What Diagnosis is an assessment of whether or not you are autistic. It has a yes or no answer
- Who Diagnosis should be conducted by a psychologist
- Where You can be referred to a psychologist by:
- Asking your GP to refer you to a psychologist
 - Asking your employer for an assessment
 - this could be paid for by your employer, speak to your Human Resources manager
 - or through government funding for disability employment, call Access to Work
 - Asking the college where you study for an assessment
 - for university students this can be paid for by the Disabled Students Allowance, speak to the disability support team at your university
 - Going to see a psychologist
 - and paying for the assessment yourself

Pitfalls

- There are different types of test used at diagnosis. Seek advice on this from the NAS helpline (0808 800 4104) and make sure you know what type of test you are being offered, and that it is right for you. One test asks the candidate's parents questions about the candidate's childhood development. This won't work for you if aren't in contact with your parents
- The diagnostic process tends to miss adults many of us have learnt to look normal. Make sure the psychologist you see is used to assessing adults not just children
- The diagnostic process tends to miss women. Women manifest autism differently to men. If you are a woman, make sure your assessor understand autism in women
- Some professionals think an autism diagnosis is an assessment of whether someone is coping with life or not. This is because they are looking at autism in terms of degrees of divergence from being normal. Remember whether you are coping depends on things that change, like having a supportive boss, you either are or are not autistic, and this will not change

2. Identifying Co-Morbid Conditions

What

- Autism is one of a cluster of **thinking differences**
- Having more than one of these differences is very common
- When you have your autism assessment look for a psychologist who can also assess adults for:
 - dyslexia, dyspraxia, dyscalculia, attention deficit (hyper activity) disorder, and Tourette's syndrome
- You will probably have characteristics of several thinking differences and your diagnoses will be the best fit to describe who you are
- It is helpful to see the whole picture of how you think without having to have multiple assessments

Who A psychologist

Where You may need to advise your funder on the service to which you need to be referred. Don't limit yourself to Lambeth, some assessors use Skype and work internationally

What

- Mental Health conditions
- Autistic people are very likely to have mental health issues like anxiety and depression

Who A psychiatrist who understand mental health in autistic people

Where Your GP can make a referral

Pitfalls

- Check that any treatment you are offered is suitable for autistic people. For example some autistic people do better expressing themselves visually in art therapy rather than talking to a therapist
- The therapist should also know how to work with autistic people. Don't be afraid to ask what training and experience they have and what they understand autism to be, as this can vary considerably

3. Assessing Your Support Needs

What

- You will need an assessment of your support needs for each area of your life, here are some examples from my personal experience:
 - The Community Mental Health Team will assess how you can be supported to manage your mental health
 - Social Services assess the support you need with daily living
 - Your university will help you arrange an assessment paid for by the Disabled Students Allowance. Your university can help implement the support
 - Your employer will need to assess the support you need at work
 - Talk to your Human Resources manager
 - Call Access to Work
(it's the employee who makes the call)

Who

Expertise for each of these types of assessment vary, but in general tends to focus on knowledge of the field in which you are operating. So the key point is that you ask to be assessed by someone who understands autism in adults as well as – mental health, universities, the workplace etc.

Pitfalls

- Your support needs will vary according to the task you are doing. The assessment you had for your last job might not be relevant for your current job
- Use your previous experience of being supported to tell the assessor what works for you. The best expert on you is you

Step By Step

Assessment is a step-by-step process. It is extremely poor practice for the steps to be merged. The author has heard of cases in which people have been refused a diagnosis of autism because support services were not available. Whether someone is, or is not, autistic is a matter of fact, which does not depend on the state of local support services. Remember, your route to accessing services starts with diagnosis.

Another form of poor practice is for the NHS to offer diagnosis of autism as part of a general mental health assessment. In my view this type of assessment is offered because in the past autism was wrongly thought to be a form of psychosis, and psychiatrists still tend to be used for autism diagnosis. These mental health assessments assume that autism should only be diagnosed if 'symptoms' cannot be explained as being part of a mental health condition. Even if the candidate being assessed does not have mental health issues this type of assessment mixes up assessing how the brain processes information, with how the mind sees the world. Many autistic people, especially woman, have historically been misdiagnosed as schizophrenic.

It's About You

Diagnosis is not something that happens to you, it happens with you. Ask to see and sign off the diagnostic report and make sure you know which organisations are keeping copies of the report.

The report may include personal information about you which is the evidence for the diagnosis. You may not want others, such as your employers to see this. In addition to your copy of the report ask the diagnosing practitioner for a simple letter which states that you are autistic, which you can use to seek support services.

Where To Seek Advice

The National Autistic Society Lorna Wing Centre for Autism

An NAS diagnostic centre of expertise in Bromley. This centre can offer advise on diagnosis, or carry out the assessment.

020 8466 0098

lornawingcentre@nas.org.uk

NAS Helpline

Another source of information on diagnosis is the NAS Helpline 0808 800 4104.

Support After Diagnosis

Autism Matters

Autism Matters offers training to individuals and families. This training can help if you want to better understand your own, or a family member's autism, and learn some strategies to address any challenges. The training can include developing a personal profile of how you, or your family member, is affected by autism.

Training is available face-to-face in Reading (£45 per session), or via phone or Skype if you would like training in another location (£35 per session). Some lower rate places are available for people unable to afford the full price.

For a free assessment contact:

caroline@autismmatters.org.uk

www.autismmatters.org.uk

Section Four - Registering with Lambeth Council as Disabled

*TIP - This section is about autistic citizenship in Lambeth.
Finding your voice and making sure it is heard.*

Registering yourself as disabled with Lambeth Council, is an important action. The register is a way in which the council can estimate the need for disability education, health, and social care services. At the moment Lambeth Council has difficulties planning the services local autistic people need because they do not know how many autistic people live in Lambeth or what their needs are. The NAS website suggests that at least 1 in 100 people is on the autistic spectrum. This would mean that there are approximately 2,300 autistic adults and 700 autistic children in Lambeth. But Lambeth Council only knows about those people who already receive a service such as special education or residential care. Only a tiny proportion of the 2,300 autistic adults we must assume live in Lambeth can be identified in this way. The real level of need is unknown.

Lambeth Council is supposed to maintain registers of people living in the borough who have “permanent and substantial” disabilities. That’s us folks, our autism isn’t going anywhere and it means we face substantial disablement. The onus is on us to make ourselves known to the council. Both because registration is voluntary and because my experience of registering is that I have to remind the person maintaining the register that I exist each year, and ask for information. I have never been asked what my needs are or offered information. The obvious way to change this state of affairs is for us all to register and make our needs known.

LAG is in contact with the councillors who hold the remit for vulnerable children and adults. You can raise issues with LAG or contact the councillor for your ward (neighborhood) or the councillor for vulnerable adults yourself. Contact details are in the final section of this guide.

Local services for autistic adults are planned by a steering group at the council which was set up following the Autism Act. This steering group is now about three years old. It is chaired by the council’s Autism Lead Officer Laval Lebon (contact details in

the last section of this guide). Prior to the Autism Act addressing the need for services for autistic adults had neglected. This means that there was a lack of expertise within the council, and the steering group was set up by pulling in people with experience in neighbouring fields. The group is made up of council officials, and providers of local services, who have experience of learning disability and mental health. (Autistic people are not necessarily either learning disabled or mentally ill). This means that those commissioning services for autistic adults should not be assumed to have a good grounding in autism. Lambeth Council are still in the process of training their staff and contractors on autism. Meanwhile service providers should only be assumed to be expert in the fields where they have a track record of providing support (that's learning disability and mental health not autism).

While the council holds focus groups to consult with the parents of disabled children they do not have a consultation mechanism for autistic adults (they have yet to seek us out). Meanwhile the steering group needs a democratic way of selecting members who are autistic and members who care for autistic adults, and facilitating their involvement with disability support and funds for carer cover. This is not yet in place. All the more reason for autistic adults to make themselves known to the council.

Once registered as disabled you will be issued with a wallet card certifying that you are registered as disabled with Lambeth Council. This is a useful proof of disability to have when requesting disability discounts and seeking support services.

Remember to renew your membership each year, there is no reminder service for renewal.

Request a registration form by:
020 7926 5555 – social services call centre
infoservice@lambeth.gov.uk

Section Five - Disability Benefits

TIP - This section will help you work out how to:

- * Look at your financial situation as a whole
- * Find advice and support
- * Understand what disability benefits are for
- * Understand who counts as disabled when claiming benefits
- * See what disability benefits are available
- * Use tax breaks
- * Find other support

The benefits that are available, and the rules about who is eligible, change regularly. So please check with the NAS helpline, 0808 800 4104, that you have the most up-to-date information.

What's in This Section

Support for Disabled Carers

Autism has been observed to run in families so you may have several disabled people in your household across a number of generations. For information on carer's benefits and specific benefits for those caring for disabled children please refer to the partner booklet to this one: 'Did You Know?'

'Did You Know?' also lists services which provide benefits advice for carers. Most of these services however, work on the assumption that the carer is not also disabled.

Disabled Adults Living Full Lives

This section talks about support for everyday living. Benefits which support disabled people at a place of learning or at work are dealt with in the sections of this guide for those topics.

The Big Picture

Remember that disability benefits fit into a wider picture of welfare benefits. If you are a parent or out of work, other benefits will come into play alongside your disability benefits. You may be offered general advice, for example, by staff at Jobcentres who do not always have information on disability out of work benefits or how they form a package of support with other benefits. You should consider seeking advice from organisations that support disabled people.

