Material and Resource Review/ Évaluation des ressources

Educating Children with Velo-Cardio-Facial Syndrome
Cutler-Landsman (2007)

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This book is a guide to educating children and adolescents with Velo-Cardio-Facial Syndrome (VCFS). VCFS is a genetic syndrome involving a microdeletion on the long arm of chromosome 22. Children with VCFS often have developmental and learning difficulties, but there has been a paucity of published information on the educational needs of these children, until this book. Part I of the book was written by the lead author Donna Cutler-Landsman and contributing authors, while part II is written solely by Ms. Cutler-Landsman. Ms. Cutler-Landsman is an educator with 30 years of experience teaching children in grades 5-8. She has also been a cooperating teacher with the School of Education, University of Wisconsin-Madison for 15 years and an educational consultant regarding the special education needs of children with VCFS. Ms. Landsman-Cutler has a child who was diagnosed with VCFS in 1994 when he was in 4th grade, enabling her to share personal experiences and insights as well. Contributing authors include: Robert Shprintzen, PhD; Tony J. Simon, PhD; Wendy Cates, PhD; Bronwyn Glaser, MA; Stephan Eliez, MD; Doron Gothelf, MD; Merav Burg, MA; Karen Golding-Kushner, PhD; and Anne Marie Higgins, RN. All are leading researchers and professionals well versed and published in the topic of VCFS.

The targeted audience for this book includes professionals in the fields of speech-language pathology, psychology, education, genetics, pediatrics and other professionals involved in the care of children with VCFS. Parents will also benefit from the book as it will help them better understand their child and his/her educational needs, as well as help them to advocate on behalf of their child.

The purpose of part I is to provide an overview of the medical, neurocognitive, psychiatric and communication issues that children with VCFS often face. Part II focuses on educational interventions starting in the 0-3 year-old range and extends through the school years and into adolescence. There are three appendices. Appendix A, "Accommodations" lists classroom accommodations for a variety of issues such as academic delays, organization of assignments, test writing, behavior and more. There are also specific accommodations to consider for children with nonverbal learning disability. A "Teacher Awareness Questionnaire," with answers appearing in Appendix B, is designed to help develop understanding of how VCFS differs from other genetic syndromes including Down Syndrome and Fragile X. Finally, Appendix C has "Exercises for Understanding" that include questions and hypothetical scenarios with the purpose of helping educators discuss and plan for the needs of a child with VCFS.

The book is well organized and while one can access just the chapters that are related to their child's age, information in other chapters can be quite useful regardless of the child's grade in school. Part I will help the reader understand how VCFS is diagnosed, and identifies the characteristics, typical neurocognitive and communication profiles and psychiatric issues associated with VCFS. There is also information about psychoeducational and communication tests. The information is generally clear, concise and provides a comprehensive overview. Parents and professionals will benefit from a better understanding of VCFS and its sequelae.

In Chapter 1 Dr. Shprintzen outlines the history of the nomenclature of VCFS and the various other names it has been called in the past (Di George syndrome, Shprintzen syndrome, conotruncal anomalies face syndrome). While the collective authors have decided to continue with the name "velo-cardio-facial syndrome," perhaps it would be less confusing to use the genetic nomenclature "22q11 deletion syndrome" or "microdeletion 22q11 syndrome," the chromosomal area affected in VCFS. While most of these children do have palate (velo), cardiac (cardio) and typical facial features there are some that may only have 2/3 characteristics. However, they all have the microdeletion.

There are a few lists in Chapter 1 that I thought would be especially helpful for parents when advocating for their child at school and for teachers in planning for a student with VCFS. The first entitled "Learning Issues" lists the relative strengths and weaknesses in learning noted in this population. It is important to identify each child's individual strengths and weaknesses so the teacher can get a sense of what to look for and how to prepare for difficulties before they arise. Another list that is beneficial is a timeline for education-related interventions. This helps parents and teachers to assess the student's current and future needs.

Part I ends with the "Velo-Cardio-Facial Syndrome Specialist Fact Sheet." This lists the 186 anomalies and characteristics that can be associated with VCFS. It also provides incidence and prevalence information. While this information may not be terribly useful for educators as no child will have all of the characteristics and anomalies, it does give them the sense that these children are a complex, heterogeneous group and that many factors may affect their performance in school.

Part I contains a confusing and contradictory passage about the relationship between verbal and performance IQs in children with VCFS. One sentence on page 17 reads "This pattern of performance IQ being significantly higher than verbal IQ, indicative of a nonverbal learning disability, seems to be true for most VCFS children, but not all." However, the two sentences proceeding and the two sentences following this sentence state the opposite, that children with VCFS typically have higher verbal IQs than performance IQs.

Part II is laid out very nicely with the chapters progressing by age/school stage. Parents and educators may benefit from tips in any of the chapters as they are based on children's strengths and weakness that may affect them at any age. In many of the sections, there are bulleted lists that highlight teaching strategies for a certain academic area. For example in the section "Mathematics", Chapter 10, there is a list of what an instructional approach should include that combines suggestions for direct instructions and strategy instruction. There are case vignettes to help illustrate some of the difficulties children with VCFS experience at different stages in school. A weakness for Canadian readers is that the educational laws and policies referenced by the author pertain to the American education system. While the laws may not be the same, many of the principles on special education appear to be similar in both countries.

Appendix A is particularly useful in determining which accommodations might help the child with VCFS reach their fullest potential in school. These accommodations will be particularly beneficial to parents when advocating for their child, and for teachers developing a student's individualized education plan. Many of the accommodations will also be helpful to other professionals such as S-LPs and OTs when planning assessment and therapy sessions with the children.

This is an excellent book to help professionals, educators and parents better understand VCFS and the educational needs of these students. Ms. Landsman-Cutler is argues that there is little research available on educational interventions for children with VCFS, but that these children need support today. There is no "cook book" approach to teaching children with VCFS. Ms. Landsman-Cutler and the other authors stress the importance of looking at the child's individual strengths and weakness and providing support where needed. All intervention approaches should be analyzed as to whether they are benefiting the child and modified as appropriate.