IEP Resources and Recommendations for the Educational Setting

2023 International CHARGE Syndrome Conference

Authored by: Alysha Croke, DPT, PCS, Lauren Kling, DPT, Catherine Murphy, DPT, Emily Weber, DPT

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1. Individualized Educational Plan (IEP)

This is a broad list of supports and compensatory strategies, such as positioning supports, that might be appropriate to include in an IEP for students with CHARGE Syndrome. Since they are supports and strategies rather than skills the student is building, these needs are not addressed in the IEP goals and should be listed elsewhere. Depending on state laws and district practice, they may fall under the PLEP/PLAFP, Modifications, or Accommodations sections of the document - please refer to your state laws for guidance on including these supports and compensatory strategies in the IEP. Not all of these items will be appropriate for every child. This list is meant as a resource for providers and families and should only be used as a reference when determining the individual needs of the student.

Presentation
● Experience-based learning ● Repeated exposure to activities ● Materials and instruction provided within student's visual field ● Function-based activities ● Calendar system ● Clear beginning, middle and end to tasks ● Daily visual schedule ● Consistent routine ● Part task and whole task demonstrations ● Structured transitions ● Total communication approach to language (AAC, tactile sign language, whole objects, tactile symbols, etc.) ● Use of "First, Then" system* ● Multiple-step schedule system* **A student may use the "First, Then" system and then, once they had mastered use of a 2-step system, the number of steps in the routine could be gradually increased*

Setting
• Predictable environment • Individual instruction • Frequent position changes throughout the school day • Opportunities for out-of-chair on the floor in prone, quadruped, sitting, and kneeling positioning across school settings • Opportunities for out-of-chair supported standing with upper extremity support or with stander/body weight harness across school settings • Opportunities for standing desk work • Supportive “relax” seating (e.g. bean bag) • Seating available in hallways for longer distance travel • Medical staff trained in vital sign monitoring and assessment • Deafblind teaching strategies across providers
Timing
• Extra time to process information • Highly structured use of time • Movement and sensory opportunities built in across school day • Pacing strategies during movement activities • Fatigue management/frequent scheduled rest breaks
Response
• Increased latency time • Behavior management and behavior support plan • Behavior strategies: Token board and emotions cards • Finished box • Manipulatives • Practice/repetition • Total communication approach to language (AAC, tactile sign language, whole objects, tactile symbols, etc.) • Use of adaptive jigs and tools where necessary • Tactile models and materials

Equipment

DME

- Supine/prone/sit-to-stand stander
- Gait trainer/walker for mobility
- Bathroom mat table for hygiene care
- Positioning supports such as peanut balls, Kaye bench, etc. to achieve modified developmental positioning
- Supports such as peanut balls, Kaye bench, etc. to provide different positioning opportunities
- Stroller/wheelchair for mobility within the building and transportation
- Hi-Lo activity chair for transportation and positioning support across school settings
- Adaptive seating across school settings
- Slant board for optimal material positioning
- Upper extremity support for self-supported standing (grab bar, railing, wall-mounted ladder, etc.)
- Body weight supported harness (HOPSA dress) via swing mount or lift track
- Resonance boards
- Material suspension frames/position boards/APH adaptive trays
- Switch-adapted ride-on car

Bracing

- UCB Orthotics
- Bilateral Supramalleolar Orthoses (SMOs)
- Bilateral Ankle Foot Orthoses (AFOs)
- Standing, Walking, and Sitting Hip Orthoses (SWASH)
- Dynamic Resting Splint
- Bracing for trunk support (Dynamic Movement Orthosis (DMO), Soft Spinal Orthosis (SSO), Thoracic Lumbar Sacral Orthosis (TLSO))

Other

- Pulse oximeter - finger sensor/ear clip sensor/toe sensor
- Specify additional student medical equipment (e.g. nebulizers, EpiPen, etc.)

Transportation

- Stroller/Wheelchair with transit option
- Wheelchair accessible transportation
- Carseat for positioning support
- Booster Seat for positioning support
- Transportation Vest for positioning support/safety
- Bus monitor for safety
- Buckle buddy for safety
- Ramp access for vehicles with tall single step (e.g. 15 passenger vans)
- Specific seating arrangement for safety/mobility access