A general principle when applying for benefits is to make sure that you look at your/your household's financial situation as a whole. Those selling you financial products may know about tax free saving thresholds but will not know about the amount of savings which will make you ineligible for benefits – an ever shifting mile post. Those that know about benefits (such as staff at the Jobcentre) do not always know about disability benefits, and those organisations that do know about disability benefits may not be able to put this information into the context of the rest of the benefits system, let alone advise you on your, or your family's, financial situation as a whole.

Looking at the big picture is especially important since the introduction of the benefits cap, which limits the total amount of benefit that a household can receive from all their benefits. The cap will affect you if you have not claimed disability benefits or have been refused disability benefits. However, if someone in your household is in receipt of a disability benefit – that's Disability Living Allowance, Personal Independence Payment, or Attendance Allowance – then your household is exempt from the cap.

Organisations that know about disability benefits usually know very little about how autistic people should apply for them. The assessment process for disability benefits was not designed with conditions like autism in mind. The focus is on physical disabilities, so a certain amount of 'reading between the lines' is needed to see how an autistic applicant can answer the questions on application form. For example, your ability to walk is not just a matter of whether you use a walking stick, it's also about how you find your way without getting lost. It is a good idea to seek specialist advice on what to say in each section of the application.

Of course other disabilities may be part of life for you and your family. You may wish to seek advice from organisations which have expertise in these disabilities. Don't be afraid to ask for this in a format that works for you. You can then ask an organisation that understands thinking difference (disabilities like autism, or dyslexia if that's part of the picture in your family) to help you represent the whole picture of your family's needs in your benefits application. Don't just list all your disabilities, say how they impact on each other. For example, an autistic mother coping with sensory overload in a supermarket, will struggle to read the ingredients of every possible purchase to manage her hyperactive son's diet. Lots of everyday issues can add up to a big challenge. And this won't be obvious to assessors unless you tell them what life is like for you.

Remember that all advice services exist to support vulnerable people, so you can ask for material to be offered to you in a format you understand.

Where to Get Advice and Support on Benefits

I suggest you seek advice from a service that specializes in autism, such as the NAS helpline 0808 800 4104. Who can help you navigate your, or your family's, eligibility for benefits and help you include information on autism within the application form criteria.

Don't panic! Advice services are there to help you at each step of your application. And if you'd rather appoint someone (a family member or friend) to handle your financial affairs on your behalf you can do so.

General Benefits Advice

These services can be difficult to contact so you will need to be persistent.

Every Pound Counts

Lambeth Council's benefit advice service. This service can advise you on your eligibility for benefits and help fill in benefit claim and appeal forms (although the

complex area of disability benefits is not their area of expertise).

020 7926 5555 – Lambeth Council’s Social Service’s call centre
infoservice@lambeth.gov.uk

Citizens Advice Bureau Lambeth

Citizens Advice Bureaux offer free general advice on issues such as the law. They do not necessarily have disability expertise.

0844 243 8430 Lambeth area – 10am – 4pm, M-F

020 8674 8993 - Streatham Hill direct

www.mertoncab.org.uk - Streatham Hill direct

The Lambeth Law Centre, linked to Lambeth and Merton CAB, has offices throughout Lambeth: <http://www.lambethlawcentre.org>

Advice on Disability Benefits

Disability Law Service

A national service for disabled people offering information and advice about disability rights – employment, education, benefits factsheets, and community care.

020 7791 9800

www.dls.org.uk

Disability Advice Service Lambeth

DASL (pronounced dazzle) is Lambeth council’s disability advice service. It is a partnership of different organisations which are contracted to Lambeth Council to offer advice on issues such as housing and benefits and can help you apply for benefits. This is a general service without dedicated autism experience.

General Enquiries

020 7738 5656 (answer phone will redirect you to):

020 7095 5720 - Lambeth Resolve: don't be surprised if your phone call is answered with the words 'Age Concern', which is one of the DASL partners

Direct Payments Support Service

0207 642 0041/2016

<http://www.disabilitylambeth.org.uk/contact/>

Advice on Autism and Benefits

YELL SOS

Run by and for disabled people this service can advise you on what to claim and help you apply. The service is a sister organisation to Learning Societies. Learning Societies supports disabled students with their studies but found that study was impaired when students didn't have any money to live off. YELL SOS has lots of experience supporting young, and not so young, autistic adults and they know how to stand up to a benefits system that wasn't designed with autism in mind. They are based in Yorkshire and can speak with over the phone or email.

01723 377343

yellsos@learningsocieties.com

National Autistic Society - Helpline

The NAS can offer specific advice to autistic people and their carers on claiming benefits. They know about eligibility, application procedures and making appeals from the autistic point of view.

0808 800 4104

www.autism.org.uk

What Disability Benefits Are For?

Disability benefits (PIP and DLA) are paid directly to disabled adults. They are non-taxable and not means tested, and you can claim whether or not you are in work, because these benefits are designed to compensate for the additional costs people face due to being disabled. (An example of an extra cost is a wheel chair user who can't board a bus because the wheel chair space is already occupied so is faced with paying for a taxi to avoid being late for work). PIP and DLA help disabled people with the tasks of daily living like preparing food, communicating and getting around. (Other benefits provide support for other areas of life like staying in work). Receiving PIP or DLA won't disqualify you from claiming other benefits. In fact the reverse is true. While PIP or DLA won't furnish you with a fortune, being in receipt of one of these benefits can have a significant effect on your budget, it is the proof of disability that opens the door to other benefits and discounts.

Being Disabled

Disability benefits can be claimed by disabled people. Many autistic people see themselves as different rather than disabled. But they may still need to claim these benefits to cope in a non-autistic world.

The law defines disability by comparing disabled people to healthy people. Those with short-term health issues are sick and those with long-term issues are disabled. Long-term means that you have had the issue for at least a year or that doctors expect your condition to last at least a year. When claiming disability benefits specific qualifying periods determine eligibility. For Disability Living Allowance and Personal Independence Payment someone has to have been disabled for three months and expected to remain disabled for a further six months. While for Attendance Allowance (for those who make a new claim for disability benefits after the age of 65) someone has to have been disabled for six months and there is no time criteria for how long someone is expected to remain disabled.

Autistic people are not unhealthy versions of normal people. What we do have is a life long condition that impacts our daily lives. We are therefore counted as disabled under the law. If when applying for benefits you are asked when your condition started the answer is the eternal moment when you were a twinkle in God's eye.

What Disability Benefits Exist?

Disability Specific

Some disabilities entitle people to specific support. This will only apply to you if you have other disabilities as well as autism as there is no support specific to autistic people. Support for other disabilities like blindness (the blind person's tax allowance) are not listed in this guide. There are also specific benefits for people who were injured in the workplace. For information on these see www.gov.uk

General Disability Benefits

For People of Working Age (16 - 64)

There are two disability benefits for disabled people of working age. Personal Independence Payment (PIP), and Disability Living Allowance (DLA). PIP is replacing DLA but some people are still receiving DLA because they have not yet been assessed for PIP.

Please note that DLA is not being replaced for children. If you are a parent of a disabled child you will need to check the details for claiming DLA on behalf of a child as part of your household's benefit claim. See the partner guide to this one, 'Did You Know?'

Personal Independence Payments (PIP)

Each disabled person in a household needs their own PIP or DLA payment. If you have not yet claimed disability benefits you should apply for PIP for yourself (as should your partner if they are disabled) and DLA for your disabled children.

You will need to complete an application form in which you can enclose supporting evidence, like diagnostic reports. For PIP there is a possible second stage. If the Department for Work and Pensions think it necessary in your case, you could be asked to attend a face-to-face assessment. So it is sensible to state in your application form any communication needs you have for face-to-face meetings.

You should prepare for both parts of the PIP assessment process by seeking specialist advice from an organisation with a track record in supporting autistic people through PIP. You may want to find an advocate to accompany you to the face-to-face assessment.

The long application form is designed to cover all types of disability. But it isn't obvious how to complete the form when discussing autism. Everyone, no matter how competent a professional they are in other areas of life should seek help completing the form. It is especially important for autistic people to seek help as we often find forms baffling and can't 'read between the lines' to see what a question is getting at or how it applies to our circumstances. Call the NAS helpline, 0808 800 4104.

Call the NAS helpline, 0808 800 4104 as a first step in your application. It is important to seek advice early in your application process. The PIP application begins with being asked questions over the phone. If you cannot communicate in this way ask someone to say this on your behalf when they call to request your application form, and you will be sent a paper based alternative to the phone interview, as well as the standard application form. Once you receive your forms you have to complete them within a deadline, and you'll need all the time allowed to prepare the detailed account of all areas of your/your household members' lives, necessary for a meaningful decisions to be reached. Any resulting benefits can be backdated to the time when you requested the forms.

Here are some general tips. When completing the application forms for the disabled members of your household it is worth stating on each application that the disabled people in the household depend on each other. This makes the point that an autistic adult who cares for an elderly parent has their own support needs as they carry out the caring role.

Awards are supposed to reflect an individual's needs but are normally considered by those who are not autism experts. You need to help the assessor see how autism affects you, and the rest of your household. Using examples from your daily life, state on your application, your needs, the impact of these needs on each member of your household, and the risks for each family member of your needs not being met.

For example, if you write that when you have a meltdown (experience sensory overload to the extent that you lose your ability to engage with your environment) in a supermarket you return home without all the ingredients for your evening meal, state that the impact is that the whole household does not get a healthy balanced supper. Your health, and your ability to parent and care for older relatives, has been undermined. Do not assume that if you say that you have frequent meltdowns that their impact will be obvious to the person reading the form.

