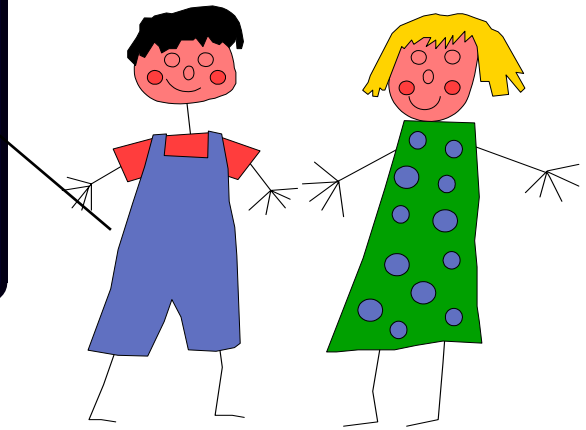




An OAASIS Publication
for Parents and Professionals

**COMPLEX
AND SEVERE
LEARNING
DIFFICULTIES**



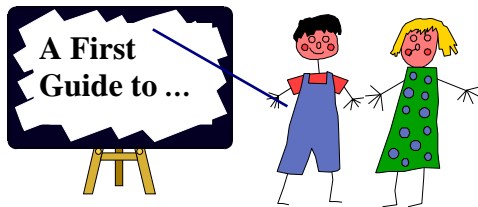
Complex and Severe Learning Difficulties

Published by

OAASIS

*Office for Advice, Assistance,
Support and Information on Special Needs*

*OAASIS is a part of **Cambian Education Services***



Complex and Severe Learning Difficulties

A First Guide to Complex and Severe Learning Difficulties : Price: £4.00

By Phil Champion, Anil Mistry et al, 1997, 2003

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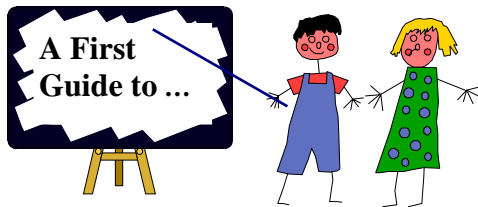
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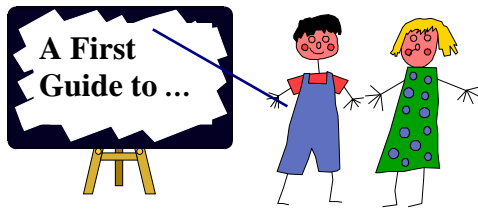
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Complex and Severe Learning Difficulties About First Guides

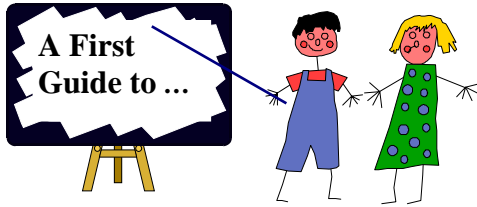
- **This First Guide** was developed at OAASIS (Office for Advice, Assistance, Support and Information on Special Needs) to provide a quick and easy reference pack of information on the difficulties experienced by young people with complex and challenging needs.
 - **OAASIS** offers:
 - a **telephone Helpline** for advice on matters to do with special education. Ring **01590 622880** usually manned between 10 and 4.30p.m., Monday – Friday.
 - various **publications** including
 - Free Information Sheets on various learning difficulties and other aspects of special education.
 - The *First Guide to ...* series. Other titles are listed on the opposite page.
 - *What is?* cards. Small cards describing briefly a disability. Useful for informing others. Cards are available on: ADHD, Asperger Syndrome, Attachment Disorder, Autism, Dyspraxia, Epilepsy, Obsessive Compulsive Disorder, Semantic Pragmatic Disorder and Tourette's Syndrome.
 - *Do You Know Someone with Autism?* booklet. Written by a former teacher at The Forum School for the brothers, sisters and classmates of a child with autism.
 - **OAASIS** can be contacted by writing to OAASIS at Brock House, Grigg Lane, Brockenhurst, Hampshire SO42 7RE; sending a fax to 01590 622687; emailing oaasis@cambiagroup.com or ringing the Helpline.
 - **Hill House School and Broughton House & College** offer residential education (with a waking day curriculum) for young people aged 11-19 years and adults aged 16-30+ with severe and complex learning difficulties, including autism, coupled with challenging behaviours.
 - Hill House School, Broughton House & College and OAASIS are a part of Cambian Education Services. For further information on the Cambian Education schools and colleges please phone 0800 288 9779.
 - OAASIS welcomes contributions from families, professionals, and individuals who would like to contribute ideas for inclusion in the pack.
 - There may be a small charge for the Guides to cover OAASIS printing and packing costs. See the OAASIS Publications List for a full range of literature available.
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Complex and Severe Learning Difficulties **Contents**

