



WILLIAMS SYNDROME
GUIDELINES FOR TEACHERS

by

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FOREWORD

Williams Syndrome (WS) is a rare condition, occurring in approximately 1 in 20,000 live births. As a result, most professionals will not have encountered a child with WS before, and they will understandably know little, if anything, about the characteristics and difficulties associated with the condition. The purpose of this booklet is to provide teachers with information about this rare disorder, and to elaborate on the special learning difficulties and needs of affected children.

The contents are based on research undertaken by the authors and others, which demonstrates that WS is associated with a number of distinctive behavioural and psychological features, which differentiate children with this condition from others with learning difficulties. Of course every child is different, and not everyone with WS will show all of the characteristics and difficulties described here. Nevertheless, it is hoped that this information and the advice and suggestions that follow will be of benefit to teachers, learning support assistants and others who work with children with the condition. A separate information booklet for parents is available from the Williams Syndrome Foundation.

We adopt the practice of referring to the child with WS as "he/him" and "she/her" in alternate sections.

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DESCRIPTION OF THE SYNDROME

Williams Syndrome (WS) is a genetically determined, intellectually disabling condition. Most affected children develop severe feeding difficulties in the first year of life, including vomiting, constipation and refusal to feed, and they may be irritable and cry excessively. A proportion of the children are found, on testing, to have raised levels of calcium in their blood. This subgroup with Infantile Hypercalcaemia is generally treated with a low-calcium and vitamin D-restricted diet and the feeding difficulties then improve, either rapidly or, in some cases, more gradually. Many of the children also have a distinctive facial appearance, and renal and cardiac problems (a heart murmur, narrowing of the main arteries leading from the heart), which may be severe or quite mild. They may also have dental abnormalities, back and joint problems, raised blood pressure and a delayed rate of growth, including low stature and a slight build. The average adult height is 5 ft for females and 5ft 6in for males.

GENETIC CHARACTERISTICS

Williams syndrome is a rare genetic disorder, with a prevalence of between 1 in 7,500 and 1 in 20,000. It is caused by a deletion of approximately 21 genes on one copy of chromosome 7. This is sometimes known as the Williams syndrome critical region (WSCR). Our understanding of the consequences of the deletion of these genes is very limited. However, research is beginning to identify the effects of some of the commonly deleted genes. The first of the deleted genes identified was the elastin gene. Deletion of this is associated with issues regarding connective tissue, such as heart disease, premature ageing of the skin and hoarse voice. The deletion of the elastin gene is extremely common in WS, occurring in 95-99% of individuals. As such, it is often used as a genetic marker for WS, with the deletion typically being assessed using Fluorescent in-situ Hybridisation (FISH). Other deleted genes have been hypothesized to have roles in visuo-spatial difficulties (LIMK1), level of intellectual disability (GTF21), facial characteristics (GTF2IRD1), differences in brain structure (CYLN2), hypercalcaemia (BAZ1B) and diabetes (STX1A). Overall, it appears that while some genes may have a direct effect, many genes may interact with other genes at various stages throughout life to produce the characteristics of WS.

Most cases occur sporadically, and the risk to parents of having another child with WS is no higher than the original risk. Brothers and sisters of WS individuals, too, are not at any increased risk of having children with WS. However, people with WS themselves have a 50% chance of transmitting the condition to their children.

Children with WS tend to be delayed in their development and they show a range of learning difficulties, varying from mild to severe. About 50% have severe learning difficulties, while the remainder have mild to moderate learning difficulties. Overall the children's verbal abilities are markedly superior to their visuo-spatial and motor skills. Furthermore, they show a distinctive pattern of abilities and particular behavioural and personality characteristics which are common to most individuals with this syndrome, and which set them apart from other children with learning disabilities.

ABILITIES OF CHILDREN WITH WILLIAMS SYNDROME

- Mild to moderate learning difficulties
- Relatively good spoken language, but poorer comprehension
- Fluent and articulate speech by school age, incessant chatter
- Marked gross and fine motor problems
- Marked visuo-spatial difficulties

Children with WS tend to be very outgoing and sociable, and by school age most develop fluent and articulate spoken language. They love talking and interacting with adults and are mostly helpful, cooperative and eager to please. Many chatter incessantly but at a superficial level, and often in a formal, adult-like style, with frequent use of sophisticated vocabulary, stereotyped phrases and clichés. Taking turns and keeping to the point in conversation may be especially difficult for them. In many cases their understanding of speech is not as good as their spoken language and this together with their highly developed sociability may be deceptive in suggesting that a child is more able than he actually is. In contrast to their relatively good speech, many children with WS have visuo-spatial problems and difficulties with gross and fine motor co-ordination. So they may be slower than usual in learning to sit and to walk, and they may find tasks like riding a bicycle, doing up buttons, cutting with scissors and holding a pencil particularly difficult to master. They tend to have poor posture, an awkward gait and limitations of joint movements. Because of their motor and perceptual problems they may also be fearful of heights and of negotiating stairs and uneven surfaces such as grass, gravel or sand.

Many of the children are overactive and find it difficult to sit still and concentrate on particular tasks for any length of time. On the other hand, they can become fascinated and preoccupied by particular objects or topics and spend a great deal of time absorbed with these. While many are very friendly (and even over-friendly) to adults and often actively seek out adult company, they may have difficulty in making and keeping friends of their own age, often managing somehow to antagonise their peers.