If you have been refused support or offered support which does not meet your needs ask to have your claim reviewed. It may not be until you appeal, that your case(s) receive(s) thorough consideration. Be persistent, the number of cases where people were initially turned down for PIP but were awarded PIP on appeal is quite high. (Although asking for your claim to be reconsidered could also mean losing benefit).

Keep records of your application and assessment interview. You will be reassessed for PIP routinely, even though autism is a condition that does not change.

If you are found to be eligible for PIP your payment will be between £21.55 and £138.05 a week (amount at date of publication) depending on how you are affected by your disabilities. Not all autistic people receive the same amount.

Disability Living Allowance (DLA)

Over the next year those receiving DLA, (except those who have reached pensionable age) will be reassessed and transferred to PIP, if they meet the criteria for PIP.

To fill in the forms on-line or call to request a paper forms.

08457 123 456

www.gov.uk

For Disabled People of Retirement Age (65+)

Your needs as a disabled person will be considered alongside your entitlements as a state pensioner. As a retired person you should expect to lead a full life. You will still need support with daily living tasks after your retirement. Make sure that the person

assessing your needs realises that you have a life-long disability. If you experience confusion this is not 'just part of getting old', it is part of a condition you have had all your life. The person with an autistic brain in which dementia has taken hold is not the same as a typical person with dementia.

Attendance Allowance

Attendance Allowance is for people making a new claim for disability benefit after they have reached the age of 65. If you claimed DLA or PIP before reaching 65 you will continue to receive DLA or PIP after the age of 65, even if your disability needs change as you age. If you claim Attendance Allowance you could get £54.45 or £81.30 a week (amount at date of publication) to help with personal care (that's activities like washing and dressing). Attendance Allowance is paid at two rates. Your payment rate depends on the level of care that you need because of your disability.

The other benefits you get can increase if you receive Attendance Allowance.

How to Spend It

Value Added Tax is a tax on consumption which in an ideal world would stop us from consuming so much we need half a dozen spare planets. But it is unhelpful to tax products disabled people don't have a choice about buying. As a disabled person you don't have to pay VAT on products you buy for your own use, rather than to sell for profit, such as DIY supplies to adapt your home. To find out more about the specific items and services which are tax exempt see:

www.gov.uk

Other Support

You may find that state benefits leave you with a shortfall in paying for the support you need. You can also apply for support from charities and community organisations.

You may need to engage with these organisations anyway to arrange support which you will pay for with your state benefits. Ask for everything you need.

Remember any organization providing the public with a service can take your needs as a disabled person into account. The help available may not be advertised so don't be afraid to ask. For example, free directory enquiries is available for people who struggle to use directories, and you could ask your phone network for an easy to remember phone number. A great habit to get into is daring to ask for the help you need.

Help with prescription charges is available to those claiming certain benefits and tax credits, or who qualify as being on a low income. If you don't qualify for free prescriptions you can save money through pre-payment which caps the amount you will pay over a fixed time period. See:

www.nhs.uk

Section Six - Social Services

TIP - This section is about accessing help from Social Services. You can ask for an assessment of your support needs whether you have an diagnosis of autism or not.

- * What the assessment involves
- * How to ask for an assessment
- * What kind of support you can expect
- * What to do if you are not offered support

The Assessment

Lambeth Council's Social Services can offer a range of support to disabled people. The first step is to have them assess your needs.

This assessment looks at both what Social Services can offer, how Social Services can help you access other Lambeth Council services, and whether Social Services can apply to other sources of support, such as charities, on your behalf.

Remember that it is your whole household that is being assessed. What Social Services offer you depends on: the needs of the disabled people (of all ages) in the household, the needs of the carers (disabled or otherwise) in the household, the needs of any non-disabled children in the household, and whether you have help from your extended family. Your income is not considered.

Make sure that the person carrying out your assessment understand autism (in adults, in children if you also have autistic children, and in learning disabled people if relevant) and can accurately assess the severity of your household's needs. Make sure that the assessor understands that they are looking at your needs as a disabled person, as a disabled carer and the needs of the household as a whole.

Asking For An Assessment

You have a right to ask Lambeth Council for an assessment or re-assessment. There is often a long wait for an appointment so explain the urgency of your situation when you request your re/assessment.

You can refer yourself to Social Services or ask your GP to make the referral.

Either way ask for a needs assessment (community care assessment).

1. Find an advocate who can help you communicate your needs at the assessment and find out when they have time in their diary
2. Phone Lambeth Council social services on 020 7926 5555 or email infoservices@lambeth.gov.uk:
 - a. Ask for an assessment for someone on the autistic spectrum stating your communication needs
 - b. Adults on the autistic spectrum with at least normal intelligence can baffle inexperienced professionals who struggle to understand the challenges that intelligent autistic people can face in day-to-day situations. Ask to be assessed by someone with experience of assessing non-learning disabled autistic adults, and who does not have a mental health background.

[Assessments are usually carried out by social workers. Social workers who work with adults typically have experience supporting people who are either learning disabled or mentally ill. Autistic adults are not necessarily either.]

IQ scores average out ability across a number of areas. Anyone with an average score of over 70 is not classed as learning disabled. Autistic people can have strengths in one area and weaknesses in another. But if your average score is 70 or more you are not classed as learning disabled.

Autism was once, wrongly, thought to be a mental health condition. Some mental health professionals have not up-dated their understanding of

autism. Even if you have mental health needs as well as autism you should have your support needs assessed by someone who understands autism as a thinking difference. You need to be supported as an autistic thinker with mental health needs, not a typical person who is mentally ill and who can be offered some general autism support alongside generalist mental health support].

3. Do not be surprised if the person who answers the phone is not helpful or tries to put you off
 - a. If they don't immediately offer you an appointment with a social worker explain that you are writing to Social Services about your disability and need for an assessment, and that you wish to send your letter to the appropriate team manager and need their name and address
 - b. If you are not given a name of a relevant manager in Social Services address your letter to the 'Head of Social Services' rather than delay writing
4. Keep a copy of your letter (paper photocopy or computer file)
5. If you have not received a response within two weeks, contact the council and ask for an update on your case
6. If this does not elicit a response, write to the Head of Social Services. Your letter will be passed to the person dealing with your case. You could also contact your local councillor for support at this stage
7. You can phone the NAS Helpline, 0808 800 4104, for further advice if you have still not been offered an appointment

Sample Letter requesting an assessment from social services

(Your name)

(Your address)

(Your telephone number)

[Date of letter]

FAO: Gill Vickers
Head of Adult Social Services
Pheonix House
10 Wandsworth Road
SW8 2LL

adultsocialcare@lambeth.gov.uk

Dear Ms Vickers

Re *(Your name, date of birth, address)*

I would be most grateful if a social worker could contact me at the earliest opportunity, in relation to my support needs: I have an autistic spectrum condition. Please arrange an assessment of my support needs, under The Autism Act as a matter of urgency. Some of my needs are:

[Where they are relevant you may wish to include some of the following examples in your letter. Add your own examples. It is important that you are clear and accurate about what you need.]

Life Skills

Support with – dressing, cooking, laundry, cleaning.

The need to be able to travel independently and use public transport safely.

The need to develop financial independence/ability to manage own money.

Managing My Disability

The need to improve my diet. [Some autistic people eat only a limited range of foods].

The need to improve my sleep. And support to cope with the stress of not being able to sleep.

Personal Safety

The need to learn how to avoid attracting negative attention in public.

The need to understand personal safety outside the home, how to recognise and avoid risk situations; reporting risk; stranger danger.

Meeting Basic Needs

The need to maintain my independence.

The need for suitable housing.

Mental Wellbeing

The need for mental health support from a service which understands how to support autistic people with their mental wellbeing.

The need to avoid social isolation and associated depression/mental health issues.

I have issues with [depression, obsessions, panic attacks, agoraphobia, anxiety] which I must manage as an autistic thinker.

The need for counselling relating to: bullying, sex education.

The need to discuss how autism affects me.

The need to be able to explain autism to others.

It is important that the assessor understands autism in adults who are not learning disabled and does not have a mental health based approach to understanding autism.

My access needs for information are [...] and my preferred method of communication is [...].

Please send me a copy of Lambeth Council's eligibility criteria and assessment procedure, before the assessment.

Please ensure that I am given a written copy of any assessment before it is signed off. That referrals to the support services identified as relevant and agreed with me are prompt, and please also provide advice on what support is available locally.

Please acknowledge receipt of this letter in the first instance, and contact me as a matter of urgency, to arrange a time for an assessment in the near future. I look forward to hearing from you soon and in any case within 28 days.

Many thanks.

Yours sincerely

(Your name)

Types of Support

We advise you to do your own research (for example by calling the NAS Helpline, 0808 800 4104) on types of support which councils can offer and ask for what you need. (In fact ask for what you need during the assessment, where you will be able to raise your needs and ask about services).

Direct Payments

You can ask for direct payments so that you can choose and hire the person who will provide care for your household.

If You Are Not Offered Support

If you have been assessed as not meeting the eligibility criteria to access community care support (support from Social Services) Lambeth Council will pass you to their TOPAS team who offer basic advice the about local services and sources of support for autistic adults. Be warned these services are thin on the ground. But you can ask for another Social Services assessment in the future.

TOPAS (Team Offering People Advice and Support)

Want to know what services for disabled people exist in Lambeth? (There aren't many). Ask the Social Service call centre to connect you to TOPAS.

020 7926 5555 – Lambeth Council's Social Service's call centre
infoservice@lambeth.gov.uk

Section Seven - Housing

TIP - Being suitably housed is a key part of managing being autistic.

