

Information for parents

Assistance for children with VCFS - starting out

With permission, this information is from Donna Cutler-Landsman's presentation at the 13th Annual International VCFS Educational Foundation Conference, Brisbane, 2-4 November, 2006

Most children with VCFS will require special assistance at school at some stage in their school lives. Some estimates put the proportion as high as 90%. There are various kinds of assistance, including:

- additional class teachers
- specialist teachers
- teacher's aide support
- support classes
- special schools.

Early intervention is best way to begin the process of helping young children with VCFS, and most research suggests intervention before age 3 years is best. There are various approaches to early intervention including:

- individual therapy sessions with Speech Pathologists, Occupational and Physiotherapists, and specialist teachers
- attendance at early intervention preschools and groups
- specific parent training programs.

Organisations which provide early intervention services include:

- Lifestart
- Learning Links
- Department of Education and Training
- Macquarie University

Primary areas of concern are usually cognitive skill acquisition, speech and language delays, behaviour and social interaction, and fine and gross motor skill development.

The needs of individual children will of course change as the child grows older, but the need for assistance of some kind will probably be constant. Most children will need assistance throughout their school years in the areas of academic growth, social relationships and the development of every day life skills.

Children with disabilities and learning difficulties can be supported at local government schools and private schools. Additional support can be provided by schools through resource funding, additional teaching, support from a consultant or teacher's aide. Schools need to know in advance that they will be enrolling a child with special needs, so parents should inform their school of their child's need for specialised services as early as possible so that appropriate arrangements can be made.

Educational and psychological assessment of children with VCFS

Psychological and educational assessment of children is usually conducted as part of the process of identifying their needs. Psychological assessment usually consists of standard tests of intelligence or development, and may also include assessment of behavioural and social skills. The most commonly used tests of intelligence are the various Wechsler Scales for children (WISC-IV, WPPSI-III). Others include the Stanford-Binet Intelligence Scales 5th Edition.

Frequently used developmental assessments include the Griffiths Mental Development Scales and the Bayley Scales of Infants Development. Developmental assessments are usually conducted with very young children to provide a 'snap shot' of their current abilities and needs.

Intelligence testing and developmental assessments are not necessarily accurate predictors of school performance. Some children with VCFS show a large variation between various domains assessed, for example verbal and non-verbal skills. Scores should be interpreted with caution, particularly 'full-scale' scores and scores derived when a child is young and has had little intervention or experience in formal education settings.

One disadvantage of some tests of intelligence, including the Wechsler scales, is that some of the performance scale sub tests are timed. This can cause children with VCFS to appear less capable than they are as their speed of processing and task completion can be slow. Another difficulty



arises because children with VCFS have variable test taking skills, and many can give up easily when unsure of an answer.

Most tests of intelligence include tasks from the following areas:

- problem solving and reasoning ability
- expressive and receptive language skills
- short-term memory skills
- auditory processing skills
- non-verbal processing skills
- visual/spatial skills

Additionally, some measures include assessment of academic achievement, fine and gross motor skills and motor planning skills.

If the child with VCFS shows behaviours that may be of concern in a formal assessment situation, for example short attention span, alternative methods of deriving information need to be considered. There are many checklists and rating scales which provide useful information about behaviour, attention, social skills, emotional adjustment and daily living skills.

Informing school personnel about VCFS

Most school personnel are not very familiar with VCFS. They will need to be provided with useful and appropriate information. Ideally such information should be made available to school personnel before the child with VCFS commences at school. The enrolment process for children with disabilities, learning difficulties, or specific medical conditions generally includes a pre-enrolment meeting with parents and staff at which such information can be given and explained.

There are many useful information sheets about VCFS which can be down-loaded from the Internet. Teachers and teacher's aides appreciate accurate, sound information about conditions affecting children in their classes, particularly if the information includes guidelines about educational or behavioural support strategies.

