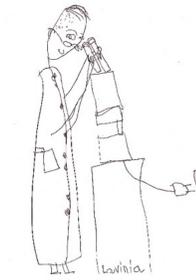


The Development of an Educational Checklist for Individuals with CHARGE Syndrome



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Introduction

CHARGE syndrome is a rare genetic disorder which affects every sensory system and often results in significant medical, communicative, developmental, and behavioral difficulties. The multiple impairments associated with CHARGE syndrome create a host of educational needs which must be met by school teams and related professionals. Because CHARGE syndrome is a rare, heterogeneous population, schools often lack the understanding needed to properly address the educational needs of students with CHARGE syndrome.

The Checklist

The Checklist is a tool which was developed in collaboration with the CMU CHARGE Syndrome Research Lab and an international panel of experts in CHARGE syndrome (David Brown, Nancy Salem-Hartshorne, Beth Kennedy, Rob Last, Jude Nicholas, and Kasee Stratton) to help schools effectively understand and address the educational needs exhibited by individuals with CHARGE syndrome. The Checklist includes an introduction to CHARGE syndrome, a glossary, recommended resources, and a comprehensive compilation of recommendations from professionals and experts in CHARGE syndrome. The Checklist has five categories:

1. Characteristics and Concerns
2. Educational/Support Needs
3. Team Members
4. Examples of Strategies and Accommodations
5. Consulting Professionals.

Limited Example of Checklist

	Characteristics and Concerns	✓	Educational/Support Needs	Team Members*	Examples of Strategies and Accommodations	Consulting Professionals**
Medical	Heart defects		Understanding stamina and lifting limitations	Nurse; Special Education Teacher	Provide additional travel time when walking	Primary Care Physician; Medical Specialist
Sensory	Deafblindness		Access to environment; understanding the complexity of combined vision and hearing loss; knowledge of deafblind-specific intervention	Deafblind Consultant/Teacher; Intervener	Simultaneously address the impact of visual and hearing loss; make information available through multiple sensory systems; direct instruction	State Deafblind Projects; Ophthalmologist; Audiologist
Developmental	Delay in intellectual/cognitive development		Curricular modifications; encourage exploration of and access to environment; recognize the potential of the child; concept development	School Psychologist; Deafblind Consultant/Teacher; Intervener	Modify curriculum through accommodation, adaptation, or making the curriculum parallel or overlapping	State Deafblind Projects; Private Licensed Psychologist
Communication	Expressive communication (e.g., vocabulary acquisition, articulation of speech and sign, breathing difficulties)		Multiple opportunities/methods for communicating (e.g., gestures, sign language, augmentative strategies, etc.)	Speech-Language Pathologist; Sign Language Tutor; Intervener; School Psychologist	Utilize a total communication approach; interpret body language and gestures as communication; teach communication based on child's interests; create a responsive environment; offer augmentative and alternative communication devices	State Deafblind Projects; Private Licensed Psychologist
Behavior	Physical behaviors (e.g., scratching, hair pulling, biting, self-injury)		Environmental scan/accommodations; identification of reasons for behavior (e.g., pain, sensory, environmental, etc.); determination of importance and immediacy of intervention	School Psychologist; Behavior Consultant; Deafblind Consultant/Teacher; Intervener	Functional behavior assessment; interpret behavior as communication; address behavior without taking away communication; consider pain and anxiety	Private Licensed Psychologist; Primary Care Physician; Psychiatrist; State Deafblind Project

* Parents and special education teachers should be considered a team member in every area

** State Deafblind Projects should be consulted frequently

Conclusions

Individuals with CHARGE Syndrome have multiple needs, which *must* be addressed and accommodated by the schools. Given the complexity of CHARGE syndrome, it would be unrealistic for one team to have expertise in every area required for comprehensive services. This educational checklist is a compilation of professional recommendations and can be used by schools as a tool for designing services for students with CHARGE syndrome.

Recommended Resources

<https://www.chargesyndrome.org/>

<https://nationaldb.org/>

<https://www.chargesyndrome.org/for-professionals/education-professional-packet/>

<https://www.chargesyndrome.org/families/resources/management-manual-for-parents/>

<https://www.sense.org.uk/content/charge-information-pack-practitioners>

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