- * Finding a suitable home
- * Adapting your existing home
- * Paying the bills
- * Managing living independently
- * Autism and neighbourhood safety

Finding a Suitable Home

If you are homeless or your home is not suitable for you because of your disability you may be a priority for a move into suitable council housing. You can move from the private rented sector, or from an unsuitable council property. You can ask Social Services for help with housing or contact Lambeth Council's housing call centre who can pass you on to other teams.

If you are seeking a council home you will need to make your needs as an autistic person clear. The size of home you will be allocated will depend on the size of your household. It may be assumed that you can share a bedroom with your partner when in fact you need your own space. Your autistic children may also need to have their own bedroom. You may need to seek specialist support when applying.

The Bidding Support Team helps people to apply for council properties and can make bids on behalf of those who find it hard to place bids on their own behalf.

Housing Call Centre

020 7926 4200

housingoptions@lambeth.gov.uk

(the Housing Options Team use the email address for the housing call centre)

Adapting Your Existing Home

Adaptations to make your existing home safe and accessible are also possible, whether you are a council tenant, rent in the private sector or are an owner-occupier. An occupational therapists will have to assess your needs. To request an assessment contact Social Services.

020 7926 5555 – Lambeth Council's Social Service's call centre
infoservice@lambeth.gov.uk

Disabled Facilities Grants

Local councils provide Disabled Facilities Grants to disabled people who own their own homes and need to adapt their homes so they can continue to live there. The grants were designed to help people who are physical disabled (ramps) and not the autistic people who face issues like sensory overload from noisy neighbours (and need sound proofing). You will need to state clearly what your needs are as an autistic person. Receiving a grant will not affect your eligibility for any benefits that you're getting.

Paying the Bills

Housing Benefit

Housing benefit is for people who are living on a low income, whether they are in work or living on out of work benefits. Eligibility criteria apply. The expectation is that young single people will live in a house they share with others. You may need your own space, or be unhappy about sharing a house with people you do not know. Seek specialist advice and support when applying.

Council Tax

Council Tax is calculated by looking at the value of your home. If your home is worth more because you have added features which help you manage your disability (like a downstairs bathroom) you may be able to get a reduction to your Council Tax.

Managing Living Independently

The support you need to live independently should be part of your Social Service assessment. You can have support provided by the council (or their contractors) or make your own arrangements.

Direct Payments

If you've been assessed by the council as needing care and support from Social Services you can choose to have direct payments. (You might need to ask for direct payments). Direct payments mean that you manage your own support budget and can hire whoever you choose to provide your support.

The Independent Living Fund

The Independent Living Fund gives disabled people the opportunity to live in their own home in the community rather than a residential home. Disabled people use the fund to hire people to deliver personal care (help with tasks like washing and dressing) and domestic tasks. The fund is only available to people already in receipt of it.

Autism and Neighbourhood Safety

Tackling anti-social behaviour in your neighbourhood:

- If you are in immediate danger, or, a crime is being committed call **999**
- To report an issue to the Metropolitan Police which is not an emergency call 101
- Also, contact Social Services and ask for support
- Or call the council's Anti-Social Behaviour Team. Explain that you are autistic and maybe at an increased risk of hate crime, and that you struggle with communication. You should refuse to attempt to resolve issues with anti-social neighbours informally without support. (The Anti-Social Behaviour Team is not part of the housing department. If you need to be re-housed in another neighbourhood you should contact the housing team)

Anti-Social Behaviour Team

020 7926 4000

Section Eight - Education and Disability Support

TIP - Many autistic people, especially those diagnosed as adults, were not well served by their schooling. To reach your potential you will need to access learning, in a way which works for you, throughout your career.

- * How to move into adult education
- * Learning skills for your first job
- * Lifelong learning

Moving Into Adult Education

Education Advice 18-25 Year Olds

Disabled people who are aged up to 25 are entitled to support from Lambeth Council to access education and employment.

If you have a statement of special educational need you can access support from the Personal Advisors in the council's Special Educational Needs department. These advisors were formerly part of the Connexions service.

Call the council switchboard 020 7926 1000

and ask for:

Erika Alleyne, or

Jacqueline Coker

If you were known to Social Services before reaching adulthood you may already be on the books of the Children with Disabilities Team who might go on supporting you:

Annette Ramsey

Team Manager

Children with Disabilities Team

020 7926 6675

Other Social Service teams which might offer you support are: the Multi-Agency Team (MAT Team) and the youth team for those Not in Education or Employment Team (NEET Team). The NEET team works with people up to the age of 19, their programme for helping people enter education or work had targets which may not be suitable for disabled people.

Geraldine Abrahams
Team Manager
Multi-Agency Team
020 7926 5724
gabraahams@lambeth.gov.uk

Patricia John
Team Manager
Not in Education or Employment Team
Ask the switchboard to connect you to Patricia John

Work Skills Training For 18-25 Year Olds (Getting Your First Job)

CareTrade

CareTrade is a charity which helps 18-25 year old autistic Londoners gain work skills. You need an autism diagnosis to access this service.

Work placements are typically catering opportunities in the Guys and St Thomas's NHS Trust and tend to suit those who are less academically able.

www.care-trade.org

Lifelong Learning (Education For Adults of All Ages)

Adults with special educational needs access support according to the type of training they are doing.

When applying for a course of study make sure you check what the disability service at that college or university offers and whether you are comfortable working with this

service. Ask if there are current or former students you can talk to about their experience of disability support.

Lambeth College

Lambeth College offers further education to the people of Lambeth including support to access this training for students 16+ with learning support needs, ask for autism specific provision.

020 7501 5010

www.lambethcollege.ac.uk/courses/category/learning-support

University Students – Disabled Student Allowance (DSA)

Students at or applying to university, should apply for the Disabled Student Allowance. DSA pays for the support disabled people need to study at university.

DSA is not part of your income and is not taxed. You do not have to declare DSA when applying for means tested benefits and should refuse to do so even if you are asked (some parts of the benefits system don't talk to other parts). DSA has a job to do – pay for your disability learning support – and it is ring fenced for that purpose.

DSA pays for the diagnosis of thinking difference disabilities such as dyslexia and autism, which can be helpful as diagnosis through this route can be provided by a psychologist and not, as is the case in many NHS assessments, by a mental health practitioner.

It also pays for an assessment of your disability support needs in relation to the requirements of the course you are doing, and funding for that support including referral to autism specific support services. However, the budget is capped, no matter how many disabilities you have (autism, dyspraxia and depression, for example) you get the same budget to spend. The cost of diagnosis comes out of this budget, what you spend on diagnosis you can't spend on support.

When your support needs are assessed have your diagnostic reports to hand (whether the DSA paid for the diagnosis or not). Be ready to talk about the tasks you

will undertake in your course and have ideas prepared on the support you think you might need given your diagnosis and the way your disability affects you. The assessor can advise you on what support is available but make sure you are in control of what you are offered and who supplies it. Often universities have contracts with suppliers, and they may not be your first choice. The rules about what support is fundable are somewhat strange. Push for your report to state what you need not what your assessor thinks you can get. Ask to see a copy of your report and seek independent advice before you sign anything off. The NAS offers some support to students and may be able to advise you.

Postgraduates have more choice about who provides their disability support than undergraduates. If you are a postgraduate and are unhappy with the support offered by your university you maybe able to switch to an alternative supplier. DSA at postgraduate level is capped you may well have a shortfall in funding the support that your DSA assessment recognises that you need. Your university may be able to help and you should consider applying to charitable foundations. However your support is funded you as the disabled person will be able to choose who supplies your support.

<https://www.gov.uk/disabled-students-allowances-dsas>

Section Nine - Work

TIP - Making work work for autistic people means:

- * Work benefits for disabled people
- * Accessing help in finding work
- * Training in your workplace on serving your autistic clients
- * Standing up for your rights in the workplace
- * Accessing support to do your job
- * Career development

Work Benefits for Disabled People

Employment and Support Allowance

If you are disabled and out of work you will need to claim Employment and Support Allowance (ESA) not Job Seekers Allowance (JSA). You may need to seek specialist support to apply, as staff at Jobcentres do not always understand ESA, or tell disabled people even the basic fact that they need to claim ESA.

ESA is not the same as JSA. Jobcentres check that Job Seekers Allowance claimants are seeking work. The process is different for those claiming ESA. ESA also has different criteria than JSA on the length of time for which it can be claimed and whether or not claimants need to have made National Insurance contributions. It is possible to claim ESA if you are in work or self-employed, because this benefit recognizes that disabled people have particular challenges in earning a living we may not be able to work full time and can be on low incomes. So as always as a disabled person navigating the benefits system seeks specialist advice.

Applicants complete a form and then attend a Work Capability Assessment which determines the extent of their ability to work. Assessing an autistic person's ability to work is not straight forward and assessors are not always knowledgeable about autism. After significant problems with assessing many types of disability the government are replacing the organization (ATOS) who are contracted to carry out the assessments. It is essential that you seek specialist advice and you might need

to find an advocate for the assessment.

Income Support (for those aged 16-60)

Income Support is being replaced by ESA. Existing claimants have their low incomes topped-up. The benefit is for those working less than 16 hours on an average week or not working at all. Income Support has disability premiums which apply at different levels. Being in receipt of Income Support automatically qualifies you for Housing Benefit and Council Tax Reduction and you may receive help towards health costs, such as prescriptions.

Working Tax Credit

The Working Tax Credit tops-up your earnings if you are on a low income. You may get extra money if there are any disabled people in your household.

Support for Disabled People in Finding Work

Work Choice

Work Choice is a government programme to help disabled people who find it hard to work get jobs. You may be offered a place on this programme at a Jobcentre. The programme does not focus on the issues autistic people have accessing the workplace. Check what you are being offered before you decide to take part. The programme looks at: training and developing your skills, building your confidence, and interview coaching.