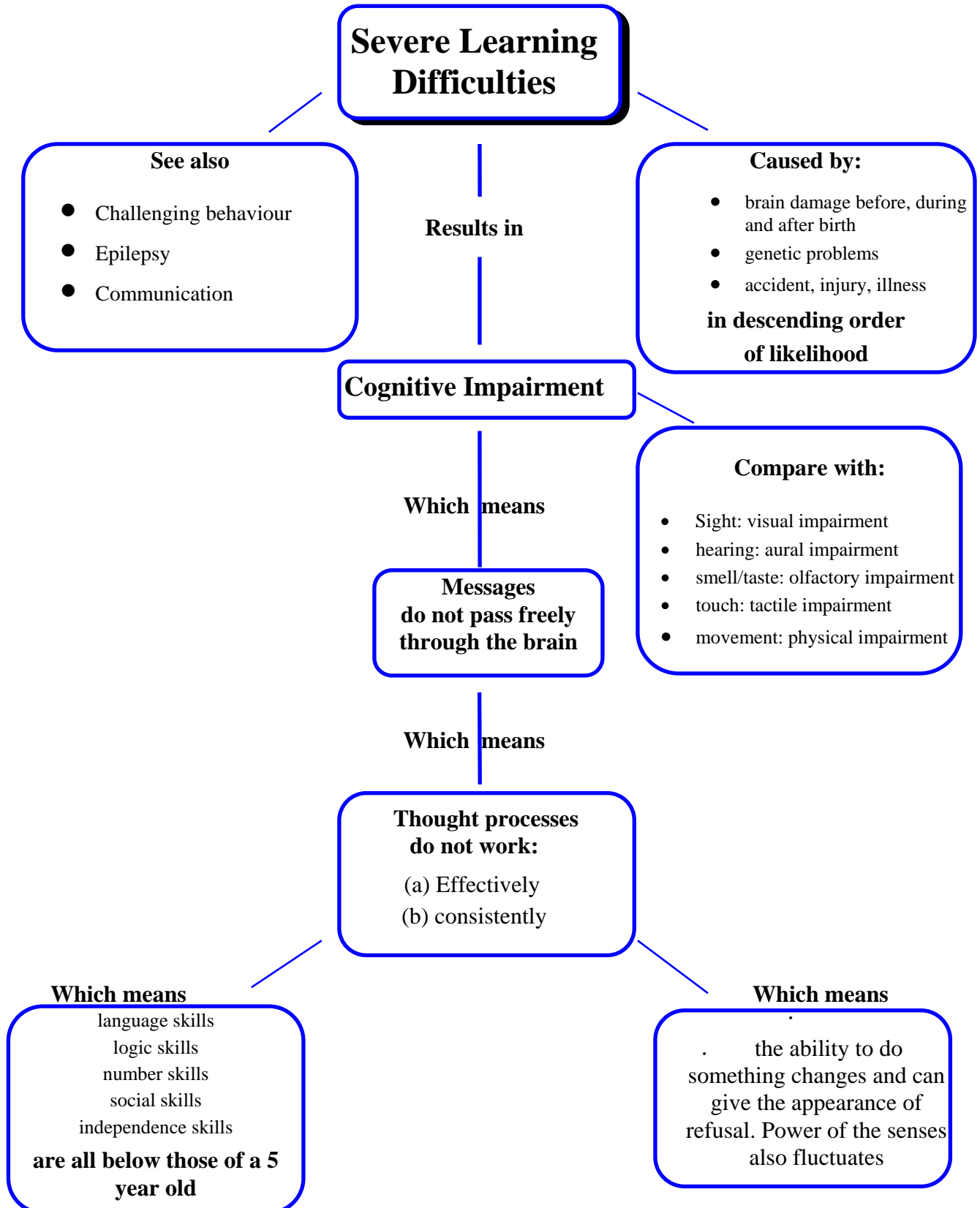
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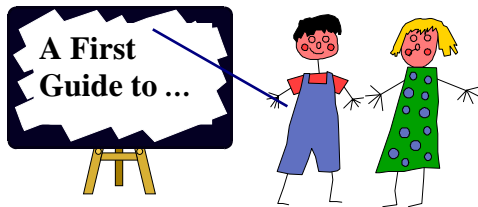
- Basic Introduction to Severe Learning Difficulties**
- Basic Introduction to Managing Challenging Behaviour**
- Basic Introduction to Communication**
- Basic Introduction to Epilepsy**
- Positive Approaches and Behaviour Support**
- Recommended Reading** Other useful OAASIS publications