Children with WS are often described as having anxious personalities and worrying excessively about themselves and others. Toileting, eating and sleeping problems (including settling down to sleep and waking in the night) are fairly common. Most are also hypersensitive to a variety of noises, such as loud bangs, clapping or laughter, and they may become tense and fearful when hearing or anticipating these sounds.

BEHAVIOUR OF CHILDREN WITH WILLIAMS SYNDROME

Overactive	Excessive anxiety & worry
Limited concentration span	Preoccupation with objects/topics
Sociable & outgoing	Hypersensitive to sounds
Overfriendly to adults	Fearful of heights/uneven surfaces

Teachers often report finding children with WS baffling and difficult to teach because their apparently superior verbal and communicative abilities mask significant difficulties in other areas, including comprehension of language, hyperactivity and attention deficits, and severe visuo-spatial difficulties. This can result in an overestimation of their overall abilities. Of course every child is different, and not all children with WS will show all of these characteristics and difficulties to the same extent. However, the research undertaken over the last 25 years indicates that these features are common to many of them, and that unless they are tackled early on they may well persist into adulthood. In the following pages we describe the particular learning and behaviour difficulties and needs of children with WS, and present suggestions and guidelines for their remediation. The methods and approaches we will describe are well tried and have been used successfully to cope with a wide variety of difficulties. They can be adapted for use with any individual child.

TYPE OF SCHOOLING

As already described, children with WS have an unusual pattern of abilities, often with relatively good spoken language but poorer perceptual and motor skills and concentration difficulties. As a result, they have special educational needs that are quite different from those of other children, and it can be quite difficult to find a school that will be exactly suited to their particular learning needs. Their verbal skills and highly developed sociability may suggest a relatively high level of ability, but if they are placed in an ordinary school or in a school for children with Moderate Learning Difficulties they are often unable to cope because of their lower abilities in non-verbal areas and their limited concentration. On the other hand, if they are placed in a school for children with more severe learning difficulties children with WS may well miss out on much of the verbal and social stimulation from which they could benefit if they were among more able children. There is no one type of school that is ideally suited to their needs. Finding the most appropriate school will depend on the individual child's level of ability (which can range from mild to severe learning difficulties), and also on the provision in the particular schools that are available locally.

Some of the children start off in mainstream schools and cope very well there at the primary level, though typically with additional help from learning support teachers and/or assistants for some part of the school day. At the secondary level some of these children move to special schools, where they can benefit from more individualised teaching and learn at a slower and less pressurised pace. A few WS children continue in mainstream at the secondary level, for example attending a remedial class for some lessons and their ordinary class for other lessons.

Mainstream schooling is by no means appropriate for all or even for the majority of children with WS. Many of the children need the slower pace and more individualised attention that are currently provided in special schools and units. Each child's needs will be different. In a study we undertook in the late 1980's we found that:

- 30% attended schools for children with Severe Learning Difficulties
- 30% attended schools for children with Moderate Learning Difficulties
- 30% attended schools for children with complex special educational needs
- 10% were in mainstream schools

With the greater emphasis that is now being placed on integration and inclusion, we are seeing increasing numbers of children with learning difficulties, and thus also more children with WS, being educated in mainstream schools, with varying amounts of additional support. We believe that for inclusion to work effectively for children with WS, classroom settings, which offer substantial support and a great deal of flexibility are necessary. Typically this will require:

- extra adults in the classroom
- small classes
- intensive involvement of specialist teachers
- learning support assistants
- carefully structured and graded work plans
- teamwork between classroom teacher, assistant, specialist teachers and speech and occupational therapists

SPEECH AND LANGUAGE SKILLS

In the pre-school years children with WS may be particularly slow to develop speech, and at this time verbal stimulation will obviously be vital. Structured language teaching in the early years is also important, involving as it does the building up of vocabulary and comprehension of

labels, verbs, instructions etc. Prompting and imitation are useful tools, as are praise and other rewards to encourage motivation. Children with WS will benefit from speech and language therapy at all stages of their development, and the therapist should also work closely with parents and teachers and provide suggestions on programmes and activities that can be carried out at home and at school in order to expand the child's spoken language and language comprehension.

By school age, most children with WS will have developed fluent, articulate speech with sophisticated, wide ranging vocabularies and complex and grammatically correct sentences, which are quite out of keeping with their general level of learning difficulty. They may use long words and unusual phrases which they have heard other people use and remembered, and they may chatter to anyone they meet, if given the chance. However, their speech can also be inappropriate and repetitive, especially when talking about topics of particular interest to themselves. Many use chatter and incessant questions to initiate and maintain social contact with other people, and they are adept at using their superior verbal skills to get attention. In addition, they are inclined to exaggerate and over-dramatise events in conversation with others. For example, they may describe minor mishaps as major tragedies.

WS children's understanding of language is in many cases more limited than their expressive language might indicate. They may, for example, be able to recite instructions or stories word for word, yet have difficulty understanding the most basic of concepts. Sometimes they echo or repeat phrases and sentences spoken by the person they are interacting with, often with little understanding of what the person is saying. If the echoing is caused by poor comprehension, it will be helpful to point this out to the relevant adults (parents, school staff etc.) and to suggest that they try to simplify their speech. Similarly, if the child responds to an adult's comments or questions inappropriately or irrelevantly, this may be because he does not fully understand them. Again, it may be necessary to simplify instructions and comments to make sure the child understands what you and other adults are saying. However, if the child's echoic or irrelevant speech is simply a habit he has developed, then ignoring his utterances and distracting him by moving on to another topic can be a useful method of discouraging such non-meaningful verbalisations.