NAS Guide to Finding Work

NAS' Prospects employment services (now disbanded) produced a handbook for autistic people on finding work, in consultation with autistic people. Ask the NAS Helpline, 0808 800 4104, for your copy of – 'Finding Work: a job searching and work preparation handbook for employment professionals and people with autism, including Asperger syndrome'.

To Deliver Better Services to Autistic People

Training on autism can be of varying quality. Often the voice of autistic people is not heard. There are a number of excellent trainers who are autistic themselves and who

train people in a wide range of professions about the autistic people they serve. Autscape Chat is the best place to find them.

<http://www.autscape.org>

Think the diversity training at your workplace has missed something? Ask Autism is a service set up by the NAS. It is headed by Damian Milton an autistic man. Using the autistic point of view this service can train your colleagues to deliver a wide range of services to autistic people.

0141 285 7117

askautism@nas.org.uk

<http://www.autism.org.uk/our-services/training-and-consultancy/ask-autism/resources.aspx>

To Be Better Employers of Autistic People

If on the other hand it's the human resource practices at your workplace that needs to be addressed the RMT union's Janine Booth has developed a training course on disability rights at work. It trains union officials on how to stand shoulder to shoulder with their autistic colleagues in the face of bullying and prejudice. Both stage one and stage two of this training are free to union members.

Last year the TUC produced its first handbook on autism – see the TUC website.

The TUC has a Disability Conference in May each year. Contact the TUC for details.

tuc.org.uk

The Help You Need To Do Your Job

Access to Work

Need support to do your job? Call Access to Work. Access to Work can support you in gaining an autism diagnosis and assess your need for support at work: which can be mentoring, office environment changes, changing how you are managed,

equipment such as IT software and noise cancelling headphones, and transport help for those who cannot get to work using public transport.

0345 268 8489

atwosu.london@jobcentreplus.gsi.gov.uk

<https://www.gov.uk/access-to-work>

Key4Learning

In my view one especially good organisation which Access to Work, or your employer can refer you to is Key4Learning. Key4Learning is run by Jo Todd who has a great deal of experience in making the workplace work for autistic professionals, offering them coaching and advocating for their workplace support needs.

enquiries@key4learning.com

Learning Societies

Another switched on outfit that really values autistic people and is run by one of our own is Learning Societies. They support the whole person whatever their mix of thinking differences (whether those traits fall under one diagnostic heading or several) and will not only help you get your diagnoses, get a needs assessment and support at university, but will then make sure you get support at work and can sort out your benefits and access counselling. Marvellous. Based in Yorkshire they provide support via the wonders of modern technology.

01723 377343

yellsos@learningsocieties.com

Career Development

RADAR (Royal Association for Disability Rights)

RADAR is run by disabled people for disabled people and has a membership of over 800 disability organisations and individuals.

Doing Life Differently is RADAR's growing series of guides dealing with various

aspects of life whilst managing ill health, injury or disability (IID). Titles available for free download are: Doing Work Differently, Doing Money Differently and Doing IT Differently. What could be more relevant to the workplace? The author of this guide was at the launch event for 'Doing Work Differently' and recommends it's approach to career development.

RADAR also run leadership training for disabled people with expert mentors. It's an excellent course and the author speaks from experience.

020 7250 3222

radar@radar.org.uk

Google - Disability Rights UK

SHAPE Arts

Are you building a career in the arts? SHAPE Arts works with artists working in all media and who have all manner of disabilities. The support offered such as workshops on copyright is intended for people with serious artistic ambition.

<http://www.shapearts.org.uk>

Section Ten - Parenting

TIP - This section looks at how to be an autistic parent in a world which assumes that, disability plus parenting, means the child is disabled.

Pride and Proactivism

Autism has been observed to run in families. Autistic parents are role models for their autistic children as well as offering unique thinking to those of those of their offspring who are not themselves on the autistic spectrum.

Autistic children are best supported by parents who take a pro-active approach to their own disability. If you as a disabled parent are baffled by the paperwork you are dealing with on behalf of your child. Say so, the organisation you are sending the forms to have a duty to help you complete them.

Disabled Parents Network (DPN)

Being a Disabled Parent has not historically attracted as much support as parenting a disabled child. Here to make the point that disabled adults have families too – not irrelevant for the autistic community as autism tends to run in families – is the Disabled Parents Network.

The Disabled Parents Network is a national member lead organisation that provides information, advice and support to disabled parents and parents-to-be and those who support them, professionally or informally. You do not need a referral to the network you can simply contact them.

The network has received what they describe as a significant number of enquiries from autistic parents who have experienced prejudicial assumptions about their ability to parent, and had to challenge 'child protection' actions against them instead of being offered support to parent. But help is at hand.

The network offers:

Publications

Publications from the DPN website are free to disabled parents.

Support Service

A confidential service providing information, support and advice. Leave a message on the answer machine or email your issue to the network.

On-line Forum

A free online forum where you can share ideas with other disabled parents.

Peer Support Register

Network members can seek advice from other disabled parents. The network can put you in touch with disabled parents who have a similar disability, or live near you.

Local Network Links

Link up with the disabled parents who are offering peer support and influencing service provision near you.

07817 300103 - Helpline and General Enquiries

information@disabledparentsnetwork.org.uk

<http://disabledparentsnetwork.org.uk>

On-line Forum: <http://www.disabledparentsnetwork.org.uk/cgi-bin/discus/>

[discus.cgi?pg=topics&access=guest](http://www.disabledparentsnetwork.org.uk/cgi-bin/discus/discus.cgi?pg=topics&access=guest)

Facebook: [http://www.facebook.com/#!/pages/Disabled-ParentsNetwork/](http://www.facebook.com/#!/pages/Disabled-ParentsNetwork/110710459009048)

110710459009048

Twitter: DPNUK

Section Eleven - Travel

TIP - This section looks at:

- * Applying for discounts
- * Driving
- * Public transport
- * Taxis and minibuses

Applying For Discounts

Don't assume that help with travel is only available to people with physical disabilities. The Autism Act requires that service providers take autism into account. So eligibility criteria for services are not allowed to ignore autism. Ironically, given that autistic people are literal thinkers, there is a certain amount of 'reading between the lines' needed for an autistic applicant to match their needs to the criteria for help with which they may be presented. For example, the ability to board a bus is not just about climbing a step, it's about reading a timetable and navigating a route. But don't let this put you off from applying. Help is at hand.

Proving Your Need For Support

The first step (no pun intended) to accessing help with travel is obtaining proof of your disability. This used to mean proof that you were in receipt of Disability Living Allowance (DLA).

DLA is being replaced by PIP. If you haven't yet applied for disability benefits you will need to apply for PIP. If you are in receipt of DLA at some point this year you will be assessed for transition to PIP. Either way call the NAS helpline, 0808 800 4104, for advice.

If you are in receipt of DLA it is simpler to apply for transport help before you are assessed for PIP. This will avoid delay in accessing support, and avoid the uncertainty about your eligibility for transport support that will exist while your PIP application is being assessed.

PIP and DLA have a mobility component which looks at a disabled person's difficulties with travel. When you apply to the Department for Work and Pensions for PIP use examples from your daily life to explain why autism makes it more difficult for you, (if you are an autistic person who cares for someone else, make two applications, one for each of you), to walk or use public transport, than it would be for a non-autistic person (or carer). The support you are awarded for mobility will need to be cited when you apply for transport support.

Think about each stage of a journey from making plans, checking information and buying tickets, to arriving at your destination, and say why each stage is affected by the various challenges faced by autistic people: sensory sensitivity, information processing, and communication barriers. Think about the impact on your life of not being able to travel easily and why your inability to travel means that you are at risk of harm – for example not being able to manage your health by travelling to hospital appointments. Say where you travel to, places of education, employment, health, etc., and say why being able to travel is essential to your being able to function in society as a disabled person (and carer). (See the guidance in the disability benefits section on presenting information when applying for PIP).

Form of Transport Support

There are several types of transport help available for which you can apply. None of these forms of support is means tested. If you don't have PIP or DLA, you can apply for some of these forms of help in any case. Make your needs clear on your application for transport supporting and include a letter about your need for support from a professional such as a doctor.

You can apply for some types support by contacting Lambeth Council or by asking either your social worker or your GP to contact the council. Social Services can pass your request to the council's Parking Team and Accessible Transport Team.

020 7926 5555 – Lambeth Council's Social Service's call centre
infoservice@lambeth.gov.uk - Lambeth Council's general enquiries
accessibletransport@lambeth.gov.uk

Driving

Motability

The government scheme for accessing an adapted car. See www.gov.uk

Car Tax

Disabled people can get a reduction in their car tax, see www.gov.uk

Blue Badge (disabled parking badge)

Blue Badges allow access to disabled parking bays and parking on single yellow lines with impunity if the badge is displayed.

Blue Badges are issued to people not cars. Many disabled people don't own cars or drive but need those driving them to be able to park in disabled bays. The badge is therefore a handy thing for a disabled person to have in their pocket.

Lambeth Council offers badges to those people whose disability warrants such support. Think about how parking affects your ability to cope with your disability, and how where you park is affected by your autism. Discuss this with your doctor when asking for a letter in support of your application and/or quote relevant parts of your PIP/DLA application on the application form for the badge.

White Badges

White badges, a type of car window sticker, are issued by Lambeth Council to disabled people, so that we can identify that our cars/the cars we are usually driven in, are used by a disabled person. The sticker quotes the car's registration details.

The aim of the white badge is twofold: to ensure that a disabled driver can access the parking bay intended for their own use and situated outside their own home; and to allow the driver to remove their blue badge from their car so that it does not attract thieves.