Complex and Severe Learning Difficulties

Basic Introduction to Severe Learning Difficulties





Complex and Severe Learning Difficulties

Basic Introduction to the Management of Challenging Behaviour

Recognising and defining challenging behaviour:

The term 'challenging behaviour' came into use in the 1980's when major efforts were being made to close long stay hospitals and put into practice the philosophy encapsulated in the term 'normalisation'. Previously, people had been seen as having 'difficult' or 'problem' behaviour or as being, of themselves, 'difficult' or 'problems', and in that sense the individual themselves 'took blame' for the behaviour. The new thinking tried to move away from the blame culture and to look at different ways of approaching challenging situations.

It was recognised that people with learning disabilities would still engage in behaviours which were problematic for themselves or for those around them. It is clear from various research papers that real progress has been made in the ability of services to understand and respond to people with challenging behaviour.

How do we define challenging behaviours? There is no one definition which clearly states what is meant by challenging behaviour in a way that makes sense to all those who work with people who challenge.

Emerson *et al* (1987) defines challenging behaviour as -

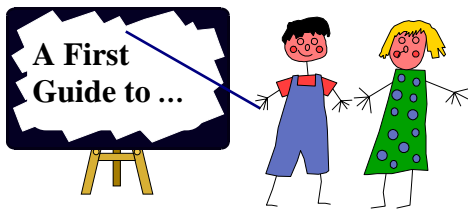
'Behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely seriously to limit or deny access to and use of ordinary community facilities'.

Severe challenging behaviours feature:

- Physical aggression
- Destructiveness
- Self-injury
- Temper tantrums
- Wandering off
- Antisocial behaviour
- Inappropriate sexual behaviour

Why do challenging behaviours occur?

- Medical reasons
 - onset of a seizure
 - onset of physical changes during puberty
 - toothache, stomach-ache, headache, etc
 - reaction to colourants/additives in food or drink
- Biological reasons
 - Down's syndrome
 - Hurler's syndrome
 - Tourette's syndrome
 - Lesch Nyhan syndrome



Complex and Severe Learning Difficulties

Basic Introduction to the Management of Challenging Behaviour

- Other

- Response to environment
- Learnt behaviour
- Communicative

(See section on Communication in this Guide.)

Sometimes - indeed often - this behaviour has been 'learned' over many years and can be used very effectively by the student to avoid tasks, escape a situation or activities that they do not like.

- Emotional
- Mental health problem

How do we cope with Challenging behaviours?

Parents and carers will cope with the various challenging behaviours of the people in their care differently. Some may find, for example, damage to property far easier to deal with than, eg screaming and self-injury. Some will be less worried by inappropriate behaviour in public than others.

While some behaviours will clearly worry people individually, the extent to which the *service* is actually challenged in its ability to cope will vary.

So how do we deal with challenging behaviours?

Now you have read the basic introduction to severe learning difficulties, those of you with young families may be tempted to think that you need read no further:

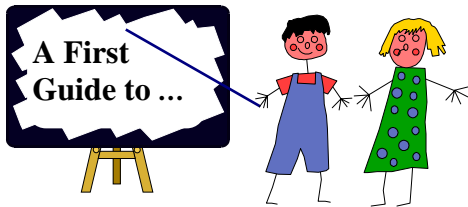
Your children are at the same developmental level. That is not true. Everyone has to understand that just because someone has severe learning difficulties or autism, you cannot treat them as if they are two or three years old.

