



**Spectrum**

A befriending service for children with disabilities in the Camden area



## **SPECTRUM HANDBOOK, 2014 - 2014**

**The purpose of this handbook is to provide you with an overview of what Spectrum is and does, what we expect of you and any other helpful information we think you may require. Good luck with the year ahead!**

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## **What is Spectrum?**

Spectrum is a student-led charity established in 1982. Its primary aim is to link students to children with disabilities or special needs living in the Camden area. The three main objectives of Spectrum are:

- To provide a befriending service to children with disabilities or special needs, enriching their lives and providing them with opportunities they may not otherwise encounter.
- To provide respite for families and carers of the children.
- To allow students an opportunity to learn more about physical and mental illness and the impact on the lives of children and their families.

## **Visits and Outings**

Each child is linked with two students. Contact with the child takes place through visits and outings, arranged through prior contact with the child's parents/carers.

Home visits are a great way to get to know your child and their family better. Use these early visits to learn as much as possible about your child's needs and interests. Don't be afraid to ask lots of questions!

With the parents consent, outings may also be organised. The nature of these outings depends on the preferences and needs of the child. Ideas may include: visits to the cinema, swimming, bowling, walks in the park etc. Try to get as involved as possible in the child's own interests.

There are also group outings and parties organised throughout the year to places such as the zoo, aquarium and theatre. There is usually also an annual residential weekend to an activity centre near London. These group outings are a great opportunity to meet other Spectrum volunteers and children and your participation is strongly encouraged

As a minimum, it is expected that students visit their linked child once every two weeks. Understandably, at times when students are particularly busy (i.e. around exams), this may be difficult. In this case it is paramount that the parents are made aware when the next visit may be possible. Please ensure that over these periods regular contact continues - don't leave your child and their family in the dark!

We stress that it is very important for you to always go **in pairs** to visit your link for your child's safety and your own protection.

We also expect you to fill out a logbook documenting all visits/outings with your child.

## **Keeping Children Safe**

If on any outing, you are 100% RESPONSIBLE for a child's welfare. Many of the children are hugely vulnerable and may lack a sense of danger, therefore it is important to:

- **Never leave a child unattended or out of sight**
- **Be vigilant when in dangerous situations** i.e crowded areas, crossing roads
- **Inform yourself thoroughly of any specific needs** the child may have i.e. medications, allergies, nappy changing.
- **Alert the necessary people immediately if a child is missing.** These may include security staff or senior Spectrum members (if on a group outing)

### **Child Protection**

If you have any concerns whatsoever that there may be a child protection issue, involving your own link or anybody in the family, please do not hesitate to contact your supervisor to talk things through. We are happy just to listen to concerns/worries however small you think they may be and this will all be in complete confidentiality.

If we feel any issue needs to be escalated we will talk this through with you first and then refer on to our child-safeguarding officer – Ain Satar. The issue will then be discussed amongst an experienced clinical team and if necessary referred onto the relevant authorities. We want to emphasise that any concern to you, is a concern

to us and don't be afraid to talk things through if you are unsure.

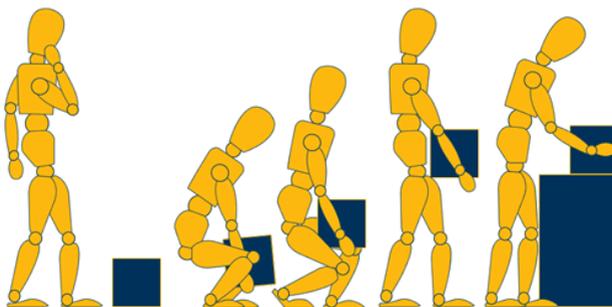
## **Keeping Yourself Safe**

Don't forget to look after yourself on these outings too! Be aware of the places you will be going to whether or not they are appropriate for both you and you link!

Look after your back and make sure you are not putting your body under too much stress when playing, racing, chasing, leapfrogging ....

And remember when moving objects/children

- Assess the load and reduce the risk of injury to you or your link (try and use two of you!)
- Bend you knees and keep your back straight
- Don't twist around whilst moving



## **Expenses**

**Spectrum reimburses members for ALL costs** incurred during visits, outings and residential trips.

- **Keep hold of *all* receipts** and regularly record any expenses. Remember to get printed receipts of your Oyster travel expenses from the tube station if you require reimbursing for this
- **Print and fill in an expenses form** (find on <http://www.rums-spectrum.org.uk/>). Attach the relevant receipts and drop it into the Spectrum Box in the VSU office (Upstairs in the Lewis Building)
- The treasurer will check the box on the **1<sup>st</sup> of every month**, and will notify you by email when your cheque is ready to be collected.