Your Own Personal Disabled Parking Bay

If you need Lambeth Council to locate a disabled parking bay outside your home you

can ask them to do so. Use of the bay requires a blue or white badge to avoid parking fines.

Congestion Charge Exemption

Once you have your Blue Badge from Lambeth Council contact Transport for London for Congestion Charge Exemption. (As the charge won't encourage those that can't use public transport not to drive applying the charge would be a tax on being disabled).

To register for the exemption you will be charged £10. Your exemption is then valid as long as your Blue Badge is valid: and if you apply for renewal of your exemption within 90 days of being issued with a new badge your renewal will cost you nothing.

0343 222 1234

www.cclondon.com - to find the application form online click on:

- Discounts and Exemptions, then
- Blue Badge Holders Discount

Public Transport

Freedom Pass

Free travel on all forms of public transport in London (buses, trains, underground, DLR) and local buses throughout the country. Applying to Lambeth Council for a disabled person's Freedom Pass means sending them information on your mobility needs similar to that with which you furnished the Department for Work and Pensions when making your PIP/DLA application. Recycle your efforts.

Disabled Persons Rail Card

Don't miss out on discounted travel outside London. Have your train fares cut by a third by buying either an annual or three year Disabled Persons Rail Card. The price is £20 for one year or £54 for three years. Those in receipt of PIP/DLA are eligible, here's the link to the application form.

<http://www.disabledpersons-railcard.co.uk>

Taxi's and Mini Buses

If you cannot drive or use public transport, taxis and mini buses may be for you.

Taxi Card

If you have difficulty using public transport you can apply for a Taxi Card which will offer you reduced taxi fares for a fixed number of journeys per year. Travellers pay a typical fare of £2.50 per journey, and never more than £10.80 for longer journeys, and can make up to 96 journeys per year (fares for 2014). The scheme aims to help people access shops and doctors appointments.

Anyone whose disability has lasted more than 12 months (that's us, autism is a lifelong condition) can apply. Application forms are available from Lambeth Council who forward the applications to London Council.

Call the accessible transport team (details above).

Dial-a-Ride

Dial-a-Ride is a service offered by Transport for London. It's for people who can't use public transport. You can apply for membership if:

- You receive the higher rate mobility component of PIP/DLA, and/or
- You receive the higher rate Attendance Allowance, and/or
- You have a Taxi Card, and/or
- You have a letter from a health professional explaining your mobility issues

Members contact Dial-a-Ride between 9am - 4pm the day before their journey to book a mini bus to take them and one carer to a destination in London for free.

For more information or to apply to become the contact details are:

0343 222 7777

DAR@tfl.gov.uk

Section Twelve - Leisure

TIP - This section tells you:

***What there is to do**

- Social
- Sport
- Arts
- Outings

*** How to get a discount**

*** How to access Accessible Toilets**

*** Who you can have fun with**

*** Finding the courage to try something new**

What There Is To Do

Social

LAG's Adult Social Group

A weekly group for Lambeth's autistic adults. Members are mainly learning disabled people who are capable of engaging in the clubs activities and use speech to communicate.

Each week there is either a meeting at:

Stockwell Resources Centre - Mondays 19:00 – 21:00

Football, basketball, table tennis, pool, wii, arts and crafts.

or, an Outings:

Bowling, Cinema, Restaurants, Museums and more. All at affordable prices.

If you would like to come to the club, find out what we are doing this week by emailing:

lambeth@nas.org.uk

The First Thursday Book Group

LAG and Lambeth Libraries proudly present: the First Thursday Book Group. Come to Clapham Library on the First Thursday of each month (except December) 6.30pm-8.00pm, to join other local autistic adults in discussing our book for the month over a glass of wine. Books supplied by the library and chosen by the group. You don't have to live in Lambeth to join the library, you don't need a diagnosis to join the group, and we won't make you read the book. £2 if you have a glass of wine.

Paper Tiger

Alain English, (a Scot with an unfortunate name), beat poet, hosts Paper Tiger a monthly evening of performance poetry by a mix of regular stars and open mic-ers: including some super autistic artists.

The event is held on the third Friday of the month and costs £5. The fun starts at 8pm, although early birds can sign up for the open-mic from 7.30pm.

The venue is Vauxhall's Tea House Theatre: a lovely performance space and café in a converted pub: 139 Vauxhall Walk, SE115HL.

events@teahousetheatre.co.uk

<https://www.facebook.com/pages/Paper-Tiger-Poetry/253646711363938>

Stim Rock Express

Stim Rock Express is a London based drama group for autistic adults which aims to bring autistic people together to develop confidence through drama, and to put on shows which give autistic people a voice. To get involved email Jenny Berman. (There are no meetings at present the next show will be when there are enough people to form a cast).

introspectroom@gmail.com

The Original Autistic Book Group

Members of this long established and very welcoming all autistic book group, take it in turns to choose what book to read for the next meeting. Choices have ranged from factual books on wildlife, to stories from popular culture, and the literary classics. The group meets each month in Pinner for vibrant discussion of what they have read which takes in autistic points of view on the characters and stories. The group is a great place to meet people and make friends. For more details contact Janet Gothelf.

janet.gothelf@clearer-perspectives.com

Northern Lights

Northern Lights is a monthly meet up group of twenty or so autistic adults of all ages. To find out what the group is doing next contact Beth Jacobs on Facebook:

<https://www.facebook.com/Bethyjacobs?fref=ts>

Autism London/ALAG (Autism London Asperger's Group)

Autism London is a charity which is part of 'mcch', a group which provides services such as supported living for learning disabled and autistic people.

ALAG is a monthly support group for London based autistic adults which started 12 years ago and is still going strong. More structured than the informal 'pub-based' meet up groups, this group uses a community hall, is facilitated by professional support workers, and a discussion topic is planned for each meeting (any group member can suggest a topic). There is also of course opportunity to make friends. The first half hour of the meeting is spent socialising over refreshments.

If you have a diagnosis which is somewhere else on the spectrum other than Asperger's syndrome the group may still be for you. The group simply aims to support those on the spectrum living with some degree of independence.

ALAG meets in Kentish Town on the first Tuesday of each month 6.30pm – 8.30pm. Members pay £2 and non-members £3, which covers the cost of the refreshments (vegetarians are catered for). To arrange to attend your first meeting contact Ethney

Anderson.

0845 6037954

ethney@autismlondon.org.uk

<http://www.mcch.org.uk/autismlondon/supportgroup/index.aspx>

Sports

Wheels for Wellbeing

A local charity which supports disabled people of all ages to cycle for exercise and as a form of transport. The focus is on adapted bikes for physical disabled people but Wheels for Wellbeing understands difference and is a friendly place to get on a bike for the first time.

020 7346 8482

info@wheelsforwellbeing.org.uk

<http://wheelsforwellbeing.org.uk>

Werewolves of London Ice Hockey Club

An ice-hockey club for people of all ages, who are autistic or learning disabled. They are based at the newly refurbished Streatham ice rink. The club meets on Saturdays 4.30-6.30pm. Open to all abilities. Contact Mike Dwyer.

mike@werewolvesoflondon.org.uk

<http://werewolvesoflondon.org.uk>

Arts

Clapham Pottery

This not for profit community organization is a small friendly place with a mission to get people from all backgrounds making art with clay. They can help with affordability.

<http://www.northstreetpotters.com/pottery-classes>

Outings

Museums

Lots of museums are free so it doesn't matter if you're only there 10 minutes before you have a meltdown. It's best to go early or late when they are less busy.

Science Museum

Join LAG's email list to be sent details of early openings specifically for autistic people. Adult only late openings held on the last Wednesday of the month at 18.45 onwards has proved popular with LAG's adult group, and are a free and fun evening out.

0870 870 4868, or

020 7942 4000

www.sciencemuseum.org.uk

London Transport Museum

This museum is an example of one that offers free entry for one carer who is accompanying a disabled person.

020 7565 7298

www.ltmuseum.co.uk

Disability Discounts

Some people feel awkward asking for concessions and asking for disability discounts means announcing that you are disabled in public: assuming your autistic behaviour has not announced this already. My philosophy is different. Every time we ask for the help we need we raise awareness of the needs of everyone living with autism. The more times we ask, the easier it becomes to ask. The little victories lead to the big victories. (Practice being assertive at the theme park ghost train and you'll be ready to face the government agencies ghouls). And of course if support is available we take it – we deserve to have fun too. Have as much fun as you can, whenever you can, damn it, and that includes winking at the theme park officials.

Carers can be discounted too. Loads of places offer carers discounts (free or reduced price tickets for the person accompanying you) as long as you have some kind of proof of disability with you, for example, the London Aquarium and London Eye offer a free ticket for someone's carer. So put some proof of your disability status (a Blue Badge, letter offering you DLA, ability to calculate square roots backwards) in your handbag and always have it with you like the breath mints/condom/spare hankie you've had since you were a Girl Guide, and you'll always be prepared to ask for your discount.

Cinema Exhibitors Association Card

You've bought yourself the cheapest cinema ticket you can, a student ticket for example, but the cost of your carer's ticket still makes seeing the film prohibitive to your household's budget. Wait! You don't have to buy an extra ticket for your carer (family member or friend accompanying you to the cinema), they can accompany you - as a CEA card holder - to the cinema for free. (On the condition that if you need help managing your disability, including evacuating the premises in the event of fire, terrorist activity or similar, than it is your carer who will attend to your needs – always read the small print).

A small fee (about a fiver) and a passport photo, is all someone in receipt of PIP/DLA needs apply for a CEA card. Cards are valid for a year, and CAE is atypical-information-processing-friendly enough to post you a reminder when it's time to renew. The CEA card is a gem, it's valid at most cinemas and I have even used it at art galleries and museums.