2. IEP Goal Areas

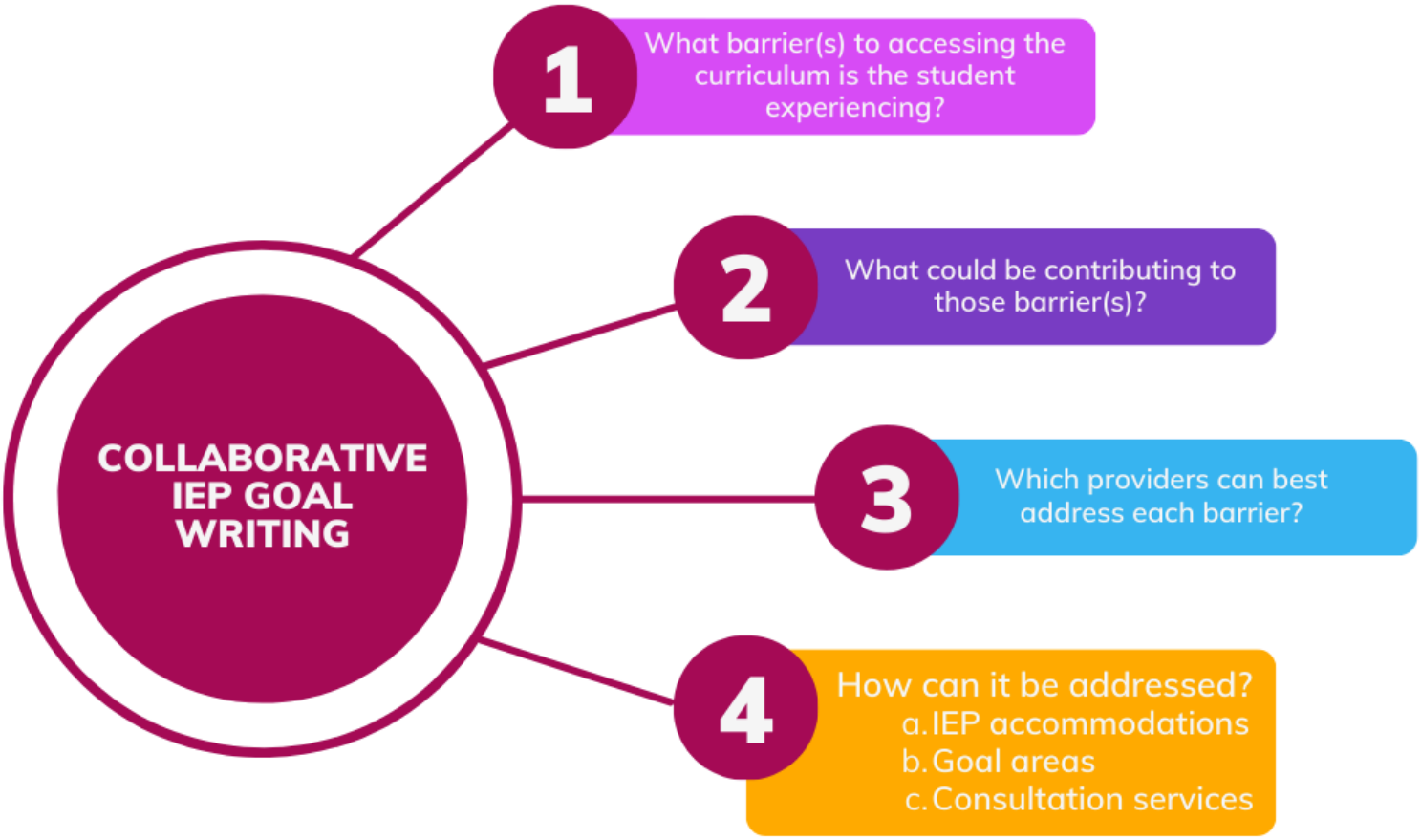
This chart provides broad examples of goal areas for children in various stages of motor development (pre-gait, early ambulator, independent ambulator) along with general intervention targets. Goals areas should be based on skills the child is actively building rather than what services they receive or what they participate in. Activities like stretching programs and exercise routines should only be part of direct physical therapy services when the programs are being developed. These activities should transition from direct service to consultation and from a goal area to the “Additional Information” part of the IEP once a program has been established and incorporated into their day. At that time, if the student needed assistance to carry out the routine it would be done with trained classroom and physical education staff or with the family at home. This information can be used by providers who are considering creating collaborative goals to address needs in the school setting. It is also a good resource for families to have an idea of what to expect as your child progresses through the stages of development.