Sometimes schools can make time available to conduct in-service education for teachers and teacher's aides about specific conditions that affect children, and are happy to invite guest speakers to address staff. Parents can be excellent advocates for their children in this regard, either speaking themselves or organising someone who can explain VCFS to school personnel. If there are any videotaped presentations about VCFS, these make excellent stimulus material for in-service programs or staff meetings.

Psychologists, specialist teachers, speech pathologists and medical practitioners who understand the cognitive, behavioural and educational issues associated with VCFS can help to explain the child's deficits and how VCFS impacts upon learning and behaviour. Since a child with VCFS may have 'splinter skills' (areas of particular strength) teachers may wrongly interpret academic difficulties as laziness or as indicating lack of motivation.

Schools are dynamic environments in which many things change. Teachers leave and new staff arrive. Children change class, and programs change. It is therefore vital to maintain good and continuing communication with schools so that the needs of the child with VCFS are not forgotten, and that changes in school program or policy do not adversely affect the child with VCFS. Daily communication books, and regular meetings or telephone conversations with teachers, help to maintain open lines of communication with schools.

Research findings: VCFS and learning

Although there is a wide range of abilities in children with VCFS, virtually all will experience difficulty in school at some stage and will need some degree of assistance. Research into VCFS is ongoing, and medical science continues to make great advances in knowledge about VCFS and other medical conditions. The challenge is to relate these findings to daily functioning.

Magnetic Resonance Imaging (MRI) studies have shown that there are definite neurological differences in children with VCFS which are associated with many of their learning difficulties. Some of these differences relate to structural differences in the brain, including the vermis, parietal lobe, hippocampus and pons. There are also differences in brain volume.

Areas of learning difficulty in children with VCFS include:

- Problem solving, abstract reasoning, and making inferences.
- Reduced initiative and self-regulation.
- Difficulty remembering complex directions or verbal information.
- Slow information processing.
- Deficits in attention, and distractibility.
- Problems with initial encoding of information.
- Problems with 'working memory'.
- Problems with executive function, that is, the ability to plan and organise.



- Low threshold to frustration.
- Poor maths problem solving and maths concept development.
- Gaining information from class presentations, note-taking, or videos.

Children with VCFS often have variable test results due to:

- Difficulty generalising knowledge to novel situations such as tests.
- Difficulty understanding the format of tests.
- Making careless errors.
- Difficulties expressing all they have learned in written form.
- Fatigue.
- Difficulty with recall of information without cues.

Learning strengths may include:

- Maths calculation skills.
- Rote memory, particularly with well-encoded information.
- Basic spelling and written language.
- Decoding of words, and reading for basic information.
- Simple, focused attention.
- Computer skills, for example word processing.
- Rhythm and musical skills.
- Pleasant, engaging personalities and a willingness to learn.

Educational goals

Most students with VCFS can progress through a typical school curriculum at a slower pace and with curriculum modifications and assistance. Others will need more intense instruction in a smaller, more structured setting. Most children with VCFS benefit from small class sizes, but it is important not to underestimate what a child with VCFS can achieve given a supportive learning environment and a carefully sequenced curriculum.

Most students with VCFS learn to read, do basic maths, and can understand a general social studies and science curriculum. Some excel in music, so this area may offer a positive outlet for a student with VCFS. In addition to academic growth, educational goals for children with VCFS should include social skills development, functional daily living skills, improved communication skills and opportunities to enhance self-esteem.

Older students with VCFS may also need work-related goals and direct 'on the job' coaching and assistance. Self-advocacy goals should also be included. Many students with VCFS will need assistance understanding the consequences of their behaviours, and finding a path through school rules and course requirements.

A 'case manager' who is sensitive to the needs of the child with VCFS is critical to success in a school setting. Children with VCFS need a trusted adult at school who can help them negotiate through the challenges they face, be their mentor, 'coach' and advocate. This role is sometimes taken up by a particular teacher, the school counsellor, or another member of staff. Sometimes this is an obligatory role, and sometimes completely voluntary.

Looks can be deceiving!