Generally people find the most challenging behaviour to be that which is directed at themselves or others that could be termed 'aggressive'. Aggressive behaviour is not the only type of challenging behaviour that some of our students exhibit; but it is usually the one with which most people have difficulty coping.

Looking behind the actions

The reasons individuals indulge in challenging behaviours is as varied and complex as the individuals themselves. We have to look beneath the surface of these behaviours and attempt to establish a *function* for the behaviour (more about the function of behaviour can be found in the *Positive Approaches and Behaviour Support* section of this Guide).

All behaviour serves one or more functions. Usually, our students exhibit a hierarchy of behaviours and it is up to us, with the help of parents, psychologists and other consultant experts, to interpret these.



Complex and Severe Learning Difficulties

Basic Introduction to the Management of Challenging Behaviour

The most common reasons for a student exhibiting difficult or inappropriate behaviour are, usually:

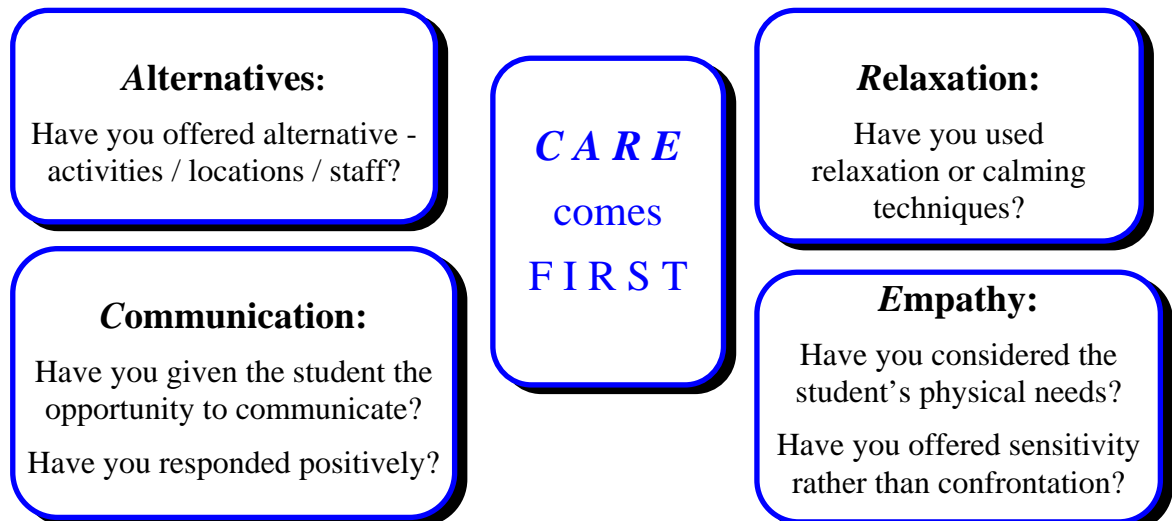
- **to have their immediate needs met.** For example, they are
 - hungry
 - thirsty
 - wet
 - hot or cold

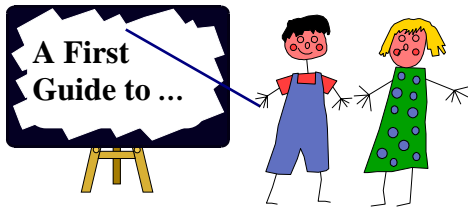
How can we help the students?

- By trying to understand the reasons for the behaviour (ie ‘function’) and remembering not to put *our* adult perceptions of what we ‘think they mean’ as the only reasons for the behaviour.
- By looking for patterns in the behaviour. For example,
 - where does it occur
 - when does it occur
 - with whom does it occur
 - what happens: before - during - after.
- By allowing them time and space to make themselves understood.
- By protecting ourselves and others as and when necessary in ways that meet our philosophical non-aversive / positive approaches paradigm. (See paragraphs below and section on SCIP in this Guide.)
- By accepting that the behaviour is part of the individual at this time and using a mixture of the above techniques to deliver care / education plans. A consistent approach will help reduce challenging behaviour and teach “alternative” more appropriate or relevant skills.

