

# CHARGE Syndrome Educational Priorities

CHARGE syndrome is a rare genetic syndrome, which often affects every sense: vision, hearing, smell, taste, touch, proprioception, and vestibular. CHARGE is an acronym, standing for the characteristics initially believed to best describe the syndrome:

Coloboma

Heart defects

Atresia or stenosis of the choanae

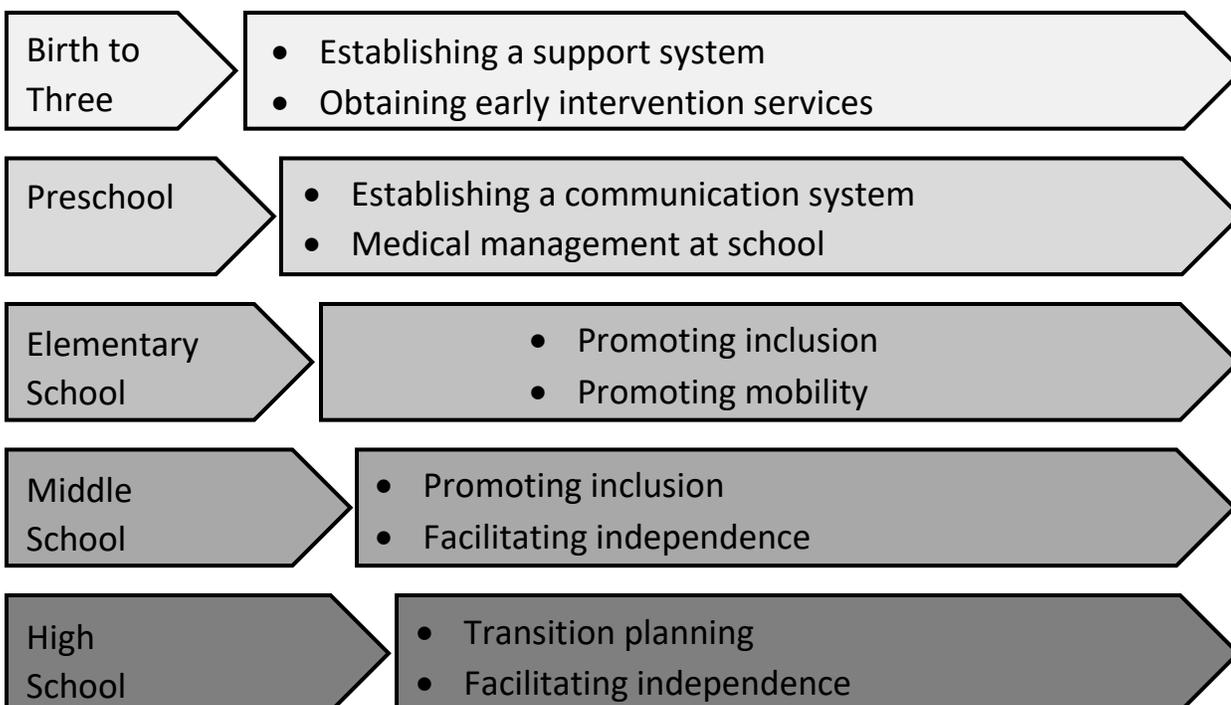
Restrictions of growth and development

Genital hypoplasia

Ear abnormalities and hearing loss

However, this acronym is no longer used for diagnostic purposes. A CHARGE diagnosis is made based on the presence of major (i.e., coloboma, choanal atresia/stenosis, cranial nerve anomalies, and a characteristic CHARGE ear) and minor anomalies (i.e., genital hypoplasia, developmental delay, heart malformations, short stature, orofacial cleft, and tracheoesophageal fistula) and genetic testing (*CDH7* gene mutation).

Educational management of individuals with CHARGE is complex, given the extensive medical complications, sensory loss, and related issues individuals with CHARGE experience. It can be challenging to know where to begin in providing educational services for individuals with CHARGE. **Communication** is a fundamental educational priority at all ages. Additionally, the following educational priorities have been identified across the lifespan:



\*Note: Many priorities and resources covered in these factsheets are applicable to individuals who are deafblind but do not have CHARGE Syndrome.

# CHARGE Syndrome Educational Priorities: Birth to 3-Years

## Priorities

### Establishing a support system

Children with CHARGE syndrome are medically complex. They often spend the first several years of life in and out of the hospital. Parents quickly become knowledgeable of the extensive medical needs of their child and learn how to manage their child's medical care. Because medical care can be overwhelming, establishing a support system for families of children with CHARGE with professionals and other families who understand CHARGE syndrome is crucial. Additional supports that provide families an excellent way to interact with other families and professionals with knowledge of CHARGE are state and national CHARGE conferences and organizations.

