



**ADULTS WITH WILLIAMS SYNDROME
GUIDELINES FOR EMPLOYERS &
SUPERVISORS**

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WHAT IS WILLIAMS SYNDROME?

Williams Syndrome (WS) is a rare, genetically determined condition occurring in approximately 1 in 20,000 live births. It is associated with a number of distinctive physical, behavioural and psychological features, which differentiate affected individuals from other adults with learning difficulties.

THE ABILITIES OF ADULTS WITH WS

- Mild to moderate learning difficulties
- Relatively good spoken language, but often with poorer comprehension
- Fluent and articulate speech, incessant chatter
- Marked visuo-spatial difficulties
- Gross and fine motor problems
- Marked concentration problems

a) Language and Communication:

The relatively good language and communication skills of adults with WS can be misleading and give the impression that individuals are more able than they actually are. On the surface most people with WS appear fluent and articulate, and they often have sophisticated and wide ranging vocabularies. However, their speech can also be inappropriate and repetitive, especially when talking about topics they are particularly interested in. They may also exaggerate and over-dramatize events in conversation with others.

In many cases their comprehension is more limited, and inappropriate language may result from the use of words without fully understanding their meaning. In conversation, many adults lack the intellectual ability to imagine what other people may be thinking or to see somebody else's point of view. Consequently their speech tends to be one-sided, which may well antagonize or irritate others. People with WS often use chatter and incessant questions to initiate and maintain social contact with other people and to get attention.

b) Perceptual and Motor Abilities:

People with WS have particular difficulties with gross and fine motor coordination, with visual discrimination tasks, with orienting themselves and objects in space, and with judging distances, depths and directions. Even something as apparently simple as walking down stairs or on an uneven surface like grass or gravel, may prove extremely challenging. A fear of heights is common, and crossing the road can be a particular problem because individuals often find it difficult to judge accurately the speed and distance of cars. Difficulty with fine-motor coordination may make individuals appear clumsy and slow when performing delicate or intricate tasks, such as doing up buttons or threading a needle. Some individuals have a marked hand/arm tremor when performing such tasks. Handwriting is also affected by these difficulties.

c) Concentration and Attention Span:

Distractibility and limited attention span are significant problems, and adults with WS often find it difficult to concentrate on tasks for long periods.

d) Reading, Writing and Numeracy:

The educational abilities of adults with WS vary considerably. Their relatively good verbal skills, including a very good memory for sounds and words, and excellent auditory sequencing skills, facilitate the acquisition of reading, and about 50% do learn to read, at least at a basic level. Writing is more difficult to master because of the additional visual and fine motor skills required, but many individuals with WS attain at least some basic writing ability, and can write simple sentences. Because of their fine motor and visuo-spatial difficulties many have problems holding a pen or pencil; forming letters, spacing out words, and aligning words can also be difficult. Deficits in number work and arithmetic are common, and this makes coping with money a particular obstacle.

PROBLEMS IN SOCIAL AND PERSONAL RELATIONSHIPS

a) Over-friendliness:

Adults with WS love company, are eager to please and will often seek out people and engage them in conversation. They may approach strangers in an over-friendly and over-familiar manner, and will often tag along with them. This can be a major worry for parents and carers, who fear that they are too trusting and could be taken advantage of if not sufficiently supervised. Individuals with WS may occasionally seek affection and physical contact in ways that would be acceptable in a child (e.g. hugging, kissing and touching) but which are inappropriate in an adult. Such behaviours usually illustrate poor understanding of the boundaries of different types of relationships, and may be a real barrier to acceptance in the ordinary community. Many people with WS prefer adult company to that of their peers. They also tend to dislike mixing with other people with obvious disabilities, seeking out staff rather than joining in/socializing with other service users.

b) Poor Understanding of Social Situations:

Their good verbal skills enable adults with WS to initiate superficial social contacts. However, they tend to lack understanding of the underlying, 'unwritten' rules governing all types of social intercourse. They are often too open, direct or personal in their interactions with others, and do not recognize the social constraints that would be apparent to other people in the same situation. In other cases their social naiveté and lack of inhibition can lead them to tell tales or to say things that might hurt or embarrass other people. Such behaviour is rarely intentional or malicious, but occurs because the individual may not understand the social implications of his or her utterances. Similarly, adults with WS will not hesitate to try and gain other peoples' attention with comments and questions, or to reprimand others. Consequently they may give the impression of being rude, bossy or attention seeking, which again may antagonize others if they are not fore-warned.

WS individuals are extremely sensitive to the perceived disapproval of others. Inability to fully understand the subtleties of social interactions, and a tendency to take language very literally, may result in their becoming easily offended or upset; even mild teasing or 'leg-pulling' can cause great distress.

