

williams

**SYNDROME
FOUNDATION**

**PROFILE OF
SPECIAL EDUCATIONAL NEEDS
FOR CHILDREN WITH WILLIAMS SYNDROME**

By

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Registered Charity No. 281014

A suggested 'Hit List' for anyone writing the Parental Profile (Appendix A) for a Statement of Special Educational Needs for their child.

It is important that the Education Authority knows that Williams Syndrome children have special needs that are different from other children. Parents must give, as much information as they can, and it is worth emphasizing that these children are not like other children with learning difficulties, they have particular needs.

Please note that by no means all of these difficulties will be relevant to every child with Williams Syndrome, however, they are typical of the Syndrome and some of them will almost certainly apply to each child.

It is, therefore, worth mentioning them right at the very beginning in order to grab the Authority's attention.

1. Impaired gross and fine motor skills (implications on handwriting, games, balance co-ordination, etc).
2. Early language delay.
3. Fearful of heights and uneven surfaces.
4. Problems with eyesight.
5. Impaired visuo-spatial skills. (Implications on most practical schoolwork and games, etc.)
6. Uneven profile between apparent verbal ability and poorer cognitive skills.
7. Frequent need to "spend a penny".
8. Poor relationships with peer-group. (Difficulty in making friends, leading to social isolation.)
9. Poor concentration span.
10. Hyperactive.
11. Over-sensitive, over-anxious.
12. Problems with numeracy.
13. Obsessive behaviour.
14. Inappropriate behaviour (eg talking out of turn, talking to strangers, wandering off, following their own internal "agenda", etc).
15. Periods of anger and frustration. Tantrums.

It is also worth mentioning that:

- a. The majority of these children require a high level of support or supervision in everyday activities.
- b. Many have persistent behavioural and social difficulties.
- c. Typically WS children are candidates for special education given the language and learning difficulties, complicated by their physical vulnerability.
- d. Although language is delayed, verbosity and good articulation may mask the degree of cognitive deficit.
- e. **Almost** always WS children appear brighter than they really are.
- f. Highlight the weaker areas in your child's make-up and press (early) for the things you would like to see addressed (eg Occupational Therapy is not essential, but most WS children will benefit from it, and it is a service which is invariably in short supply; so keep pressing!).
- g. The more action parents take, and the more informed you are about the Syndrome and the "system", the better the results you will get for your child.
- h. There is a large network of professional bodies set up to help parents, who have problems with statementing. They do not charge for their services and will take you as far as representation in Tribunal if necessary.
- i. Please do not hesitate to contact Jane Guest at d.guest1@networld.com should you need any more advice (or interpretation!) of the above.

STATEMENTING – HOW TO GET THE BEST DEAL

1. The sooner the statementing process is begun the more your child will benefit.
2. Find out about the procedure before it begins. Be aware of your legal rights (Contact a Family has published "Parents Guide to Statements of Special Educational Needs" – which is a very good start.)
3. Learn about Williams Syndrome. (Literature concerning most aspects is available through or published by the Williams Syndrome Foundation.)
4. Learn about your Local Education Authority (LEA).
5. Establish a relationship with your schools' Special Educational Needs Coordinator (SENCO) and your local Educational Psychologist.

6. It is always advisable to opt for a Named Person (** see below) who will act as your counsel, guide or just a friend.
 - You can either chose someone you know yourself, or ask for one to be suggested by the LEA.
 - Whoever you choose, you should ensure that they understand the legal procedure as well as knowing how to “play the system”.
 - It is also worth looking for someone you can get on with on a personal level. Don’t be afraid to “shop around”. It is your right to choose.
7. Get as much professional backing as you can: eg GP, Educational Psychologist, Social Worker, Physiotherapists, Speech Therapists, etc. They can all make a contribution when you come to write your “Parental Profile”, which is at the beginning of the Assessment process.
8. Be informed about your local “Parent-Partnership” scheme, which has been established to provide support and advice to parents on assessments, statements and your right to appeal to tribunal.
9. Find out about suitable schools:
 - Location
 - Special Educational Provision
 - Policies and partnership with external bodies (eg Speech therapy, etc). Go visit as many as you can so that you are better able to make a well-informed request when the time comes.
10. Meetings:
 - Make notes beforehand and afterwards.
 - Stick to the point.
 - Remain calm. Do not get emotional or lose your temper.
 - Be aware of the problems (and feelings) of the professionals.
 - Be aware of your rights, but be also aware of the limitations of your rights.
 - Your “Named Person” can attend any meetings or assessment at your request. (The presence of an objective professional could be very helpful, even if only to cut through the technical jargon or just provide moral support.
11. Where possible (especially where older children are concerned) they should be involved in the decision-making.
12. Legal Rights:
 - To express a preference for a particular school – (although the Authorities are not legally bound to comply if it is not deemed suitable).
 - The LEA must keep within the time limits for issuing a Statement of Special Needs (except in certain circumstances).
 - LEA’s and school must “Have due regard to” the Code of Practice and the advice it gives. (It is worth getting hold of a copy before the process begins so that you can see exactly what your legal rights, and the Authorities

“loopholes” are – Forewarned is Forearmed”.)

13. For continuing Assessment/Statementing problems contact NASEN or IPSEA – both independent bodies which give sound help and advice. See attached address list.