DISCOURAGING EXCESSIVE CHATTER AND INAPPROPRIATE SPEECH

1. If a child has a favourite topic he talks about repetitively (e.g. trains, illness), or a set of questions he always asks, it may be advisable for school staff to ignore him when he launches into his 'favourite' topic. If they answer such 'pet' questions each time, the child will be encouraged to ask them again and again!
2. Parents, teachers and other adults too could make a rule to answer the child's questions ONCE but to IGNORE all repetitive questions and topics thereafter, and either to turn away from the child or CHANGE THE SUBJECT straight away and move on to topics that are more relevant.
3. Another useful strategy is to insist, when a child's question has been answered and he asks it once again, that HE repeat the answer that has already been given.
4. A CONSISTENT approach is important, so urge all adults to adopt exactly the same strategy at home as well as at school. With such methods, socially appropriate speech should increase rapidly and inappropriate speech will steadily decline.

PERCEPTUAL AND MOTOR DIFFICULTIES

Many children with WS have particular difficulties with gross and fine motor activities, with eye-hand coordination, with orienting themselves and objects in space, judging distances and directions, and with visual processing tasks including discrimination, sequencing and visual memory. As a result, specific remedial attention will need to be given to these areas. It is of course known that tasks such as sorting and matching objects and shapes and being able to trace over lines, are important skills to master before the child can move on to the basics of reading and writing.

Such tasks may be more difficult for a child with WS because of her particular deficits in visual perception and motor co-ordination. She will therefore need additional help and opportunities to practice skills in these areas, and teachers may want to encourage parents to practice some of these exercises with the child at home as well. Thought should be given to the way work is presented to the child; books and programmes that use a lot of colour and pictures are not the best materials to use because of visual overstimulation. Instead, teachers should try and select books and worksheets that have relatively little information on each page.

The child's visual and motor problems may also mean that she is nervous of heights, and of such activities as climbing, going down stairs, walking along a raised bar in the gym etc. She may have particular difficulties with throwing and catching a ball, cutting with scissors and riding a bike. All children will improve on these tasks with time, provided that they are given reassurance, support and plenty of practice. Occupational therapists can be very helpful in all of the above areas. They can assess and provide exercises for the WS child in the areas of co-ordination, balance, gross and fine motor activities, and they can advise school staff on exercises to carry out with the child at school. Where necessary, parents might be encouraged to approach the child's Paediatrician or the GP for a referral to an occupational therapist.

TEACHING VISUO-SPACIAL AND MOTOR SKILLS: SUGGESTIONS FOR CAPITALISING ON THE CHILDS STRENGTHS

1. Harness the child's superior spoken language abilities in training perceptual and motor skills. It often helps if she can be encouraged to talk through each step of an exercise while she is doing it and to speak out loud what she is doing. This can help her to focus her attention on the task in hand and also provides verbal reinforcement and support for the activity.
2. Introduce teaching materials using objects and themes that the child is especially interested in or even obsessed with, in order to motivate her to work on tasks in which she may not be directly interested. For example, if cars fascinate her or machines get her to trace over, copy and draw outlines of these. She will be more willing to practice pencil and paper skills if she is asked to draw something she is interested in rather than any other object or shape.
3. Try to incorporate music into appropriate gross and fine motor exercises such as balancing, ball play, threading beads etc. Clapping to music and banging musical instruments can also be used to encourage early perceptual-motor development.
4. There are many enjoyable computer programmes available, which help children to develop skills in matching, discrimination etc.

READING

The abilities of WS children vary a lot, but many do learn to read at a basic or, in some cases, at a more advanced level. As already discussed, many WS children tend to have relatively good verbal skills, including a very good memory for sounds and words and good auditory sequencing skills. In view of this, approaches to teaching reading which rely on these auditory skills and which emphasize a PHONETIC approach, are likely to be more effective than approaches which rely on the child's visual memory of how a word looks (such as the 'Look Say' approach).

Even at the beginning stages of reading it is important to show the child that printed words are meaningful; they tell a story and impart information. Where children are preoccupied by particular objects or topics (e.g. trains, pop stars, foreign places), introducing reading materials on these topics will enhance their interest and motivation to read. Parents can also be encouraged to adopt some of the above strategies when reading to (and with) their children in the pre-school and school years. Whatever one is trying to teach, it is worth remembering that children with WS can be easily distracted by extraneous visual stimuli. Thus beginning reading books, which contain many detailed pictures and colours on the same page as the printed word(s) are far from ideal. It is better to use books which have a few simple pictures or outline drawings which are less likely to distract the child.

WRITING AND SPELLING

For many children with WS attainment in writing and spelling tends to be much poorer than in reading, because of the additional visual and fine motor skill requirements of the former tasks.

When the child begins to learn to write, she will be helped to trace over and then copy the letters of the alphabet. Because of the WS child's visuo-spatial and motor difficulties, progress may be slow in this area and involve a lot of practice and repetition, including preliminary practice in pre-writing activities to improve tactile perception, motor control and eye-hand co-ordination.

Problems with forming the letters and spacing out and aligning words are common. The child may also have difficulty keeping her place, or she may skip sections. But with perseverance progress will be made.