### Obtaining early intervention services

Medical management is often the primary family focus during the first several years of a child's life. With the extensive medical needs of a child with CHARGE, it can be difficult to see beyond the medical components of CHARGE. However, based on a family's priorities, a child with CHARGE will be eligible for early intervention services. It is best for the child to receive early intervention and support services as soon as possible. Through early intervention a child with CHARGE may be eligible to receive services such as nursing, occupational therapy, physical therapy, speech and language therapy, orientation and mobility therapy, and vision and hearing services. Early intervention services may target gross and fine motor delays, speech delays, feeding difficulties, sensory loss, and more. Additionally, a child with CHARGE should receive functional vision and functional hearing assessments early in life and should be reassessed at least annually.

## Resources

- CHARGE Syndrome Facebook Page with over 7,000 members provides parents, individuals with CHARGE, and professionals a means of connecting and sharing information. Join the Facebook page at <https://www.facebook.com/groups/chargesyndrome/>.
- CHARGE Syndrome Foundation is a national organization for parents and professionals. To access resources, research, and support, visit <https://www.chargesyndrome.org/>.
- The Ohio Center for Deafblind Education (OCDBE), a federally funded project, is responsible for the registration of children with deafblindness, ages birth-21 years of age. To register a child, go to [www.ohiodeafblind.org](http://www.ohiodeafblind.org). In addition, OCDBE provides information, resources, professional development, and consultation services to families and educators.
- Ohio Early Intervention provides intervention services to children with disabilities, including CHARGE, birth-2 years. To refer a child for early intervention, go to [www.ohioearlyintervention.org](http://www.ohioearlyintervention.org).

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# CHARGE Syndrome Educational Priorities: Preschool

## Priorities

### Establishing a communication system

A child with CHARGE syndrome often has difficulty expressing his or her wants and needs and understanding others due to multiple sensory impairments and physical anomalies. As soon as possible, parents and professionals must establish a formal method of reciprocal communication with the child. Parents and professionals should work together to ensure consistency across home and school environments. Parents and professionals should always interpret the child's behavior as a form of communication. Communication skills should be explicitly targeted through intervention services (e.g., speech-language therapy). A total communication approach utilizing a combination of methods of communication (e.g., spoken language, sign language, pictures, gestures, technologies) is recommended.

### Medical management at school

Preschool may be the first time a child with CHARGE receives educational services outside the home. Parents, who may be hesitant to relinquish responsibility for their child's medical management during the school day, should provide the school team with information on the medical needs of their child. The parent's expertise can assist the school team in becoming skilled in identifying and understanding the child's behaviors, as these may be indicative of an underlying medical need. Parents and school personnel will need to determine if nursing services should be provided in the educational setting.

## Resources

- CHARGE Syndrome Book, written for parents and professionals by experts includes several chapters on communication (i.e., Chapters 25–27) and medical management (i.e., Chapters 8–19).
- CHARGE Syndrome Educational Checklist provides an overview of educationally-relevant CHARGE characteristics and methods of addressing educational needs in schools. The checklist may be used to identify services for the child. (Citation in references and resource list at end).
- CHARGE Syndrome Health Checklist provides an overview of medical management that is often required for individuals with CHARGE syndrome across the lifespan. The checklist can be used to help understand the breadth of medical characteristics individuals with CHARGE experience. (Citation in references and resource list at end).
- CHARGE Syndrome Nursing Article provides an overview of nursing care for individuals with CHARGE syndrome. (Citation in references and resource list at end).

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# CHARGE Syndrome Educational Priorities: Elementary School

## Priorities

### Promoting inclusion

Inclusion provides the individual with CHARGE an opportunity to interact with his or her peers. Critical for social learning and building friendships, inclusion should be encouraged as soon as the child begins school. Parents and professionals will need to be purposeful about promoting inclusion by taking measures to encourage social acceptance by peers and explicitly teaching social skills to the individual with CHARGE. To encourage social acceptance, a circle of friends might be implemented (See resource below). To teach social skills, social stories or manualized social skills programs may be utilized.