These plans need to be clear and concise, and have set aims / goals for both the short and long term needs of the student.

CARE comes first





Complex and Severe Learning Difficulties

Basic Introduction to the Management of Challenging Behaviour

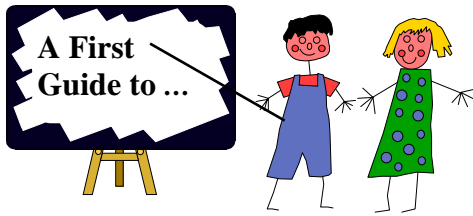
Dealing with challenging behaviour is stressful

and no-one is exempt from feelings.

You may be a parent, a brother or sister, a carer, a teacher,
there is nothing to be ashamed of in admitting to such feelings.

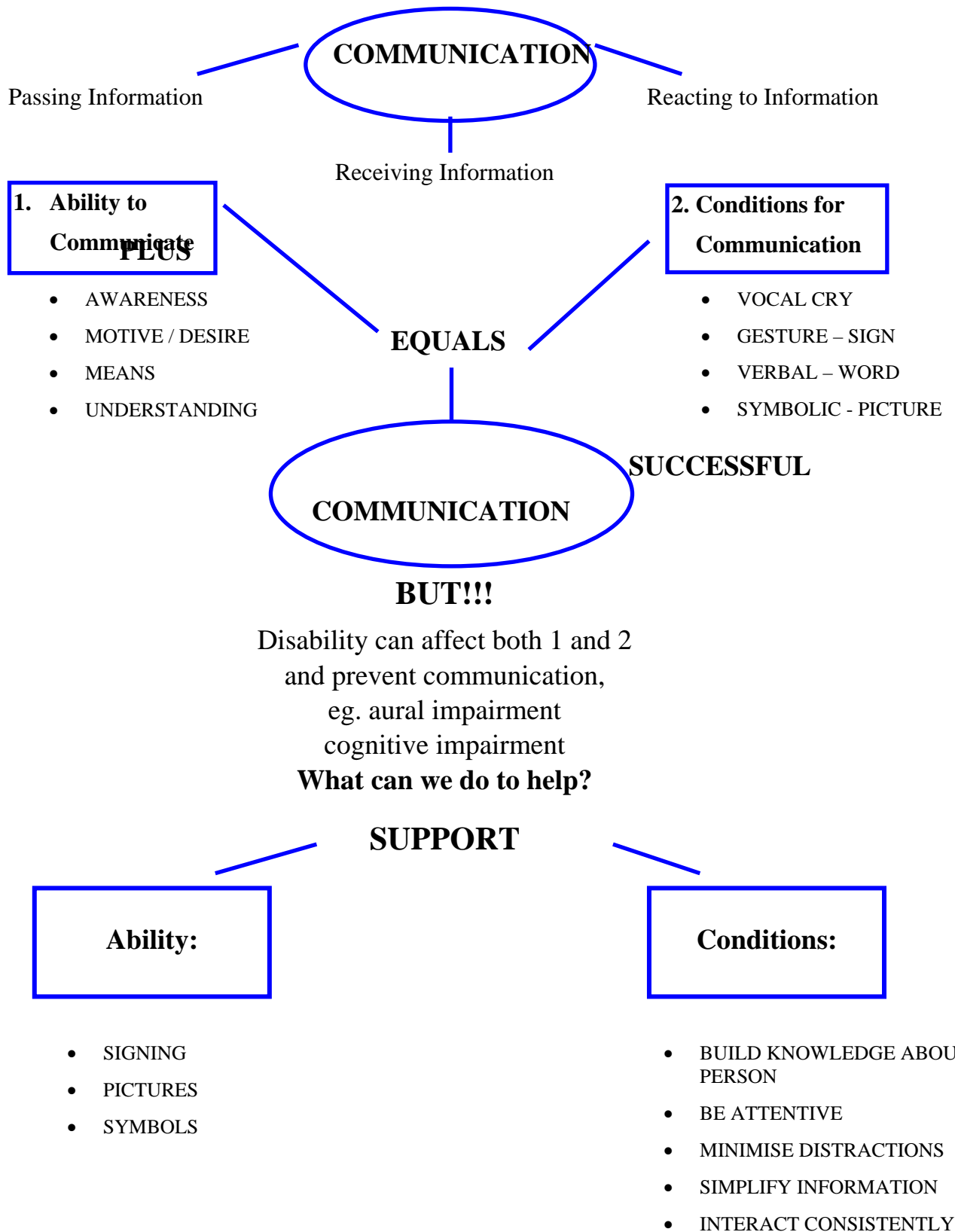
It is how **you** deal with them which matters