Again, the child is more likely to co-operate if the exercises she is given incorporate materials that bear directly upon her special interests and preoccupations. For example, tracing or copying words of things the child is particularly interested in (e.g. the makes of cars or of electrical gadgets) is likely to enhance her motivation. When she is first learning to write the letters of the alphabet, it might also be helpful to encourage her to use speech to talk herself through the exercises. Try and use the same verbal cues in the same pattern each time (e.g. "b goes down, then back up and around"). In this way the child can learn the words and then prompt herself in the

task. At later stages, for example when trying to write unfamiliar words, WS children might be encouraged to place greater reliance on the auditory channel, for example by sounding and then spelling out the word verbally, and only then translating each letter sound into a letter in print.

Like most children, children with WS love working on computers and can practise useful exercises on them. If they can write and spell but have difficulty with pencil control, they might be encouraged to use computers for free writing, thus by-passing the difficulties of writing by hand. For many children with WS writing is such a slow and laborious task that it can deter them from what might otherwise be an enjoyable exercise such as story-telling. Where typing itself is difficult, or the child cannot spell, she can be encouraged to dictate stories, homework etc. to parents or teachers or into a tape recorder, thereby still deriving pleasure from the creative process inherent in such activities.

CHILDREN WITH WILLIAMS SYNDROME MAY FIND IT
DIFFICULT TO HOLD A PENCIL OR PEN –
SOME SUGGESTIONS:

1. Encourage the child to try using a pencil grip. This device is attached to a pencil or crayon and helps to develop an appropriate tripod grip.
2. An elastic band wound tightly round a pencil or pen just above the point will prevent the child from grasping the pen/pencil too low down thereby obscuring what she has just written.
3. If the child is unable to hold a pencil or pen sufficiently tightly, or cannot exert sufficient pressure with the pen/pencil, try giving her a fatter pen or a felt-tip pen. Children may also enjoy trying out fluorescent pens.
4. The physical task of writing may be very tiring for WS children. Avoid excessive fatigue by limiting the amount of copying/writing required at any one time.

NUMERACY

Our research suggests that arithmetic is a marked area of difficulty for many children with WS. Their perceptual, visual-spatial and motor problems may make it difficult for them to manipulate numbers and to carry out arithmetic operations, as well as to comprehend the principles behind the operations. It will be important to work at the child's pace, and with frequent repetition.

Initially, teaching should incorporate materials, which can be touched and moved by the child, for example concrete tokens such as blocks. Getting the child to perform gross motor skills linked to numbers can also help to strengthen number concepts e.g. taking 5 steps, jumping 5 times. Only thereafter should more abstract items be introduced, such as pictures. Similarly, when moving on to addition and subtraction the use of concrete materials (blocks, rods etc.) is recommended until the notions are well established.

Because of their difficulties with writing and shaping numbers, it may be helpful at first to separate the task of writing numbers from the teaching of mathematical concepts and operations. Concentration on writing down numbers on the page will distract the child's attention from the mathematical operations he is trying to perform. Teachers point out that even older WS children

have great difficulty writing down numbers correctly and aligning numbers on the page, for example when adding and subtracting. Using lined or squared paper may help to ensure that sums are correctly set out on the page.

Learning to tell the time can be a further area of difficulty. If the child makes little progress despite strenuous efforts, then reliance on digital watches may be helpful. Teachers and parents can always go back and make further attempts to teach 'time-telling' on standard watches and clocks at a later date. As with any child, it is important to link time on the watch or clock to routine activities that take place at set times.

When teaching about money it will be helpful to use real money (rather than tokens or pictures) in real life settings, for example by taking the child to the supermarket to buy food.

CONCENTRATION DIFFICULTIES AND OVERACTIVITY

Poor concentration and restlessness are among the most common problems of children with WS. Moreover, most of the children are hypersensitive to noise and so may be particularly distracted or upset by incidental and irrelevant sounds at times when they are required to concentrate, for example when they are being given instructions or listening to a story. Clear and deliberate instructions while ensuring that the child is looking at you and paying attention will help her to understand what is expected, and regular prompting will help remind her to stay on task and remember what she has to do.

Where the child is fascinated or obsessed by particular topics or objects, then books or games geared to these can also be used to encourage concentration, at least initially. Alternatively, you could use something the child is obsessed with (e.g. a toy) as a reward she can play with, but only after she has first spent a set period of time engaged in more structured work. For example, you might decide that after she has spent 5 minutes in a structured activity she can engage in her favourite preoccupation/obsession for 2 minutes. This may be playing with a favourite toy, watching the builder working outside, or chatting to you. This 2 minute break would be followed by a further 5 minute period of structured work, and so on. It is also helpful to break down tasks into short, simple steps with cues such as pictures or words -to highlight what needs to be completed at each stage.

In adolescents and adults with WS, overactivity is no longer a prominent feature, but they too may be easily distracted and have only limited attention spans. Self-instruction is another method that can be used to improve concentration, and this may be particularly useful with older children and adults. In this approach you teach the pupil to remind herself to keep working on the task in hand, initially by thinking aloud and later by silent instructions to herself. So, while working, she is taught to tell herself at regular intervals to "try and sit still", to "keep on working", to "concentrate and look at what I am doing" etc.

Many children with WS are impulsive and find it difficult to take turns and wait for an adult's attention. They may repeatedly interrupt the teacher or call out because of their desire for attention. An effective approach is to reward the child if she is able to sit quietly and wait her turn, initially for a few moments, and then for longer periods of time. Here too the child's superior spoken language can be harnessed in training appropriate attending and turn taking behaviours, with the child being encouraged to remind herself to 'sit quietly and wait for the teacher' etc.