## **Communication**

- Speak clearly, at eye-level and allow plenty of time for the child to respond.
- Use 'commentary' to start interactions: talk about what you are doing together.
- Utilise any other communication aides the child may use i.e. Makaton, picture book
- If your link uses Makaton and you are keen to find out more, we offer some basic Makaton training so get in touch or visit our website!

## **Managing behaviour**

- Model good behaviour: set a good example and praise good behaviour.
- Offer choices on what to do next, let the child feel in control of activities.
- Manage behaviour positively, do not threaten, shout or belittle.

## **'CONDITIONS'**

All the children are different in their own way but here are a few general guidelines on communication and behaviour management....

### **1. Autistic Spectrum Disorder or ASD**

**What is it?**

- Umbrella term for a spectrum of disorders
- Developmental disability starting from the age of about 3

*Classified by a TRIAD of Impairment in:*

- 1) Communication – jokes, sarcasm, facial expressions
- 2) Social interaction - empathy, affection, imagination
- 3) Routine repetitive behaviour

*Dispelling the myth:* Some children will have niche intelligence but many suffer a range of learning difficulties. ASD is often linked with a variety of other medical conditions e.g. epilepsy

**Overcoming the barriers:**

- Use of language and interaction - judging sarcasm, metaphors, physical contact
- Being perceptive and adaptable
- Wide range of communication techniques (verbal-nonverbal-gestures-acting)
- Advice from parents and family

We often talk about disability as a "barrier" and children with ASD being in "a world of their own" - but the best

way to look at it is to try and understand and embrace their world. That way you will bond and interact so much better with your links - and at the end of the day have lots of fun too!

## **2. Attention Deficit Hyperactivity Disorder (ADHD)**

### **What is it?**

There are 3 different subtypes of ADHD, in which children express various behaviours:

#### **1). Predominantly Inattentive:**

- easily distracted and have difficulty maintaining focus on one task
- easily bored with an activity quickly
- can be forgetful and become easily confused
- can struggle to follow instructions
- they can daydream and seem to not listen when spoken to

#### **2). Predominantly Hyperactive & Impulsive:**

- talking non-stop
- difficulty in doing quiet and calm tasks
- lots of energy and will move around a lot, fidget, touch & play with everything they see
- some of their impulsive behaviours mean that they can be very impatient, find it difficult to wait and even more difficult to take turns
- can blurt out inappropriate comments & express their emotions and what they are feeling without restraint- sometimes seeming to act without thinking of the consequences

#### **3). Combination of the two- Inattentive, Hyperactive**

## **& Impulsive**

### **Overcoming the barriers:**

The management of ADHD involves a combination of medical treatment & behavioural treatment. Parents, school teachers and any people working closely with the child, eg. volunteers, play an important role in this management, and ways in which you can deal with and learn to manage some of the challenging behaviours, include:

#### **1). Keeping the child active & expending their energy at all times:**

- physical activities are a great user of energy, and it keeps you both fit too!
- Have some go-to activities that you both enjoy, know work well to keep them occupied and relatively calm

#### **2). Be firm with them and try to reinforce behaviours that their parents are aiming for:**

- be specific & clear with what you are saying and clarify understanding
- use rewards to help reinforce this good behaviour eg. stickers etc (sweets and sugary drinks often make the hyperactivity worse!)

#### **3). Don't be scared to get involved & interested in what the child is interested in:**

- this really helps to strengthen the bond you share and you may even develop a new hobby

#### **4). Be patient**

- Although it's easy to sometimes feel it's a constant battle with a child with ADHD, try to be as patient as you can

#### **5). HAVE FUN!!!!**

### **3. Epilepsy**

#### **What is it?**

Sudden surge in electrical activity which disrupts the normal electrical impulses and mixes up the message system in the brain – leading to seizures.

#### **Partial seizures (small part of brain affected)**

Simple (fully conscious)/complex (lose awareness)

Commonly see smacking lips and thrashing arms

#### **Generalised seizures (most/all of brain affected)**

Absence (drops), myoclonic (jerking), clonic (longer lasting), atonic (sudden relaxation of muscles), tonic (sudden stiffening of muscles), tonic-clonic (2 stages – rigidity then jerking – most common)

#### **Overcoming the barriers:**

Epilepsy is unique to each and every person with the condition and it is important to speak to the parents to get a good idea about triggers for seizures (if any) and what to do if/when a seizure happens. They will also be able to give you a good idea about activities that are most enjoyed and also ones to avoid.

Some epilepsy is incredibly well controlled by medication and you may never see your link have a seizure. But epilepsy can be very unpredictable and it is important you have these top tips in mind ....

#### **DO's:**

- Protect the person from injury - (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing them in the recovery position once the seizure has finished
- Stay with them/reassure
- Try and re-orientate after

### **DONT's:**

- Restrain the person's movements
- Put anything in the person's mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

## **4. Cerebral Palsy**

### **What is it?**

*Non-progressive* brain condition that initiates in ante/ neo/ early postnatal period. Although the brain impairment does not alter during life, physical functioning might deteriorate (secondary ageing due to disease processes).