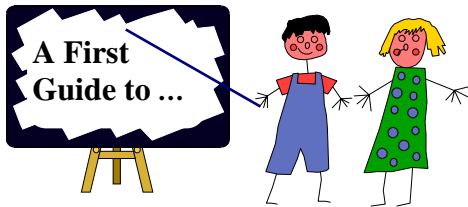
**Seek guidance from a colleague, or professional help or counselling
if you are anxious about your own ability to deal with stress
or indeed any concerns you may have
about the challenging behaviour of somebody in your care.**



Complex and Severe Learning Difficulties

Basic Introduction to Communication





Complex and Severe Learning Difficulties

Basic Introduction to Epilepsy

People who have both epilepsy and learning difficulties/disabilities pose a double challenge for their companions (relatives, friends or carers). To understand the way these two conditions interact it is necessary to be clear first of all what is meant by the term “epilepsy” and “learning difficulties”.

EPILEPSY:

Most people know someone with epilepsy. Not everyone understands why seizures (fits) happen, or what to do if they do happen. Fear and ignorance often cause more problems for a person with epilepsy than the condition itself.

Here are some of the questions which people ask about epilepsy (see also the OASIS Information Sheet on Epilepsy, available from OASIS free of charge).

What is epilepsy?

Epilepsy is a word from the Greek language. It means to take hold of, or seize. To have epilepsy is to have a recurrent pattern of seizures. There are many different types of epileptic seizures.

Who can have epilepsy?

Anyone! In the United Kingdom about one person in a hundred has some type of epilepsy.

It can affect people of any age, sex, race or intelligence. Most people with epilepsy develop it in childhood. Knowing the facts about epilepsy will help these people.

What makes someone have epilepsy?

In many cases, we do not know. For some, the cause may relate to birth difficulties, head injuries, the result of diseases or other medical reasons. In each instance, the disturbance begins in the brain. Its effects may be widespread in the body.

What does epilepsy look like?

There are many types of epilepsy. Each type may look different. This is because the brain is involved and the brain controls all our actions and feelings. What happens during a seizure depends on which part of the brain is affected.

Can epilepsy be cured?

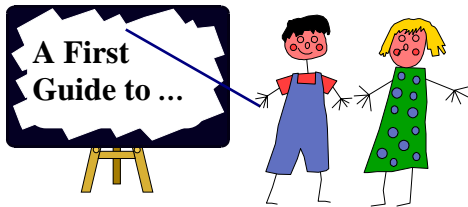
No, but in most cases it can be controlled using drugs. These have to be taken regularly to work properly.

How do people cope with epilepsy?

Most people can come to terms with their seizures, but can never be sure how others will react. This anxiety may be far worse for them than their seizures.

LEARNING DIFFICULTIES:

Most people relate the term ‘learning difficulty’ to levels of IQ (intelligent quotient). People with scores of between 70 and 85 have moderate learning difficulties but usually function quite well in terms of communication and physical ability and lead independent lives. Those who score less than 70 have severe learning difficulties and very often, but not always, struggle with communication (see *Basic Introduction to Communication*) and movement skills.



Complex and Severe Learning Difficulties

Basic Introduction to Epilepsy

People with scores of less than 55 can usually only exchange a few words and so conversation with any sort of complexity is not possible.

There is a strong relationship between severe brain damage, severe learning difficulties/disabilities and epilepsy. The prevalence of epilepsy in people with severe learning disabilities is 30%, and in people with profound learning disabilities 50%. In contrast, the prevalence for people with mild learning disabilities is 6% (Rutter *et al*, 1970).