Because many of the children are easily distracted by what is going on around them (perhaps even more so than other children with learning difficulties), they are likely to pay attention and work better in settings that are quiet and free from distraction. If possible, the child should be seated close to the teacher, and away from distractions such as windows and doors and talkative classmates. Short periods of work interspersed with frequent breaks will also be necessary. Since sitting for long periods can be very difficult for children who are restless and overactive, they will benefit from opportunities for controlled movement, such as delivering messages to the office or sharpening pencils. Most need one-to-one guidance and attention from an adult in order to complete a task. Working with the child on her own or with very few other children, in a quiet room, and for short periods of time, is likely to be more rewarding for both the child and adult.

TO BUILD UP THE CHILD'S CONCENTRATION SPAN

1. Reward the child with praise or toys for sitting still and listening, or for engaging in some constructive activity such as looking at a book or doing a puzzle, for longer and longer periods of time.
2. Initially require the child to sit still and pay attention for 1 or 2 minutes, and immediately thereafter reward her with a favourite toy or activity and praise. Adult attention and conversation are likely to be particularly effective reinforcers.
3. Gradually, through a series of stages, build up to work periods of 5, 10 and then 15 minutes.

In every aspect of teaching
CAPITALISE ON THE WS CHILD'S STRENGTHS:

1. Utilise the child's superior VERBAL abilities to teach perceptual and motor skills e.g. by getting her to talk through a given task or exercise.
2. Many children with WS have considerable aptitude for MUSIC AND RHYME. Teaching through music, songs and rhymes can speed up the learning process, and encouraging talents in playing musical instruments can boost self-confidence.
3. A particularly good MEMORY in certain areas (for faces, routes, past events) is another characteristic of WS children, which can be helpful in teaching.
4. Children with WS often have a PREOCCUPATION/ FASCINATION with particular objects or topics (machines, pop stars, disasters, insects etc.). Incorporating these into teaching materials for reading, writing and perceptual exercises will enhance the child's interest and motivation to work.

COPING WITH BEHAVIOURAL AND
EMOTIONAL DIFFICULTIES

a) Anxiety

Children and adults with WS are often described as being over-anxious and easily upset by criticism and frustration. They may worry excessively in anticipation of a class test or a visit to the doctor, about the health of their families and even of strangers, as well as about unfamiliar situations and all kinds of imagined disasters. This concern and sensitivity for the needs of others can be an endearing aspect of the WS person's personality, which makes people warm to him. But this over-anxiousness may also mean that he frequently demands attention and seeks reassurance from teachers and other adults. It is advisable for adults to strike a balance between being comforting and reassuring to the child in such circumstances but not making too much fuss of him, since this may well reinforce and exacerbate his feelings of upset and worry. You and other school staff may find that you are spending a great deal of time comforting the child, but with no decrease in his level of expressed anxiety. If this is the case, you might decide to adopt the following strategy:

- Put a fixed time limit on the time you spend comforting the child. For example, you might agree to spend one or two minutes reassuring him if he expresses anxiety.
- Then move on to another topic of conversation or task.
- In this way the adults acknowledge the child's anxiety and provide comfort and reassurance, but also circumscribe it within time limits so that it does not become just another way of gaining unlimited adult attention.

Because of his sensitivity the child may be very susceptible to stress and to the demands of others, and may find it difficult to cope in environments that are excessively demanding. The typically good verbal abilities of children with WS can lead adults to over-estimate their abilities and expect them to do tasks that are beyond their capabilities. If it is felt that the child is becoming more anxious or difficult than usual, then it will be important to examine the home and school environments to ensure that the demands being placed on him are not excessive. In general, children with WS do best with a predictable schedule and a set routine, and benefit from preparation before changes in activities and in routines. Remember that stress and anticipatory anxiety can often be reduced by spending a brief period ahead of time preparing the child for a difficult task or event, enumerating the difficulties to be faced and talking through possible outcomes with him.

b) Preoccupations, Obsessions and Stereotyped Behaviours

Children and adolescents with WS often display intense fascinations and preoccupations with certain objects (such as insects, cars, or electrical gadgets), particular topics (disasters and violence on the news, illness, future events such as birthdays and holidays etc.) or an obsessive interest in certain people (a particular member of the school staff, a classmate or neighbour). They may spend a great deal of time absorbed with these topics and talk about them continuously. It is best if you can nip such obsessions in the bud before they get a real hold; so if you suspect that a particular behaviour is becoming obsessive, try to divert attention elsewhere, and introduce new activities and interests for the child. If the preoccupations are already well established try to circumscribe them to keep them within acceptable bounds.

For example, if a child is very preoccupied with a certain toy, or becomes attached exclusively to one other child, the school staff might decide to allow her to play with the child/object in question for a fixed time (say 10 minutes every day or two) but only if she controls her preoccupation in between these times. If unable to do this she would forfeit some of her 'special time' with the child/object. The aim is to bring the preoccupation under control and gradually to reduce the amount of time spent in this way. Alternatively, time spent with the object or person the child is obsessed with could be used as a reward for desired behaviour in other areas. For example, the child might be awarded stars on a star chart for completing arithmetic assignments, for concentrating in class, for finishing her dinner etc. And once she has earned a pre-agreed number of stars she can be rewarded with an opportunity to play with her favourite friend or toy.