Diagnosis might not be confirmed until motor milestones of sitting, crawling and walking, when abnormalities more likely to be perceived.

### **Types**

3 main classifications:

1. 75-88% **Spastic** - hypertonia involving single or multiple limbs.  
Hemiplegia (1 side of body), diplegia (2 limbs) or quadriplegia (4 limbs).
2. 15% **Dyskinetic** - dystonia, chorea (brief, irregular contraction), athetosis (twisting, writhing movements). Speech might be adversely affected.
3. 4% **Ataxic** - uncoordinated movement

Heterogeneous associated problems include:

- Delayed language skills
- Feeding difficulties & drooling
- Behavioural difficulties e.g. inattention, anxiety
- Epilepsy (affects 1/3)
- Learning disabilities (intellectual impairment in 45%)
- Urinary incontinence
- Poor spatial awareness & perception
- Visual/ hearing impairments

**Overcoming the barriers:**

- Encourage unscheduled play guided by the child's preferences (remember that s/he might have many timetabled medical appointments)
- Promote physical exertion & independence – don't be afraid of mess e.g. feeding; arts & crafts.

- **Equipment**

Check wheelchair is suitable – if you predict rough terrain, check you have the appropriate chair.

Hoists – get parents to teach you how to work these

- **Mobility issues**

Avoid injury by remembering your **manual handling** techniques

Encourage your child to feed/dress/clean themselves as much as possible

- Become familiar with communication aids
- Speak at eye level
- Be patient, allow them to respond
- Don't underestimate what the kids can do...

**For more information visit**

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

[www.gosh.nhs.uk/children/](http://www.gosh.nhs.uk/children/)

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

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

## **5. Down's Syndrome**

**What is it?**

Common genetic disorder caused by Trisomy 21 (extra copy of chromosome 21) in 94% cases. It has no conclusive cause or cure. It manifests with

- Learning difficulties – speech and development delay and reduced behavioural awareness (often need reminding what is right/wrong)
- Muscle weakness and problems with fine motor control
- Other associated health problems; hearing/vision impairment, digestive problems and cervical spine dislocation

### **Overcoming the barriers:**

Children with Down's have extraordinary potential and it is important to inspire independence through effective support and education. You are in an excellent position to be able to offer this!

- Take an interest in your links hobbies and enable them to flourish by getting involved yourself!
- Be aware of specific limitations and don't put your link in situations that will make them feel uncomfortable
- Use auxiliary methods of communication: actions speak louder than words!! Suggestion: lots of children use PECS or Makaton
- Encourage physical activity (where possible). Swimming is often a favourite!
- Down's individuals may tend to self-talk (thinking out loud) - not a cause for concern! But do try to encourage using an 'inside voice' when talking about private issues

## **6. Global Development Disorder**

### **What is it?**

Significant delay in two or more developmental domains (gross motor, fine motor, cognition, speech/language, and personal/social)...This term is used for younger children (typically less than 5 years), before IQ testing can be used to accurately define mental retardation. Some children will catch up with the appropriate milestones without any additional support but often

children require input from paediatricians, occupational therapists, child psychiatrists and speech and language therapists.

**Overcoming the barriers:**

- Every child is different and therefore you'll only know what activities they like by spending time with them and trying out new things
- Break down games into smaller simpler tasks and let them do things at their own pace.
- Remember you're a volunteer and not a health professional. Use this to your advantage to help your link explore their likes/dislikes, interests and hobbies! This will often involve introducing activities that they have never done before!
- If in doubt ask the parents!

## **A Child's fundamental rights**

### ***To be valued as an individual***

- Caring for and treating every child as unique
- Giving children enough time to take part, do things for themselves, to understand and be understood

### ***To be treated with dignity and respect***

- Addressing every child with respect
- Never referring to a child, or talking about them as if they are defined by their disability

### ***To be loved and cared for as a child first***

- Giving the best possible care that can be provided in every situation
- Patiently listening to children when they wish to communicate, even if it is difficult to understand

### ***To be kept safe***

- Not exposing children to unnecessary risks and protecting them from abuse at all times

### ***To have fun!!***

## **How to make the most out of Spectrum!**

- You are in an incredibly privileged position! Respect this.
- Visit your child regularly so that you get to know them and their parents!
- Be a friendly face and set a good example. Often our volunteers are seen as important role models!
- Share ideas with other volunteers. On our website and at socials
- Don't be disheartened if a planned activity doesn't work out
- Regularly check the spectrum website ([www.rums-spectrum.org.uk](http://www.rums-spectrum.org.uk)) and Facebook group to keep on top of Spectrum news/events. And lookout for our monthly newsletter for Spectrum updates and top tips!
- **HAVE FUN and ENJOY SPECTRUM!**