Pre-Gait		
Endurance	**Gross Motor/Functional Strength**	**Balance**
• Head and neck control • Positional endurance (e.g. quadruped, sitting, kneeling, standing)	• Rolling • Transitions in and out of developmental positions (e.g. quadruped, sitting, kneeling) • Transitions between the floor and standing • Transitions to and from a chair • Crawling • Adapted sports activities	• Protective responses • Static and dynamic positioning (e.g. quadruped, sitting, standing) • Reaching outside base of support

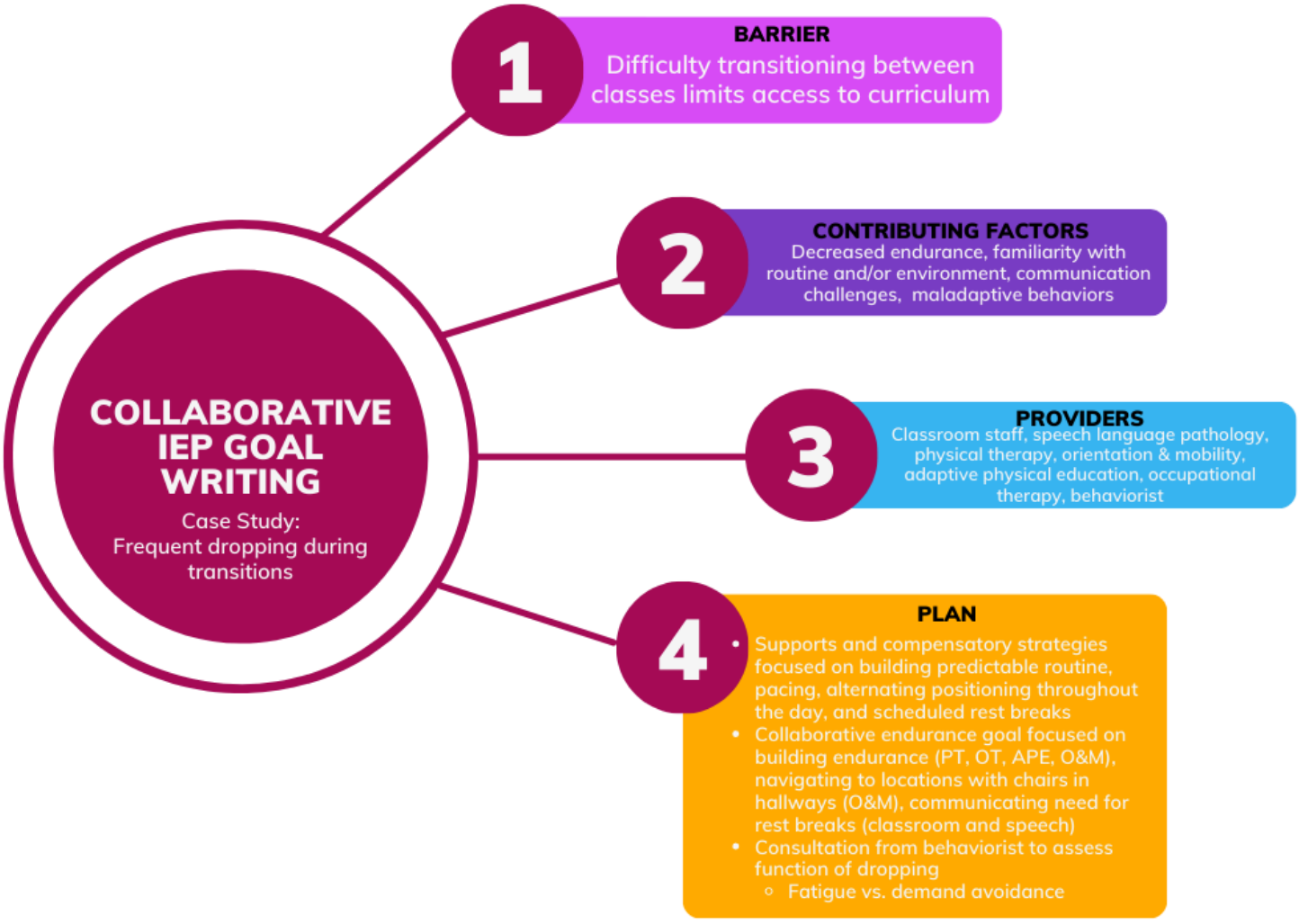
Early Ambulator		
Endurance	**Gross Motor/Functional Strength**	**Balance**
• Positional endurance (e.g. quadruped, sitting, kneeling, standing) • Sustained activity tolerance (e.g. standing, walking, cycling)	• Transitions in and out of developmental positions (e.g. quadruped, sitting, kneeling) • Transitions between the floor and standing • Transitions to and from a chair • Picking items up from the floor • Pushing or pulling heavy items • Ambulation with physical assistance or assistive device • Stair mobility • Adapted sports activities • Accessing playground structures	• Protective responses • Static and dynamic positioning (quadruped, sitting, standing) • Reaching outside base of support • Standing on variable surfaces • Increased single leg stance time • Dynamic movements in a variety of planes • Accessing playground structures
Independent Ambulator		
Endurance	**Gross Motor/Functional Mobility**	**Balance**
• Positional endurance (e.g. quadruped, sitting, kneeling, standing) • Sustained activity tolerance (e.g. standing, walking, running, cycling)	• Transitions between the floor and standing • Picking items up from the floor • Pushing or pulling heavy items • Ambulation outside/on uneven surfaces • Stair mobility • Sports activities • Accessing playground structures	• Reaching outside base of support while sitting or standing on variable surfaces • Increased single leg stance time • Dynamic movements in a variety of planes • Accessing playground structures