Some individuals with WS display stereotyped behaviours such as rocking or hand flapping. These behaviours, which may also be displayed by other people with learning difficulties, may be particularly prominent when the individual is anxious or agitated, when she is bored or alternatively when she is absorbed in a particular task or trying to concentrate on something. In some cases rocking may actually aid concentration. However, in general it is advisable to make the child aware of her rocking or hand flapping as soon as it begins, and to ask her to stop. She will usually need frequent reminders to start with, although with time a brief nudge or pre-agreed word will usually suffice. It is often helpful to combine this approach with a reward system whereby the child is systematically rewarded if she can spend increasing periods of time without rocking. Encouraging the child to change her sitting position or the type of chair she usually sits in (when watching television, for example) may also be effective.

c) Temper Tantrums and Moodiness

Children with WS are mostly even-tempered and co-operative. But like other children they may at times have quite severe temper tantrums when they are frustrated, when they want attention or cannot get their own way. Firm and consistent handling is crucial when coping with temper tantrums. It is important to convey to the child that he will not get his own way and he will not get attention until he calms down. After all, the main reason for a tantrum is often to get an adult's attention.

Moodiness can be a feature of the emotional lability of some WS children, and it can become particularly prominent in adolescence. It may be characterised by sullenness, muttering under one's breath or by overt defiance. Here too, if distracting the individual is not immediately effective, it may be advisable to make it clear to him that moody behaviour is unacceptable and that he is expected to go out into the corridor or to a corner of the classroom until he has regained his good spirits and is ready to co-operate. In this way the adult withdraws attention from the child when he is moody and uncooperative, but rewards him with praise and attention when he is more co-operative.

Again, it is important to stress that moodiness is not an invariable feature of the syndrome, and that many children with WS are by nature just the opposite -friendly, caring, helpful, and eager to please.

COPING WITH TEMPER TANTRUMS:

1. **OBSERVE** the child carefully when he has a tantrum to try to identify the situations and events that **TRIGGER** the tantrums. For example, if fear of particular events or loud noises or provocation by another person triggers a tantrum, then try to anticipate these and divert the child's attention onto something else before the tantrum develops.
2. Teach the child more **APPROPRIATE WAYS OF COMMUNICATING** with teachers and peers to indicate his needs and wants, which would make it unnecessary for him to throw a tantrum.
3. When faced with a tantrum or other unacceptable behaviour you might decide to **IGNORE** the child and turn away for a short period of time. As soon as he stops misbehaving give him attention and praise.
4. Another effective approach to use is 'TIME OUT from Positive Reinforcement'.
 - a) **REMOVE** the child, for example by putting him in the corridor or a corner of the room, and make it clear that he cannot rejoin the rest of the class until he has calmed down.
 - b) As soon as he is quiet, **PRAISE** him for having quietened down and allow him to rejoin the class.
 - c) It is important to adopt exactly the same approach every time the child has a tantrum. An inconsistent approach will only confuse him.
 - d) At first there might be a **TEMPORARY INCREASE** in disruptive behaviour. But the child will soon come to understand that tantrums do not enable him to get his own way, and their frequency and severity will decrease.

NOTE: It is essential that such an approach forms part of a comprehensive approach to classroom management in which the main emphasis is on positive reinforcement. In addition, it is important to keep good records to ensure that a particular approach really is working for the child. If 'time out from positive reinforcement' is working, its use should decrease over a few weeks. If it does not, then another approach will be necessary.

d) Feeding Difficulties

Feeding difficulties, including vomiting and refusal to feed, usually appear in the first months or year of life and may be one of the first indications that the child has a high level of calcium in the blood. If blood calcium is raised, the child may be put on a low-calcium and Vitamin-D restricted diet, including the use of a low-calcium milk preparation. With time the feeding difficulties will lessen and disappear.

However, some children become fussy eaters and may refuse to eat all but a very limited range of foods even once they are off their low-calcium diets. Such idiosyncratic diets can cause difficulties, for example when the child is expected to eat set school meals. Once the doctors have confirmed that there is no medical reason for a limited diet, the child should be encouraged to try and eat a wider range of foods. A concerted approach by parents and school staff is likely to prove most effective. One approach is to insist, at mealtimes, that the child try just one spoonful of a food she will not normally eat, and then immediately praise her and reward her with her favourite food, and perhaps also with a favourite toy. Such an approach fits in with our knowledge of the principles of rewarding desirable behaviours. By immediately following a desirable behaviour with a reward, it is more likely that this behaviour will occur again. Gradually, the child should be required to eat larger amounts of the non-preferred food before giving her preferred foods and other rewards. Sooner or later most of the children actually begin to enjoy eating these foods as well, and they forget their earlier aversion to them.

A few children develop a habit of vomiting at mealtimes if they are made to eat foods they do not like, or perhaps as a means of gaining attention from parents and/or teachers, or when they are anxious or under pressure. In such cases, if it is confirmed that there is no physical reason for the

vomiting, it is advisable for parents and teachers to be firm and to withdraw sympathy and attention at times when the child vomits (and perhaps to insist on the child cleaning the mess herself), but to praise the child and reward her with toys or with foods she likes if she does not vomit at mealtimes or at other times in the day. Another approach is to take the pressure off mealtimes and leave the child to eat as much or as little as she wants, provided that she does not vomit, on the theory that she will eat if she is hungry. This approach will obviously only be effective if the child is denied sweets, biscuits etc. between meals. Some children dribble, and they will need regular reminders from adults to close their mouths and swallow. Again, a reward system may serve as an added incentive, with the child being rewarded systematically if she can spend increasing periods of time without dribbling.

e) Hypersensitivity to Sounds

About 90% of children with WS are hypersensitive to particular sounds, which can include sudden loud noises like thunder, objects falling or balloons bursting, hand clapping, electrical noises like vacuum cleaners and electric shavers, loud music, and in some cases even people's voices or laughter.