Phone for an application form or download one from the website:

0845 123 1292

info@ceacard.co.uk

www.ceacard.co.uk

Lambeth REAL Plus Card (aka My Better Membership Cards)

Card holders benefit from reductions to the cost (free swimming at Brixton Recreation Centre, for example) of using Lambeth Council's sports facilities. You can use your card at: Brixton Recreation Centre, Ferndale Community Sports Centre, Flaxman

Sports Centre, Streatham Ice and Leisure Centre and Clapham Leisure Centre. These centres are also where you can apply for a card. Wafting my Freedom Pass under the nose of the receptionist at the Brixton Recreation Centre was all that I needed to be offered a card. As a disabled adult the card set me back little more than a fiver.

<http://www.lambeth.gov.uk/leisure-parks-and-libraries/sports-leisure-and-parks/apply-for-a-real-plus-leisure-card>

www.better.org.uk

Practicalities

RADAR disabled toilet key

Yes RADAR again, they won't just help get into the boardroom they do bathrooms too. Need access to toilets for disabled people? Apply for a RADAR key (small charge) online, which gives access to toilets for disabled people across the UK.

<http://radar-shop.org.uk>

Who to Have Fun With

Connect and Do

Don't want to venture out alone? Try Lambeth Council's community connecting service, run by certitude. The service can match people at risk of isolation with people who share their interests. A volunteer from the service will meet you to find out what your activities interest you, match you with people who have similar interests, and then facilitate you meeting each other and taking part in your chosen activity. The volunteers and the people you are matched with, will not necessarily understand autism so be ready to explain your communication needs and social fears.

020 7737 2888

connectanddo.org

Trying Something New

Autistic people often find it difficult to access leisure activities. It might be that the activity is presented through a lot of language, or in a social environment, or the activity might mean being part of a crowd, or in a noisy place. Sometimes we as autistic person are seen as disruptive.

When trying a new activity try going early or late in the day when places are less busy. You can check opening details in advance and you may be surprised when facilities are open: you can also avoid the disappointment induced meltdown that comes from arriving at a place which is unexpectedly shut.

Section Thirteen - Mental Health Services and Autistic People

TIP - This section is about:

- * CRISIS
- * Is it just me?
- * Disability in a system focused on illness
- * Consistent care
- * Navigating your route to help without bureaucratic delay
- * Types of expert and pitfalls when working with them
- * Treatment options
- * Safe treatment checklist
- * Making a complaint

CRISIS

Any time of the day or night, if you are planning to harm yourself or someone else.

You are in crisis. Either:

- Make your way to your local hospital Accident and Emergency Department and ask to speak to a psychiatrist, or,
- Call the Samaritans on 08457 90 90 90

If you are failing to care for yourself. For example, you aren't eating properly. Call your GP for an emergency appointment at which you can ask for mental health support, or if you are already a patient of a mental health support service contact this service during their normal working hours.

Is It Just Me?

You are not alone in being an autistic person with mental health needs. Autistic people often have mental health needs. Anxiety and depression are typical in autistic people but you may have other mental health conditions.

When Illness Becomes Disability

There are two types mental health issue. Short-term issues are illnesses which can be treated in the hope of cure. Long-term issues (which last for a year or longer, or

which can be expected to do so) are disabilities in their own right alongside your autism. Disabilities are managed and disabled people supported, the aim is not cure.

When you are referred for diagnosis, needs assessment, or therapies make sure that your assessors are clear whether you have a mental health illness or a mental health disability.

Professionals also need to be aware of the illness/disability distinction when supporting you in accessing services. A sick note is not evidence of a disability, a diagnostic report is.

Autistic people are predisposed to having mental health issues. The issues are present because our brain chemistry is different. This means that when we have depression this is linked to our life long condition: autism. We are not having a temporary episode of mental unwellness. Periods of depression are part of a lifelong pattern of mental health needs.

Equally the experience of being autistic, bullying at work, social isolation and so on, means we can also have periods of mental unwellness in our lives. It is important that your mental health needs whether moments of mental ill health or long-term issues are seen as part of the overall picture of your care. If you would like to be re-referred to people who have treated you before explain to your GP why continuity is important to you.

Managing Consistent Care

The NHS has focused its budget on crisis prevention. This means that instead of helping people manage long term mental health needs so that they have stable lives people have to wait until they are in a crisis before they are given support, and the support only get them out of a crisis. Tell you GP about the support you have at work or from Social Services and try and get the different people supporting you to work together.

The NHS tend to offer their patients mental health appointments during the working day. This is unhelpful for people in long term care who are trying to hold down a job.

Ensure that your GP understands how undergoing treatment will become part of a number of responsibilities in your life.

One good way to ensure your support is joined up is by exercising patient choice about where you are treated and using a person budget from Social Services to employ your own support workers.

Navigating Services

Navigating mental health services can be complex.

At every stage of diagnosis, needs assessment, and treatment or management you need to: ask what type of service you are being sent to, if necessary ask to be sent to an alternative service that has better autism expertise or that can better meet your particular needs, and ask for a second opinion/reassessment if you have any doubts about what a practitioner has concluded. You should also ask to see and sign off any reports which are written about you and keep track of which organizations are keeping copies of these reports. Reports could be kept in several places, for example, your GP, the Community Mental Health Team, a Hospital.

The Route To Help

General Practitioner (GP)

The first person to speak to on all health matters. As the name suggests a General Practitioner has a little knowledge on every ailment, and not much knowledge on any ailment. GPs are usually better informed on physical health compared to mental health, and are only just getting to grips with autism, let alone how to support an autistic person with the mental health needs. So your GP will refer you to someone more expert.

Community Mental Health Teams

CMHT's are a general mental health service and will not necessarily understand autism, or understand it as a thinking difference. CMHT's might refer you for a mental health assessment at a hospital. Once assessed they might be involved in assessing your support needs and providing mental health support. They do not

always have expertise in supporting the mental health of autistic people and you can ask for an alternative service.

Hospitals (Mental Hospitals, or Psychiatry Departments in Other Hospitals)

You might be referred to a hospital for a mental health diagnosis, in patient treatment (usually if you are ill enough to be a danger to yourself or others), or treatment as an out patient, if your care is not being delivered in a community service like a CMHT.

Private Practice

An alternative to NHS treatment is paying for your own psychotherapy. This can be a useful option if the type of therapy you need (for example art therapy) is not available on the NHS, or you are only offered short term support on the NHS, or you are stuck on a very long waiting list.

A wide range of therapies is available at a range of prices. The British Association for Counselling and Psychotherapy (BACP) and the UK Council for Psychotherapy (UKCP) are the UK's professional governing bodies for psychotherapy and can advise you on the different types of therapy available.

Always choose a therapist who is registered with a professional body. Anyone can call themselves a psychotherapist even if they have no training. You will need to check that anyone you work with is properly qualified and that they understand autism. (The NAS Helpline has a list of therapist who self report as having experience of working with autistic clients. Even these people need to be asked what they consider autism to be as many were trained under the 'old school' which considered autism to be a form of psychosis, and the NAS does not vet the list).

British Association for Counselling and psychotherapy: <http://www.bacp.co.uk>

UK Council for psychotherapy: <http://www.ukcp.org.uk>

Janet Gothelf

Janet Gothelf a therapist based in North London with a post graduate qualifications in autism and a great deal of experience working with autistic people. You may have to pay for her services.

07958 700168

janet.gothelf@clearer-perspectives.com

Support Groups

Lambeth and Southwark MIND

Lambeth and Southwark Mind is an independent charity run by people who have personal experience of using mental health services. Join with other local people to learn how to manage your mental health. There is a course for women, and a course for BME people, if you'd like something specific.

<http://lambethandsouthwarkmind.org.uk>

Types of Expertise

Psychiatrist

A doctor who can diagnose mental health disorders and prescribe drugs to treat them. Lower doses of drugs like anti-depressants often suit the autistic brain better. Point this out to your psychiatrist (or GP if relevant). Anti-depressants are a short-term fix. You should never be parked on them.

Psychologist

Someone who's job title sounds like psychiatrist. Often confused with professionals working in the mental health field. Psychologists have expertise in how the brain processes information (among other things like understanding personality and human behavior, and being able to design airports so people don't get lost). Psychologists are able to diagnose differences in how the brain processes information such as dyslexia and autism.

Counsellor

Counselling is much simpler than psychotherapy. It is basically the opportunity to be heard by a trained listener. NHS counsellors have brief training which tends not to include communicating with autistic people, understanding the lives of autistic people or working with autistic people to tackle mental health issues.

You might be referred to a counsellor for a treatment such as Cognitive Behavioural Therapy.

Psychotherapist

Someone who, treats or helps a client manage, conditions such as depression or anxiety through methods other than drugs, for example, discussion, art or music. Ask anyone you are referred to what training and experience they have on working with autistic adults (or autistic women if applicable), what they understand autism to be, and what treatment approach they will use.

Psychoanalyst

A type of psychotherapist who explores their client's unconscious mind through, for example, analysis of the client's dreams. The client's communication is assumed to have a symbolic dimension of which the client is not aware. The psychoanalyst's interpretations of their client's unconscious desires usually assume the client has non-autistic desires and experience of life, and may not make sense to clients who are literal thinkers, as autistic people tend to be.