() WHAT CAN A NAMED PERSON DO?**

A Named Person may:

- Offer parents support and re-assurance
- Ensure knowledge of parents’ rights and responsibilities
- Encourage parents to be confident in expressing their views
- Help parents to fill in forms or write letters
- Help parents interpret and understand paper work
- Help parents prepare for or accompany to meetings
- Direct parents to other sources of information.

SOURCES OF INFORMATION FOR PARENTS

Advisory Centre for Education

1C Aberdeen Studios, 22 Highbury Grove, London N5 2DQ

Tel: 0808 800 5793 Advice Line

Email: enquiries@ace-ed.org.uk

Website: www.ace-ed.org.uk

Publishes “Special Educational Needs Guide for parents and carers”. Essential reference material for all schools as well as parents. Also has telephone help line each weekday from 10am until 5.30pm.

Association for Spina Bifida Hydrocephalus (ASBAH)

42 Park Road, Peterborough PE1 2UQ

Tel: 0845 450 7755 Help Line

Email: helpline@asbah.org

Website: www.asbah.org

Offers advocacy service and support with reading papers, appeals and dealing with LEAs.

Association for All Speech Impaired Children (AFASIC)

69-85 Old Street, London EC1V 9HX

Tel: 0845 3 555577

Email: info@afasic.org.uk

Website: www.afasic.org.uk

National organisation with network of local support groups for parents.

Centre for Studies in Inclusion in Education
New Redland Building, Coldharbour Lane, Frenchay, Bristol BS16 1QU
Tel: 0117 328 4007
Email: admin@csie.org.uk
Website: www.csie.org.uk

Produce a wide range of publications for a diverse audience. The offer information on a variety of resources including books and other materials to inform and support inclusive school development, audio tapes featuring examples of inclusion in action, information on current law and practice, discussion papers and more.

The Children's Legal Centre
38 Great Portland Street, London W1W 8QY
Tel: 0207 580 1664
Advice Line: 0845 345 4345 (9am – 6.30pm)
Email: clclondon@essex.as.uk
Website: www.childrenslegalcentre.com
Gives free advice and information on legal questions.

Contact a Family
209-211 City Road, London EC1V 1JN
Tel: 0808 808 3555 (Help line)
Email: helpline@cafamily.org.uk
Website: www.cafamily.org.uk
Wide selection of information and advice on conditions (including rare syndromes) affecting children.

Council for Disabled Children (CDC)
National Childrens Bureau, 8 Wakley Street, London EC1V 7QE
Tel: 020 7843 1900
Email: cdc@ncb.org.uk
Website: www.ncb.org.uk
Free information service and range of publications, including a list of organisations concerned with specific disabilities.

Downs Syndrome Association
Langdon Down Centre, 2a Langdon Park, Teddington TW11 9PS
Tel: 0845 230 0372
Email: info@downs-syndrome.org.uk
Website: www.downs-syndrome.org.uk
Support and information.

Independent Panel for Special Education Advice (IPSEA)

6 Carlow Mews, Woodbridge, Suffolk IP13 1EA

Tel: 01394 446575

Tel: 0800 018 4016 (Advice Line open 10am- 4pm) (England & Wales)

0131 545 0096 (Scotland - ISEA)

028 9079 5779 (Northern Ireland - SENAC)

Website: www.ipsea.org.uk

Offers free and independent advice to parents of children with special educational needs in England and Wales. IPSEA is a volunteer-based organisation and many of the volunteers providing telephone advice and Tribunal support are themselves parents of children with special educational needs who have been helped by IPSEA in the past.

The Law Society

13 Chancery Lane, London WC2A 1PL

Tel: 020 7242 1222

Email: contact@lawsociety.org.uk

Website: www.lawsociety.org.uk

Publishes series of booklets listing solicitors who do legal work and other sources of legal advice.

Mencap

123 Golden Lane, London EC1Y 0RT

Tel: 020 7454 0454 (England)

02890 691351 (Northern Ireland)

02920 747588 (Wales)

Email: help@mencap.org.uk

Website: www.mencap.org.uk

Information on services for people with learning difficulties.

Network 81

1-7 Woodfield Terrace, Stansted, Essex CM24 8AJ

Tel: 0845 077 4055 (Help line)

Email: info@network81.org

Website: www.network81.org

National support organisation for parents of children with special educational needs who want mainstream provision for their children

People First

Unit 3.46 Canterbury Court, Kennington Park Business Centre, 1-3 Brixton Rd, London SW9 6DE

Tel: 020 7820 6655

Email: general@peoplefirstltd.com

Website: www.peoplefirstltd.com

Self-advocacy organisation of people with learning difficulties.

Royal National Institute for the Blind (RNIB)
105 Judd Street, London WC1H 9NE
Tel: 0303 123 9999 (Help line)
Website: www.rnib.org.uk

Immediate, expert and confidential service regarding visual impairments on a local level.

SCOPE

6 Market Road, London N7 9PW
Tel: 0808 800 3333 (Info and advice)
Email: response@scope.org.uk
Website: www.scope.org.uk

Has an advisory assessment service, which offers independent multi-professional assessment – there is a fee for this service. Some local advocacy work.

Statementing – Special Educational Needs – England; Special Educational Needs – Wales; Additional Support for Learning – Scotland. Pub: Contact a Family Tel: 0808 808 3555 or helpline@cafamily.org.uk

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