This phenomenon is termed 'hyperacusis'. The noises are often very distressing to the children, who will typically put their hands over their ears and cry, or try to avoid the sounds, for example by leaving the room or turning off the television or radio. Some children become particularly distressed in crowded, noisy classrooms or in other settings where there is a lot of activity and noise.

In some cases the hyperacusis disappears in the child's teens or in adulthood, but in other cases it continues to be a problem. The reason for this hypersensitivity to noise is not known, but it is likely to be related to the fact that individuals with WS have lower thresholds for sounds than other people. It is possible that the noises may be physically painful to the ears, or they may simply startle the child.

COPING WITH HYPERACUSIS

The cause of hypersensitivity to noise is not fully understood, but there are certain things that can be done to make it less distressing:

1. Reassurance and a clear and simple explanation about the source of the noise often helps.
2. Whenever possible provide a warning just before predictable noises (e.g. fire drills or before switching on the food processor).
3. The reactions will often diminish if the child is able to exercise some control over the sounds that cause discomfort. For example, encourage him to use the vacuum cleaner, or to help with household chores by turning on the washing machine or food mixer.
4. The child may be reassured if he knows that he can leave the room for a few minutes at any point, if he is exposed to a distressing noise.
5. Repeated gentle exposure to the sound may help the child to get used to it. For example, tape record one or more distressing sounds and encourage him to play back the tape, quietly at first, then gradually increasing the volume.

SOCIAL RELATIONSHIPS

Some children with WS find it difficult to make friends of their own age. As children, they often show no interest in playing and interacting with their peers, and as they become young adults, their difficulties in establishing and maintaining friendships with others of their own age may become even more apparent. This can be a source of frustration to them and to their families. On the other hand, they love the company of adults, are affectionate and eager to please, and will often seek out adults to engage in conversation. They may approach adult strangers in an over-friendly and over-familiar manner, and will often tag along with them. Understandably this can be a major worry for parents, who fear that the WS child or adult is too trusting and could be taken advantage of if she is not watched and supervised all the time. Children with WS can also be over-demonstrative and seek affection and physical contact from adults outside their family in ways that are inappropriate. Such behaviours too illustrate poor understanding of the boundaries of different types of relationships.

Adults do not always interact appropriately with children with WS, and they may on occasion 'overindulge' or 'baby' them. It is important to try and educate all adults to behave appropriately with the child, but also to show tolerance and patience for any unpredictable behaviour.

Helping children with WS to make and maintain friendships with people of their own age is a complex issue. Particularly as the children move into adolescence they may be reluctant to socialise with handicapped people, but they may also be unable to make friends with 'normal' adolescents who may have little patience with them. In school there might be opportunities for the staff on duty at playtime to draw the WS child into games with her peers, and also to encourage other children to include the WS child in their play. Parents could be advised to help by inviting children from school to the house and initiating and supervising games for them to play. These could include board games, ball games and make-believe play with dolls, cars etc. They could also be encouraged to take their child to Brownies and Guides; such activities tend to appeal greatly to the children's gregarious and extrovert nature.

Parents often find that if they do not actively organise outings and activities for their older WS child, she will be satisfied to stay at home and watch television. The school might have information about local social and sports clubs for children and adults with a range of handicaps and learning difficulties, which can be usefully passed on to the WS child's family.

In some cases the child's lack of social inhibitions or social naiveté might lead her to tell tales or to say things which embarrass and upset other people. People should be made aware of the fact that such behaviour is rarely intentional or malicious, and that the WS individual is not always aware of the social implications of her utterances.

It is important to bear in mind that while some people with WS have difficulty in establishing relationships with peers, others do not. On the contrary, with their friendly and extrovert natures and also their sensitivity and concern for others, many children and adults are popular and well-liked and establish warm and caring friendships with people both within and outside their immediate families. In addition, their highly developed sociability and eagerness to please can be a great asset in the school setting and make them a delight to teach.

SUGGESTIONS FOR DEALING WITH THE
WS CHILD'S OVER-FRIENDLINESS

1. When the child meets someone she knows, or when she is introduced to a new person, she should be **TAUGHT** how to **GREET** the person in an **APPROPRIATE** way and discouraged from hugging or kissing the person.
2. Social situations can be **PRACTISED** with the child in class and at home. For example, you or another member of staff could pretend to be a familiar adult and allow the child to practise greeting you. **MODEL** appropriate greetings for the child and instruct her to **IMITATE** you. **PRAISE** her for appropriate behaviour.
3. Children can be taught simple rules, such as not to stand too close to another person and not to stare. **VIDEO** and **ROLE PLAY** techniques can be useful here.
4. Parents and teachers should start as early as possible to **DISCOURAGE** the child from approaching people she does not know. Whenever she does approach a stranger, the adult accompanying the child should indicate displeasure and firmly reprimand her.

TEACHING SELF-HELP AND INDEPENDENCE SKILLS

Where appropriate, it may be helpful to work with parents on building up the child's self help and independence skills, including toileting, dressing and washing.

a) Toilet Training

Wetting and /or soiling may persist into the school years, or they may appear as new problems, often exacerbated by anxiety or excitement. With a well worked out programme (which may include taking the child to the toilet at regular intervals, the use of star charts, rewards, penalties for accidents, and a pants alarm) most children can be toilet trained well before they start school, or helped to become clean or dry again if they have regressed.