People with learning disabilities are susceptible to all forms of epilepsy. Sometimes epilepsy and learning disabilities are both consequences of brain damage. There is a high association between epilepsy and disorders such as cerebral palsy and tuberous sclerosis.

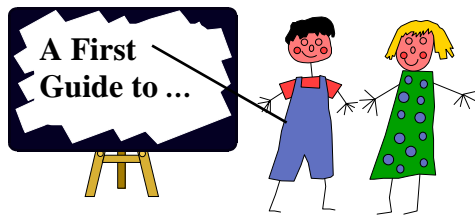
The individual with learning difficulty and epilepsy has different needs compared to an individual with epilepsy in the non-learning disabled population. Severity of learning disability can influence how well the individual can understand and discuss their condition and its treatment. Communication may lead to a need to work through a third person, either family or carers. They play an important and crucial role in interacting with doctors, specialist nurses and voluntary sector workers in arranging day-to-day management of the condition.

EPILEPSY - THE FACTS

A person with epilepsy may have more than one type of seizure (fit). Here are the most common:

- **absence**
- **tonic clonic**
- **partial**

Type of Seizure	Looks like -	You do -
<p>Absence affects the whole brain previously called <i>petit mal</i>.</p>	<p>The person looks blank for a few seconds then returns to normal.</p>	<p>Very little: be kind and understanding.</p>
<p>Tonic Clonic affects the whole brain - previously called <i>grand mal</i>.</p>	<p>The person may cry out and fall. The body jerks and the skin turns blue. The seizure will last for a few minutes. The person may be tired or confused when the seizure is over.</p>	<p>Keep calm; try to protect head and let the seizure run its natural course. Do not move person or put anything between the teeth. Be understanding.</p>
<p>Partial affects part of the brain</p>	<p>The person may appear confused and repeat movements or smack lips, or both. The seizure may be quite long and the person will be confused when it ends.</p>	<p>Do not try to stop them. Remove harmful objects, and guide them away from danger. Talk quietly. Be understanding.</p>



Complex and Severe Learning Difficulties

Positive Approaches and Behaviour Support

Basic introduction to Positive approaches and behaviour support

Because of the complex nature of our students' needs, we have to have support strategies that we can employ in order to reduce the incidence of events that challenge them. These are called *proactive* and *reactive* strategies.

Logically we employ **proactive strategies** *before* the occurrence of challenging behaviour in order to reduce the likelihood of it happening. Such strategies would include adapting the environment, activities, scheduling, communication strategies and interactions to meet a student's individual needs.

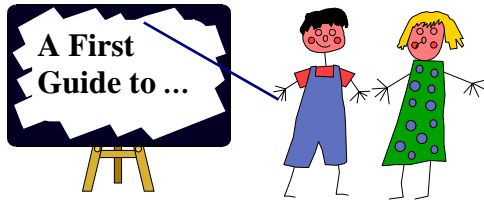
Reactive strategies are employed when the student needs more support at the time of an incident. They include verbal and non-verbal calming techniques and if necessary, physical interventions. These physical interventions are derived from the PROACT-SCIP techniques taught at the Lodden School and approved as a training programme by BILD (British Institute of Learning Disability).

All care and education staff receive 2½ days training within the first 8 weeks of their employment on positive approaches and physical interventions. The training emphasises that physical interventions should be seen as a strategy of last resort, and that all possible strategies must be used to prevent a build up to the use of a physical intervention. A limited number of staff are trained and accredited to deliver training in positive approaches and coaching in physical interventions. Each of those staff members is assessed annually to review and update their skills. Interventions at 'level 1' are taught to all care and education staff. Level 2 interventions are taught on a student specific basis.

We regularly meet to assess the students' behaviour support needs in order to develop plans that enable them to function within their establishments and community. These plans are discussed with parents and local authority personnel and professionals associated with the school or college as a matter of course.

The importance of knowing **the function(s)** of a behaviour is fundamental to this approach. This involves observing and recording the antecedents, behaviour and the consequences of that behaviour for an individual student. This recording helps us to analyse the function of that behaviour and to adjust the events that might trigger anxiety for a student, or to respond in a non-aversive manner that reduces their need to behave inappropriately.