EMOTIONAL AND BEHAVIORAL DIFFICULTIES

a) Anxiety:

People with WS tend to be over-anxious and may be easily upset by criticism or frustration, or by events that other people regard as trivial. In some cases anxiety might manifest itself as hypochondria -a tendency to exaggerate everyday aches and pains into serious illness. Anxiety may result from many different situations, but three areas in particular tend to give rise to difficulties:

(i) Excessive demands: The typically good verbal abilities of adults with WS may lead others to over-estimate their general ability, which can result in them being placed in situations that are too demanding, for example living arrangements or work settings that lack adequate support. Inappropriate demands can cause individuals to worry excessively and to become anxious or upset. As a result, they may try to get out of doing things by complaining of headaches or tiredness; they may 'escape' stressful situations by having tantrums or being aggressive; they may repeatedly ask for reassurance from others, or simply walk out of the room. If the excessive demands persist, the individual may become withdrawn, lose interest in food, activities and/or relationships, and become depressed.

(ii) Change and Uncertainty: Individuals with WS can become anxious when anticipating something new or different from their usual routine (e.g. a visit to the doctor). In the workplace, changes of staff or in the way work is undertaken can be particularly distressing.

(iii) Threat: Many individuals with WS have difficulty understanding the complexities of social interactions, and although increasing integration into mainstream society is generally a very positive trend, it is important to be aware that the outside world can also be a hostile and frightening place. Adults with WS can become extremely anxious if they feel that they are being 'picked on' or if someone is behaving in a confusing or threatening way. They can also be very protective of the people they care for (family, supervisors, friends) and can become anxious if they think that someone or something is threatening them in some way.

b) Preoccupations:

Adults with WS often display intense fascinations and preoccupations with certain objects (e.g. cars, electrical appliances, tools and machinery), particular topics (e.g. disasters and violence in the news, crime, their own health and the health of others, sports, future events such as birthdays or holidays) or an intense interest in particular people (pop-stars, television personalities or people they know -such as a particular neighbour, carer or supervisor). They may spend a great deal of time absorbed with these topics and talk about them repetitively, without being aware that other people may find this boring or irritating. Intense attachments to particular people may become intrusive and difficult for others to cope with; such overtures should be strictly curtailed.

SUGGESTIONS FOR SUITABLE WORK PLACEMENTS

(i) Appropriate Demands in the Workplace: It is important not to overestimate the abilities of individuals with WS and not to place excessive or unrealistic demands on them. Supervisors report that many adults prefer routine work and can only cope with simple tasks and instructions in the workplace. They lack strength and tend to tire more easily as they get older, so that activities that are physically demanding or which involve a lot of standing are not appropriate. If an individual is complaining of fatigue or is obviously looking tired as the day or week wears on, it may be advisable to lessen the work-load or reduce the hours worked. Visuo-spatial and numerical tasks are especially difficult for many WS individuals, so jobs requiring such skills may not be appropriate.

(ii) Adequate Supervision: Adults with WS tend to be distractible and restless, and as a result most require a high level of supervision in order to concentrate on a task. Their intense preoccupations can also serve to distract them from their work. Continuing supervision is necessary to ensure that tasks are completed carefully and promptly. Supervisors will need to provide simple explanations and demonstrations of what is required, prompts and reminders. They should also be prepared to give people with WS emotional support and reassurance should they become anxious or upset for any reason. Often adults with WS will only take instruction from someone they recognise as a supervisor. They may resent being told what to do by other people, which can cause problems with workmates. Many individuals may also indicate they have understood instructions (often as a result of wanting to please) this does not necessarily indicate that they have. This can be a problem, as many individuals with Williams Syndrome will not seek advice if they are unsure about what they should be doing. Having an approachable supervisor as a source of advice, reassurance and instruction can circumvent many of these difficulties.

Rewards can be given for completing tasks well. Similarly, self-instruction is often a useful strategy for improving concentration. The individual should be reminded to keep working on the task at hand, initially by thinking aloud and later by silent instruction to him/herself. So while carrying out a task, the adult is taught to tell himself at regular intervals to “keep working” and to “concentrate on what I'm doing”. Breaking down tasks into short, simple steps with cues -such as pictures or written instructions -to indicate what needs to be completed at each stage can also be useful.

(iii) Reducing Anxiety: Anxiety may manifest itself by the individual continually seeking reassurance from work mates and supervisors, increased repetitive movements (e.g. rocking, thigh rubbing, and hand rubbing), withdrawn behaviour, or irritability and moodiness. If it is felt that the adult is more nervous or anxious than usual, it will be important to examine both work and non-work environments to ensure that the demands that are being made are not excessive. Stress and anticipatory anxiety can often be reduced by spending a short period ahead of time preparing the adult for the task or feared event, and by explaining in detail what can be expected and talking through possible outcomes.

The majority of adults with WS are hypersensitive to certain sounds (e.g. the noise of machinery, power tools, lawnmowers, fireworks, thunder), and noisy and busy work environments may also result in increased distress. A quiet work environment, which is as free from distractions as possible, is recommended.