### Promoting mobility

Walking is commonly delayed in individuals with CHARGE due to vision and hearing loss, vestibular abnormalities, and low muscle tone. A child's communication and independence often improve when he or she begins walking, possibly due to an improved ability to self-position to maximize residual vision and hearing and explore the environment. Educators may address the child's mobility needs by providing services (e.g., physical therapy, occupational therapy, orientation and mobility therapy), environmental and curricular accommodations (e.g., adapted physical education, open classroom layout), and assistive devices (e.g., walker, gait trainer).

## Resources:

- CHARGE Syndrome Book, written by experts for parents and professionals, includes chapters on inclusion (i.e., chapters 21 and 24) and mobility (i.e., chapters 5 and 6).
- CHARGE Syndrome Physical Therapy Article provides an overview of balance and mobility in CHARGE and recommendations for addressing these concerns. The article can be accessed at <http://www.chargesyndrome.org/wp-content/uploads/2016/03/CHARGE-Syndrome-and-Physical-Therapy.pdf>
- Circle of Friends website (<https://www.circleofriends.org/>) provides an overview of social stories and can help parents and professionals implement a circle of friends with their child/student.
- Hiya Moriah, a book about Moriah, a young girl with CHARGE syndrome, can be read with individuals with CHARGE and classmates to promote inclusion. This book is available at <http://www.victorianelsonbooks.com/books/>.
- Social Stories website (<https://carolgraysocialstories.com/social-stories/>) provides an overview of social stories and can help parents and professionals implement social stories with their child/student.

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- Why I am me: All about CHARGE Syndrome, a book about Sam, a young boy with CHARGE, and his friend, Jess, can be read with the individual with CHARGE and peers to promote an understanding of CHARGE syndrome. This book is available at <https://www.chargesyndrome.org.au/store/why-i-am-me?rq=why%20i%20am%20me>

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# CHARGE Syndrome Educational Priorities: Middle School

## Priorities

### Promoting inclusion

Inclusion with peers should be promoted at every age; however, this is a crucial priority in middle school, as the child/adolescent with CHARGE may develop a heightened awareness of his or her differences and may become especially susceptible to social isolation. Parents and professionals should encourage conversations with the child/adolescent about CHARGE syndrome. Parents and professionals can promote inclusion by ensuring the child/adolescent spends time with peers, encouraging participation in sports and clubs, and promoting an inclusive school climate. Social skills should be taught explicitly to the child/adolescent, as he or she is likely miss out on many social cues due to his or her combined sensory loss. A circle of friends (see resource below) may also be beneficial.

### Facilitating independence

It is never too early to begin facilitating independence. Parents and professionals should give the child/adolescent with CHARGE as many opportunities to develop as many skills needed for independence as possible. Examples of tasks to build independence include helping with meal preparation and eating (for both oral and feeding tube eaters), helping with grocery shopping, doing household chores, and learning about money.

## Resources:

- CHARGE Syndrome Book, written by experts for parents and professionals, includes chapters on inclusion (i.e., chapters 21 and 24) and independence (i.e., chapter 24).
- Circle of Friends website (<https://www.circleofriends.org/>) provides an overview of social stories and can help parents and professionals implement a circle of friends with their child/student.
- Hiya Moriah, a book about Moriah, a young girl with CHARGE syndrome, can be read with individuals with CHARGE and classmates to promote inclusion. This book is available at <http://www.victorianelsonbooks.com/books/>.
- Social-Emotional Development Article provides an overview of social-emotional development in children and youth who are deafblind. Risk factors and intervention strategies are identified. (Citation in references and resource list at end).
- Social Stories website (<https://carolgraysocialstories.com/social-stories/>) provides an overview of social stories and can help parents and professionals implement social stories with their child/student.
- Why I am me: All about CHARGE Syndrome, a book about Sam, a young boy with CHARGE, and his friend, Jess, can be read with the individual with CHARGE and peers to promote an understanding of CHARGE syndrome. This book is available at <https://www.chargesyndrome.org.au/store/why-i-am-me?rq=why%20i%20am%20me>

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# CHARGE Syndrome Educational Priorities: High School

## Priorities

### Transition planning

Transition from school to post-secondary opportunities as an adult can be scary for parents and the adolescent with CHARGE. Transition planning should start early and should remain a pivotal focus of education throughout high school. Programming and services should include activities and goals which directly relate to transition. Developing a person-centered plan and/or personal passport are excellent ways to facilitate transition (See resources below). These tools outline the strengths and goals of the individual and detail a plan of how to help the individual reach his or her goals.