For example, student 'X' regularly slaps their teacher in class and runs out of the lesson. Staff would observe and exactly record what was happening before the slapping, what happened during the incident and after it. In this case the function of the behaviour is found to be related to the fact that the student can only concentrate for 5 minutes at a time and the slap is their way of saying 'enough, I have to get out of here'. This student's behaviour support plan therefore includes a change of activity at 4½ minutes and the student being taught to offer a red card to any staff member to signify that they have had enough and need to leave.



Complex and Severe Learning Difficulties **Recommended Reading**

Autism

Approaches to Autism NAS. 1993.

Autism: A Guide for Parents and Professionals Author: Aarons, Gittens. 1992, London: Routledge

Autism and Asperger Syndrome Author: Uta Frith. 1991, CUP

Autism: Explaining the Enigma Author: Uta Frith. 1989, Blackwell

Autism, Professional Perspectives and Practice Ed Ellis. London: Chapman & Hall

Autism: the Facts Author: Dr Simon Baron-Cohen, Dr Patrick Bolton. 1993, OUP

Autistic Spectrum Disorders Author: Lorna Wing. 1995, NAS.

Behavioural Concerns and Autistic Spectrum Disorders. Explanations and Strategies for Change. J Clements and E Zarkowska. 2000. Jessica Kingsley Publishers.

Children with Autism: a Booklet for Brothers and Sisters Author: Julie Davies. 1993, CDRU, University of Nottingham

Information on Autism and Asperger Syndrome for Schools. 1995, NAS

Living and Working with Autism NAS

The Autistic Spectrum: A Guide for Parents and Professionals Author: Dr Lorna Wing. 1996, Constable

The Handbook of Autism Author: Maureen Aarons and Tessa Gittens. 1992, Routledge

The Special Curricular Needs of Autistic Children: Learning and Thinking Skills Author: Jordan, Powell, 1990, AHTACA

Siblings of Children with Autism: A guide for families. Sandra L Harris, PhD. Available from the NAS book distributors, Barnardos Despatch Services, Tel: 01268 522872.

Treatment of Autistic Children Author Howlin, Rutter, et al. 1987, Chichester: Wiley

Understanding and Teaching Children with Autism Author: Rita Jordan, Stuart Powell. 1995, Wiley

Miscellaneous:

COPE - Compendium of Post-16 residential Education & training for young people with special needs, 8th edition. 2000, Lifetime Careers Wiltshire Ltd, ISBN 1-873408-03-X Available from Orca Book Services, 01202 665432.

NATSPEC (Association of National Specialist Colleges) Directory of colleges for people with special needs. Available from NATSPEC Tel: 01472 594014. Email chriswberry@ntlworld.com

Taking Action! Your Child's Right to Special Education Authors: Wright and Ruebain of IPSEA. 2000 Questions Publishing Co, £14.99 + p&p. Tel: 0121 212 0919.

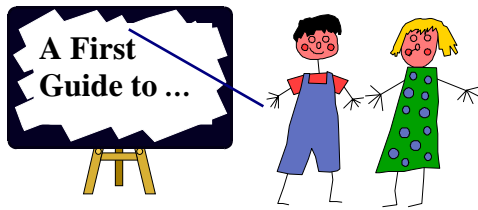
The Gabbitas Guide to Schools for Special Needs, new edition every year. Gabbitas Educational Consultants. Published by Kogan Page, available from Littlehampton Book Services, 01903 828800.

See also book lists from -

Jessica Kingsley Publishers (0207 833 2307)

The National Autistic Society (0207 903 3595)

David Fulton Publishers (0207 405 5606).



Complex and Severe Learning Difficulties And check out ...

... the OAASIS Information Sheets –

- Exams and Access Arrangements for Students with Special Needs
- Finding a Special Needs School
- Independent Special Schools – what to look for
- Books – where to find them
- Forthcoming Conferences and Seminars from other organisations
- Useful Contacts and Websites

Visit the OAASIS website for the full list of free downloadable information sheets and other publications: www.oaasis.co.uk.