(iv) Friendly and Sociable Environment: Individuals with WS get particular pleasure from meeting and helping people, and often enjoy tasks such as running errands for others. On the whole adults with WS do not work well in teams, and often resent receiving instructions or directions from others. It is generally best to give the individual a particular area of work or a list of simple tasks that are his/her sole responsibility. This can also help to enhance feelings of self-esteem.

(v) *Structured (but not repetitive) Work*: Because of their distractability and short attention spans, adults tend to get bored with repetitive work. Conversely, they dislike change and seem to work better when given a structured routine. More complex tasks can be coped with if individuals are provided with a written list or a sequence of pictures outlining task requirements.

USEFUL ADDRESSES AND FURTHER READING:

General:

Foundation for People with Learning Disabilities:
(www.learningdisabilities.org.uk) publishes many leaflets, booklets and books on general issues related to learning disabilities as well as specific areas including education, employment, accommodation, health, friendships, sexual relationships, leisure, respite care, etc.

Mencap (Royal Society for Mentally Handicapped Children and Adults)
Mencap National Centre
123 Golden Lane
London EC1Y 0RT
Tel: 020 7696 5554

Provides information about residential homes and other accommodation for adults with disabilities. Also provides details about the national network of Gateway clubs, Pathway Employment Schemes, and legal, benefits and welfare advice.

Adult Learning Difficulties Teams - available in most NHS Trusts or NHS Community Units. They tend to be multi-disciplinary teams consisting of psychologists, occupational therapists, speech therapists, psychiatrists and community workers. In some cases, social workers are also members of such teams. These professionals can give valuable advice concerning abilities and behavioural and emotional difficulties of adults with WS.

Further Education Colleges and Training Centres:

COPE: Director of post –16 residential education and training for young people with special needs. 2006.
Can be ordered through Mencap (address above)

Published by:
Lifetime Careers, Wiltshire Ltd
7 Ascot Court
Whitehorse Business Park
Trowbridge
Wiltshire
BA14 0XA
Tel: 01255 716000

Assisted Employment:

Pathway Employment Scheme (Mencap, address above). Regional network of Pathway Services around the country aiming to provide sheltered employment and supported work experience for adults with disabilities. Can be contacted locally through the Disability Employment Adviser in local Job Centres.

The Shaw Trust:
Fox Talbot House
Greenways Business Park
Malnesbury Road
Chippenham, Wiltshire
SN15 1BN
Tel: 01225 716350
www.shaw-trust.org.uk

Similar to Pathway, in that it aims to provide sheltered employment and supported work experience for adults with disabilities. Can be contacted locally through the Disability Employment Adviser in local Job Centres, or directly by phone.

Residential Accommodation:

Mencap Homes Foundation (Mencap address above)

Home Farm Trust
Merchants House
Wapping Road
Bristol
BS1 4RV
Tel: 01179 302600
www.hft.org.uk

Legal Provision:

Quin, A. (1997) "A Guide to Families Wishing to Make Legal Provision for a Learning Disabled Member" (2nd ed.) Available from The Smokery, Greenhill's Rents, London EC1M 6BN

Personal Relationships and Sexuality:

Dixon, H. (1988) Sexuality and Mental Handicap. An Educator's Resource Book. Wisbech, Cambs: LDA.

Respite Care:

Family Based Respite Care
Norah Fry Research Institute
University of Bristol
3 Priory Road
Bristol
BS8 1TX
Tel: 01173 310987
www.bristol.ac.uk/norahfry

Benefits and Entitlements:

RADAR (Royal Association for Disability and Rehabilitation)
Unit 12 City Forum
250 City Road
London
EC1V 8AF
Tel: 020 7250 3222
www.radar.org.uk

A campaigning and information-giving organization. Particularly useful for advice about benefits and entitlements.

Disability Alliance
Universal House
88/94 Wentworth Street
London E1 7SA
Tel: 020 7247 8776
www.disabilityalliance.org

Family Fund
Unit 4, Alpha Court
Monks Cross Drive
Huntington
Yorkshire
YO32 9WW
Tel: 0845 1304 542
www.familyfund.org.uk

Produce a booklet called "After Age Sixteen, What Next?" which gives advice about changes in DSS benefits and entitlements when individuals reach adulthood. The booklet is free for parents of individuals with special needs, though professionals are charged £4.00 to obtain a copy.

Independence Training:

Carr, J. & Collins, J. (1992) Working Towards Independence: A Practical Guide to Teaching People with Learning Disabilities. London: Jessica Kingsley Publishers.

Yule, W and Carr, J (1987) Behaviour Modification for People with Mental Handicaps (2nd edition). London: Croom Helm.

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Further information about adults with Williams Syndrome
is provided in the booklet

["Adults with Williams Syndrome: Guidelines for Families and Professionals"](#)

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