Perceptions can be very important in education and learning. Because children with VCFS do not look obviously impaired and may have specific strengths, they may inadvertently create the impression that they do not need assistance at school. Most teachers and school personnel will not have heard of VCFS or had any direct experience teaching a child with VCFS. They will not readily appreciate how severely VCFS can impact upon a child's learning. It therefore needs to be constantly reinforced that the learning difficulties, attention difficulties, language processing problems, and associated health difficulties of children with VCFS present ongoing challenges at school.

Pre-school issues

Speech and language development is a major priority for young children with VCFS. Speech pathology assessment and intervention is usually undertaken at this age, sometimes in the clinical setting, and sometimes in the context of group activities at pre-school. Pre-schools offer rich and varied communication environments for young children, and children with speech and communication difficulties benefit from the positive role models made available in this way.

Similarly, Occupational Therapy assessment and programming is important for many young children with VCFS. Fine motor skills such as cutting, colouring, printing, using tools, motor planning and organisation skills, and sensory integration are all developed through Occupational Therapy programs, and reinforced in the daily activities of pre school. Occupational Therapy intervention with young children is often a combination of clinical programming and support in everyday preschool activities.

Physiotherapy assessment and intervention, including gross motor skills such as balance, walking, running and stamina, is sometimes



important for young children with VCFS. Success in these areas of physical functioning is vital for young children as involvement in many daily preschool activity depends upon adequate physical mobility skills.

Social skills development is a major part of pre school programs. Skills include separation from parents, listening in a group and following directions, sharing and communicating needs to others, and trying new skills. Children with VCFS often have deficits in these social skills areas, and the earlier intervention and skills development can be commenced the more likely it will be that they will be able to function adequately in these areas.

Cognitive skill development is a primary aim of pre school education. The development of problem-solving skills, learning strategies and concept formation skills underpins successful learning later in life. Children with VCFS often have difficulty in the formation of global concepts. They tend to learn specific skills by rote and have difficulty making generalisations. Early intervention and experience in the development of broader conceptual learning is therefore vital for young children with VCFS.

Primary school (ages 5-12)

One-to-one or small group instruction, or assistance within a regular classroom, is important as memory and attention deficits make large group instruction ineffective without support. Students with VCFS benefit from direct instruction in skills rather than a 'discovery' approach to learning. This is especially true in maths.

Students with VCFS can benefit from information being presented visually as well as verbally. It is important to consider however that children with VCFS do not process COMPLEX visual material as effectively as simple visual material. This may mean that visual timetables, schedules and teaching aids need to be clear, simple, and logical in format.

Students with VCFS can benefit from specific instruction on memory techniques, test taking skills, and cues to sustain attention. Drill and practice activities can be used to help encode information into memory. Teaching techniques which emphasise 'repeat, review, repeat, review' strategies are recommended.

For students with VCFS who have listening and attention difficulties, it can be useful to break study sessions, assignments and lessons into small segments. Handouts can be provided to student with VCFS so parents can reinforce skills learned at school. Children with VCFS are known to have relatively good computer skills and can learn effectively through this medium. Keyboard skills should therefore be taught and access provided to computers. Books and taped learning

materials can be used for students with VCFS who have reading difficulties. Some students benefit from a dedicated FM system which allows ongoing access to audio presentations.

Creative projects can be used to motivate students with VCFS, and as a break during long, more formal, tasks and assignments. Music has long been known to be a good way to impart information and instructions, and can be very effective with children with VCFS who are known to have good response to music and rhythm.

Children with VCFS need opportunities to take tests with special education teachers or other assistants, with additional time allocated for exam completion. This is important practice for children with VCFS who may well be eligible for Special Provisions in external examinations such as the School Certificate and Higher School Certificate later in life.

Children with VCFS can be socially immature and disorganised. It is important to develop responsibility by helping assignment completion, organisational skills, and specific roles within the school environment. Children with VCFS often have social skills deficits. They often learn social skills best through direct instruction, and techniques such as social groups, social stories, and buddy systems. They may need help developing appropriate friendship skills, often through an organised activity that can be monitored by an adult. Some examples would include clubs and societies such as scouts, and sporting teams.