It should be noted that children with WS often need to urinate more frequently than other children, and unless it is clear that they are simply trying to gain attention or avoid work, their requests to go to the toilet are usually valid. However, if the child asks to go to the toilet very frequently it may be possible for the teachers/care staff to lengthen the intervals between toileting very gradually, for example by asking him to 'hold on' for just a minute or so, and then gradually and imperceptibly increasing this time interval.

b) Dressing

The tasks of dressing and undressing require muscle co-ordination and planning, and this is something children with WS may find difficult to master. The child may need help with putting on clothes, doing up buttons and shoelaces etc. Because there is usually so little time in the morning, parents often find it more convenient to dress the child completely, in order to save valuable time. This can become habitual, not just with a child with WS but with any young child. However, the child needs to be encouraged to independence, to learn to do things for herself.

Thus, over time you can slowly encourage her to do more of the dressing independently; for example, teach her to put on her own pants and then help with the buttons or zip.

Learning to dress can be practiced at other times of the day, and not just during the fraught morning period when time is of the essence. Clothes should be as easy as possible to put on. Elasticated waistbands, loose fitting sleeves and necklines, Velcro or popper fastenings, slip on shoes, all help to reduce hassle and increase the child's independence. Colour coding, too, is helpful. For example, putting a coloured mark or sticker inside every *right* shoe (and even putting a dab of same colour nail varnish on the big toe of the same foot) can help shoes to go on the correct foot. A coloured tab sewn into the *front* of jumpers or vests etc, can prevent clothes going on back to front.

It is helpful to break down tasks like dressing into smaller steps and teach the child one step at a time. For example, if you are working on teaching her to put on her socks, you might first put on each sock up to the ankle and teach the child to pull up the sock from the ankle. Once she is able to perform this step correctly, go on to the next step -put the sock on her foot half over the heel and teach her to pull the sock over the rest of the heel and up. The next step is to put the sock on the foot to the heel, then on to the instep, then just over the toes -and get the child to pull the sock up over more of the foot at each step. Eventually, you will be able to hand the socks to the child, and then leave them on the bed or chair, so that she can take each sock in turn, put it on her foot the right way round and pull it up. Learning to do up buttons can sometimes be helped by encouraging the child to practice on buttons 'off the body' first. Cut some buttons and button- holes off an old shirt or cardigan and get your child to practice on these. Giving the child verbal cues is also helpful. As an example, when teaching her to do up shoelaces, she can be helped to talk herself through the routine, for example by saying out loud 'cross the laces over' 'pull one through' 'pull tight' as the child performs each step. In this way she learns the words and can then prompt herself in the task.

c) Independent Travel

As the child grows older, he may be capable of learning to travel independently along familiar routes, or even further afield. Given the WS child's good verbal skills, memorizing travel instructions and travel routes might be facilitated if he learns these by talking them through. If he can read, then giving him short written instructions and /or a simple map will help. Many caregivers are reluctant to let a WS adolescent or adult out alone because they fear that he might wander off or approach strangers. This can be a real danger and therefore it is important for parents and school staff to start as early as possible to teach independent travel and safety when out. One recommendation is for the child to wear some means of identification (e.g. an engraved bracelet) in case of difficulty or an emergency.

ON LEAVING SCHOOL

The question of what the WS child will do when she leaves school can be a major worry for families. Parents should be encouraged to obtain information about the available options well before their child leaves school, and to consult with the school's educational psychologist, a special needs careers officer, and also the local Learning Disabilities Team within Social Services, about the options that are available. Our research has shown that most adults with WS continue to need at least some supervision and support in their daily lives.

People with Williams Syndrome, like all of us, go on learning and acquiring skills after they leave school. Some go to a Further Education Unit or College, or other training scheme, for a number of years after leaving school, to continue their training in independence and self help skills such as dressing, cooking, independent travel, and to learn other skills. For the longer term, Special Education Centres, Adult Training Centres or Day Centres are further options, which provide work activities and recreational facilities. A few adults obtain employment either on the open market or in sheltered employment, and some go on to independent living. Others require ongoing support and supervision in everyday activities, and continue living at home, or move to residential hostels or group homes.

It is important for the person providing vocational guidance to appreciate the unusual pattern of strengths and deficits that characterise individuals with WS, and to bear these in mind when advising families on future training and occupational opportunities for their children. Jobs that are typically considered suitable for people with mild and moderate learning difficulties include routine manual tasks, such as stacking shelves, packing, or assembly line work. However, given the WS individuals' difficulties with visuo-spatial and motor skills, and their poor concentration, routine manual jobs such as these are not necessarily the most appropriate for them. Because of their relatively good social skills and verbal abilities and their concern for others, some people with WS may be well suited to working in a helping capacity, for example in a nursery or hospital, provided that they are given sufficient supervision. Jobs, which relate directly to their special interests or preoccupations should also be considered. For example, if the individual is very interested in cars he might prefer to work in a garage, even if the job he is given there is in itself a fairly routine or unstimulating one.

In a recent study of over 240 adults, the types of jobs found were typically in shops, catering or domestic work (often in homes for the elderly or people with intellectual learning difficulties). The majority were in unpaid, voluntary or part-time positions although it was felt that many could have coped with better paid and higher level jobs had better support and opportunities been available.

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.

FURTHER READING:

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