### Facilitating independence

Parents and professionals must continuously work to provide an adolescent with CHARGE the opportunity to develop skills for independence. Skills related to independence are necessary for a successful transition to adulthood. Opportunities to enhance skills needed for independence should be provided based on the individual's interests and long-term goals. Goals may involve employment, recreation/leisure, home living, community participation, and post-secondary education. The potential of individuals with CHARGE should not be underestimated.

## Resources:

- CHARGE Syndrome Book, written by experts for parents and professionals, includes a chapter related to independence and transition (i.e., chapter 24).
- It's My Choice, a self-guided workbook, provides a template for developing a person-centered plan. The workbook can be utilized by the individual and educational team to plan transition goals. Access the workbook at [http://mn.gov/mnddc/extra/publications/choice/Its\\_My\\_Choice.pdf](http://mn.gov/mnddc/extra/publications/choice/Its_My_Choice.pdf)
- Jonas' Cooking School is a blog that describes Jonas' cooking school. Jonas, an adolescent with CHARGE aspiring to live independently, is learning to cook with his mother. Read the blog at <https://www.chargesyndrome.org/wp-content/uploads/2018/11/Jonas-Cookery-School-Jonas-Kochschule-Englisch.pdf>.
- Person-Centered Planning website (<http://personcenteredplanning.org/>) provides an overview of person-centered planning. Information on the website can be used by educational team members to gain a better understanding on person-centered planning.
- Personal Passport newsletter provides an overview of personal passports which contain information about a child and the child's interests. Personal passports can be used by educational team members to gain a better understanding of the child for future planning. Access the newsletter at <http://files.cadbs.org/200002606-b7168b8108/Fall04Knowing%20the%20Child.pdf>

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- Post-Secondary Transition Manual for Students Who are Deafblind, developed by the Ohio Center for Deafblind Education, provides step-by-step information on the development of a postsecondary transition plan for a child's Individualized Education Program (IEP). The manual is available at <https://www.ohiodeafblind.org/tools-and-resources/ocdbe-products>
- Post-Secondary Transition Toolkit, developed by the Ohio Center for Deafblind Education, provides federal, national, state, and professional resources for the development of the postsecondary transition plan of a child's Individualized Education Program (IEP). The toolkit is available at <https://www.ohiodeafblind.org/tools-and-resources/ocdbe-products>
- Transition Toolkit, developed by the National Center on Deaf-Blindness, is a compilation of self-determination resources that support the transition of individuals who are deafblind. Access the toolkit at [http://documents.nationaldb.org/transitiontoolkit/TransitionToolkit\\_Final.pdf](http://documents.nationaldb.org/transitiontoolkit/TransitionToolkit_Final.pdf)

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## References and Resources

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- Enderlin-Severson Transition Rating Scale (ESTR): <https://www.estr.net/>
- Hiya Moriah: <http://www.victorianelsonbooks.com/books/>

- It's My Choice: [http://mn.gov/mnddc/extra/publications/choice/Its\\_My\\_Choice.pdf](http://mn.gov/mnddc/extra/publications/choice/Its_My_Choice.pdf)
- Jonas' Cooking School: <https://www.chargesyndrome.org/wp-content/uploads/2018/11/Jonas-Cookery-School-Jonas-Kochschule-Englisch.pdf>
- National Center on Deaf-Blindness: <https://nationaldb.org/>
- Ohio Center for Deafblind Education (OCDBE): [www.ohioearlyintervention.org](http://www.ohioearlyintervention.org)
- Ohio Early Intervention: [www.ohioearlyintervention.org](http://www.ohioearlyintervention.org)
- PEERS® Social Skills Intervention: <https://www.semel.ucla.edu/peers>
- Perkins School for the Blind: <http://www.perkinselearning.org/videos/webcast/charge-syndrome-overview>
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- Post-Secondary Transition Toolkit <https://ohiodeafblind.org/tools-and-resources/ocdbe-products>
- Social Stories: <https://carolgraysocialstories.com/social-stories/>
- State Early Intervention Services: <http://ectacenter.org/>
- Transition Toolkit: [http://documents.nationaldb.org/transitiontoolkit/TransitionToolkit\\_Final.pdf](http://documents.nationaldb.org/transitiontoolkit/TransitionToolkit_Final.pdf)
- Why I Am Me: All About CHARGE Syndrome: <https://www.chargesyndrome.org.au/store/why-i-am-me?rq=why%20i%20am%20me>



 **Systems Development & Improvement Center**

Developed by Lillian Slavin (2019) for the Ohio Center for Deafblind Education (OCDBE).  
<https://www.ohiodeafblind.org/>