Secondary school

During secondary education, as the academic and social demands of school increase, students with VCFS may need more support to succeed. It is important to continue to adapt the curriculum and learning environment to accommodate his or her specific needs. Without adequate assistance, students with VCFS may develop more serious behavioural difficulties. Some may lose their self-confidence and will not take risks in front of their peers. Faced with frequent learning difficulties and failures, students with VCFS may grow to dislike school.

Schools need to be realistic in their expectations for children with VCFS, and be patient and encouraging towards them. Teachers must be understanding and flexible during this stage. Subject choice and guidance at this stage is also very important. Opportunities for a supervised work experience program should be included in the curriculum.

Memory, organisational and attention deficits, and the medical challenges of VCFS, can be major obstacles for a young adolescent with VCFS. Penalising or criticising students for



misinterpreting directions or forgetting parts of assignments will erode the student's self esteem. Students with VCFS may need multiple attempts to succeed on specific tasks and assignments.

Schools must recognise the potential for psychiatric issues associated with adolescents with VCFS and work to eliminate potential stressors. Some sources of stress include 'high stakes' testing, unrealistic expectations, peer group pressures and social interaction difficulties.

Many children with VCFS are reluctant to ask questions and may appear to understand work or instructions when in reality they are confused and need assistance. Teachers need to check for understanding by asking students with VCFS to restate directions, for example.

As the student progresses through secondary school and approaches school leaving age, it will be necessary to assist the student with VCFS to prepare for this next transition. Information about available community support and programs will be important, so that the student with VCFS can commence 'adult life' as fully prepared and equipped as possible. Life skills such as budgeting, cooking, running a home, caring for a pet, doing odd jobs to help others, need to be taught.

It will be necessary to continue teaching and developing social skills in realistic settings such as social groups, sporting teams and clubs, and study groups. Enhanced communication and problems solving skills will need to be developed and reinforced on an ongoing basis.

What can parents do?

Most children with VCFS remain be a part of the regular education system when school and home work together cooperatively. There are many ways in which parents can provide additional support for their child with VCFS:

- Help your child get organised for school. Teach him/her to pack bags, and teach them to read and coordinate calendars and timetables.
- Help with homework by breaking large assignments and projects into smaller units.
- Re-explain abstract concepts by using simple language and several concrete examples.
- Ask your child to repeat to you what they understand. Do this several times until you are sure that they really understand a concept.
- Help your child study and work on assignments in small chunks over several days, rather than trying to finish difficult tasks in one go.

- Encourage social activities and arrange play opportunities, even if these are with younger children.
- Teach appropriate social interaction skills, and be aware of teasing and rejection by peers. Enrol older children in activities such as sports, camps, scouts, youth groups, music ensembles, etc. Teach them how to get along with others, how to understand jokes, and how to empathise.
- Consider delaying enrolment into school for children with VCFS who are immature or clearly not ready for school.
- Help your child make flash cards and use them to help memorise information. Also use play-acting, emotional imaging, experiential (hands on) learning, and mnemonics. Make homework fun!
- Encourage physical activity (karate, golf, tennis, etc.).
- Consider hiring a tutor and consider supplemental programs such as coaching or Kumon.
- Work with your child's school to discuss special assistance in class and exams, work experience opportunities, and plans for post-secondary education opportunities. Insist on assistance from staff who are knowledgeable with the course content necessary to assist your child.
- Try to work positively with your school. Don't expect the school to deliver all the services your child will need to succeed.
- Realise that children with VCFS will need parental support, a supportive school environment and extra help to make the most of their educational experience. Given the right environment for learning, children with VCFS can be successful, productive adults.

For further information and for CD's which are audio and video training sessions designed to educate parents and professionals including teachers about the syndrome and how they can better serve their students, please see www.cutler-landsmann.com.

For more Information

If you require further information please contact:

CHERI
The Children's Hospital at Westmead
Locked Bag 4001
Westmead NSW 2145

Tel: (02) 9845 0418
Fax: (02) 9845 0421
Email: info@cheri.com.au

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