Pitfalls

- Until the 1980s autism was wrongly thought to be a mental health condition, a form of psychosis (disconnection from reality)
- Unfortunately many mental health practitioners have not up-dated their understanding of autism. They might (only might) know that autism is a difference in how the brain processes information, but my experience is that they can have trouble adapting their working methods as their training is on the mind not the brain
- You need mental health support which will work for an unhappy mind which is the product of an autistic brain

- Ensure those assessing your mental health know that you have an autism diagnosis
- Check the skills set of services and individual practitioners to whom you are sent

Treatment Options

There are many different types of psychotherapy. Only some are available on the NHS. The NHS is now steering away from offering autistic people psychoanalysis. It used to be thought that autism was a form of psychosis, a disconnection from reality, caused in infants when they did not bond with their mothers, and that this could be remedied through psychoanalysis, a type of psychotherapy that explores the unconscious mind. The NHS now realize that this was a damaging approach for autistic patients. Based on a misunderstanding of what autism is it left many patients utterly bewildered.

Cognitive Behavioural Therapy

Thesedays the NHS favours Cognitive Behavioral Therapy (CBT). CBT is popular in the NHS because it is seen as delivering results in the short-term. There are those in the autism field who see CBT as helpful for autistic people. It is much more concrete than psychoanalysis. But CBT is not a panacea for autism, and nor should referring clinicians expect that CBT will deliver a quick fix for their autistic patient's long-term mental health needs.

CBT examines the link between what we think and how we behave. A patient may be challenged to address faulty thinking. In the hands of a therapist who understands autism this can be useful. The faulty thought, 'I am a social failure', can be challenged, is it society that has failed to include you? Aren't the normal people supposed to be skilled in being friendly? But in the hands of someone who does not understand autism it can be a disaster. The patient who accurately describes the office they work in as a place where no one speaks to them will be challenges on whether they are exaggerating. So therapy becomes another places where the patient is not heard.

CBT focuses on thinking not feelings. Some autistic people need therapy where they can talk about their feelings, for example, how did they feel when they were bullied. Even good CBT may not be the only mental health support an autistic person needs.

Sadly CBT is usually delivered by people whose training has been brief and the training tends not to cover communicating with autistic people. If you would like to try CBT ask your GP to refer you to a therapist who has had training on autism.

Mindfulness

A treatment which is becoming more popular in the NHS for treating mental health needs in autistic people is mindfulness. Some research has found that mindfulness can help autistic people manage anxiety. You may wish to be aware however that what is being offered on the NHS is a cut down version of a meditation practice which has its roots in Buddhism and that ultimately mindfulness is underpinned by Buddhist philosophy. In my view it is odd that tax payers money is being used to substitute religion for Prozac.

Group Therapy

The cynics say that group therapy is half a dozen people treated for the price of one therapist. But group therapy is more than a budget saving technique, the idea is that it creates a real social situation in which real issues come up and can be discussed. But be clear why you are joining a group. I was offered NHS group therapy on the misguided notion that it would help me become more sociable. What I needed was treatment for depression, not someone trying to fix my autism as if it could be cured like a lack of confidence. I refused this type of treatment as I am unable to follow discussion in groups. I know of good group work for autistic people, (not on the NHS), where autistic people have their own group, in which they can be themselves and set their own agenda.

Art, Music and Drama Therapy

These wonderful therapies which move psychotherapy beyond its nickname of 'the talking cure' into forms of client expression which by pass the need for an autistic client to put their feelings into words are often not available on the NHS. (That's why

you're a client not a patient, you're paying for this treatment yourself from your Social Service personal budget).

Safe Treatment Checklist

- You do not have to have any type of mental health treatment unless you are sectioned: have become a danger to yourself or others and so are given treatment without your consent
- The NHS allocate patients to psychotherapists. But psychotherapy is not like having a broken leg put in a cast where the treatment of one qualified doctor is much like another. Psychotherapy depends on having a connection with your therapist. Many therapists are inexperienced in forming a connection with autistic people. If you are unhappy with the psychotherapist you have been allocated end the treatment and ask your GP for a new referral
- At all stages you the client need to be making choices for yourself. Psychotherapists don't tell people what to do. They help people make their own choices
- You cannot have the terms of treatment imposed on you. If your psychotherapist raises their fees you are entitled to end the treatment if you do not wish to pay the new fees
- The fact of your autism needs to be respected by the psychotherapist. It is not the job of those delivering mental health support to question the diagnosis you were given by other professionals. Nor is it their job to 'see past' you diagnosis to the 'real you', any more than a psychotherapist could 'see past' my Britishness to the 'real me'
- Your therapist must make some effort to learn how to communicate with you without making assumptions. For example, your inability to put feelings into words may not be a fear of the subject, it could just be autism. You should not be expected to learn to do things your brain isn't wired for. Not all autistic people can put feelings into words
- As an autistic person you are different. Your therapist needs to understand you without judging you. You will report an atypical life experience but you are not defective, your social skills and relationships are not immature, your view of the world is not wrong, or evidence of choosing not to engage with life, you will not be fine if only you were more confident. Psychotherapy cannot work if

you are being patronized or misunderstood. In psychotherapy you should be, valued, heard and validated and suggestions about how you handle life must be suitable for an autistic person (being advised to ask a friend for feedback assumes you have a friend, and one with a normal view of life)

- Remember all psychotherapy treats individuals not society. Your depression may be a sane reaction to a mad world

Making a Complaint

Remember, you may need to explain your communication needs to the person handling your complaint.

About Poor NHS Services

Here are some of the ways to complain about poor NHS services:

Complaints on service commissioning in Lambeth: contact Lambeth Council's Autism Lead Office Laval Lebon, llebon@lambeth.gov.uk

To complain about an experience in hospital contact the hospital's PALS team which deals with patient liaison.

Complaints about other parts of the NHS can be made to:

NHS Voice Ability which is an advocacy service. Helpline 0300 330 5454

About Psychotherapy in Private Practice

If you need to make a complaint about therapy you have had in private practice, check which professional body your therapist is registered with and contact that body.

British Association for Counselling and psychotherapy: <http://www.bacp.co.uk>

UK Council for psychotherapy: <http://www.ukcp.org.uk>

Section Fourteen – Faith

TIP - This section is about how to participate in faith groups, such as churches.

So far I have only met autistic people who have tried to access churches. If you have experience of another faith community please email caroline.henthorne@icloud.com

What Churches Can Do

If you'd like a local church to be more autism friendly check out the guidance on the Church of England Dioceses of Oxford website on how to ensure church services are accessible to autistic people. The guide is written by an autistic woman, Ann Memmott.

http://www.oxford.anglican.org/wp-content/uploads/2013/01/autism_guidelines.pdf

What Black Churches Can Do

Expertise on how faith intersects with culture is available from the Wandsworth based organization A2ndVoice. (Advice on the wild west of faith life for people of all races: tackling false assumptions, such as that you need exorcism because your behaviour is unusual).

<http://www.a2ndvoice.com>

What Support Workers Can Do

To educate your support worker on what to do when they take you to church see the chapter on faith in the new book, 'Lives With Autism' edited by Steve Mee. Good on tackling practicalities and unhelpful attitudes on how God sees disability and engaging with church communities most of whom are trying to be helpful.

Cults

The author is aware of autistic people who joined an Eastern religion based mediation group (not in Lambeth) and missed the social signs that they were involved in a cult. Cults attempt to control their members choices, typically in areas like, sex and money. They do this though brainwashing, for example reinforcing a message while depriving someone of sleep so that they can't think for themselves. Cults can make it hard for their members to leave. Stay safe. Ask yourself whether the faith group you are involved with respects your right to make your own choices.

Section Fifteen - Making a Complaint

TIP - Accessing services means being assertive. (Well how else are we going to start the inclusion revolution?) Here's how to do it:

If you are refused a service to which you think you are entitled, or if you feel that you have been treated unfairly by a service provider, you should consider making a complaint.

A first step should be to ask to speak to a manager at the assessing organisation or service. If this proves fruitless you can make a formal complaint.

Lambeth Council, and most voluntary organisations have complaints procedures. Ask for the organization's complaint's procedure to find out how any complaint you make will be handled.

Complaining makes a service aware of where it needs to improve, and can often make service managers think again, resulting in the complainer being offered something which does meet their needs.

Lambeth Council Complaints Procedure

For details of the Lambeth Council complaints procedure.

020 7926 9694

<http://www.lambeth.gov.uk/elections-and-council/about-lambeth/make-a-complaint-guide>

Contacting Your Councillor

You can also contact your local councillor for support if you feel that you have been unfairly treated by Lambeth Council or any of the services they provide. To find out how to contact your local councillor, contact the council and ask for any access

support you need to make contact with the councillor for the ward (neighbourhood) where you live.

020 7926 1000 – Lambeth Council switchboard

Find the name of your councillor:

<http://www.lambeth.gov.uk/elections-and-council/councillors/find-out-who-your-lambeth-councillors-are>

Disability Councillors

Lambeth Council has cabinet style governance.

18-25 Year Olds

The councillor who is the cabinet member for vulnerable children is Rachel Heywood - Cabinet Member for Children and Families. If you are under 25 years old she may be able to help you.

020 7733 7300

rheywood@lambeth.gov.uk

Adults of All Ages

The cabinet member for vulnerable adults is Jackie Meldrum - Cabinet Member for Children and Adult Services. Her remit covers disabled adults of all ages.

020 3149 6657

jmeldrum@lambeth.gov.uk

Autism Lead Officer (Adults)

All local councils have an Autism Lead Officer. While councillors are elected by local people, officials are employed by the council to make things happen. Such as planning and delivering local services. He needs to know what is and isn't working.

In Lambeth the Autism Lead Officer is Laval Lebon

llebon@lambeth.gov.uk

The Hitch Hiker's Guide to
The Galaxy has the words

'Don't Panic'

inscribed on the cover in
large friendly letters.

Possibly more useful than
anything inside the guide.