3. Case Study: Collaborative Goal Writing

IEP goal writing should have a student-focused approach. The interdisciplinary team, including the student and family, should identify what are the most significant barriers that are impacting the student's access to the curriculum and then the team should work together to try to figure out what factors are contributing to the barriers and how to address them. Based on that, baseline data should be collected and collaborative goals should be written that indicate in what settings data will be collected by team members.



Goal Writing Case Study: A student is regularly dropping to the ground while traveling through the building. As a result, they often arrive late to their next class.



4. Evaluation Recommendations

Below is a list of evaluation considerations and recommendations compiled by PTs who have experience working with children with CHARGE in the school setting. It is not a comprehensive list and each recommendation may not be applicable to each child, but it provides some ideas for school-based providers that may not have as much experience with CHARGE. Feel free to share these recommendations with the physical therapists and other professionals working with your child.

Background Information
CHARGE syndrome is a genetic syndrome with a characteristic pattern of features, leading to birth defects, medical issues, and developmental problems associated with the syndrome include coloboma of the eye, heart defects, choanal atresia, delayed growth and development, genital abnormalities, ear abnormalities (characteristic external ears and small/absent semicircular canals) and deafness. CHARGE syndrome is correlated with genetic mutation to CHD7 and diagnosis is based on the presence of at least two major and several minor features, with genetic testing being helpful but not required for a definitive diagnosis. Most individuals with CHARGE syndrome have difficulty with hearing, vision, and balance, which results in delayed motor development and communication. Despite the key features that are common with the syndrome, there is a wide variation in physical features, cognitive ability, and skills among those with CHARGE syndrome.
Posture/Alignment
There are characteristics inherent to CHARGE syndrome that can impact the individual's posture. These can include vestibular anomalies, spinal anomalies such as congenital cervical spine fusions, kyphosis, and scoliosis as well as torticollis and decreased use of the shoulders. Posture in individuals with CHARGE syndrome can also be impacted by global low muscle tone and low vision/compensatory positioning for blind spots and visual field loss (Girardi, 2016).

Muscle Performance
When evaluating the posture of individuals with CHARGE, it is common that standing may typically be assessed in motion rather than the student demonstrating static standing. This can indicate decreased endurance of postural support muscles, as continually moving allows for weight shifting between muscle groups rather than requiring sustained contraction of stabilizer muscles.
Muscle Tone
Individuals with CHARGE may demonstrate low tone, or hypotonia, globally. Hypotonia is a characteristic of CHARGE syndrome and means that the individuals with low tone both cannot activate their muscles as quickly or maintain a contraction for as long as a muscle with normal tone. This not only increases the work required to simply maintain positioning and posture, it also means that the body receives decreased sensory input through the muscles and joint receptors.
Balance
Individuals with CHARGE syndrome typically have compromised visual and vestibular systems, and therefore rely heavily on the somatosensory system for input to maintain their balance. However, as noted in the section above discussing tone, due to global hypotonia their somatosensory input is both decreased and delayed. For these reasons, the balance system in individuals with CHARGE syndrome is an area of significant impairment.
Recommendations
The student will benefit from total communication during their physical therapy sessions to communicate expectations, directions, and maintain focus on skilled activities.
The student will benefit from continued interdisciplinary communication and consultation between their team members in order to ensure consistency and carryover of skills, strategies, and accommodations across all settings.
The student will benefit from physical skills being incorporated throughout the school day that emphasize balance, coordination, and building endurance. This may be provided through direct physical therapy services or consultation to support the student in recess, gym class, and other applicable environments.

Recommendations
The student will benefit from interacting with providers who are familiar with how their diagnosis of CHARGE syndrome impacts their physical skills, particularly their posture, balance, motor coordination, and endurance. A brief, useful resource is *Physical Needs of Children with CHARGE Syndrome* (Girardi, 2016).
The student will benefit from opportunities throughout their school day that allow them to challenge their balance skills and to build their balance confidence while limiting physical support from trained staff to only what is needed to keep them safe. It is helpful to create conditions that may result in a loss of balance *when in a controlled environment and protecting them from risk of a head injury*, such as on a padded gym mat and from a low height. When these losses of balance occur, they should be met by staff in a playful and encouraging manner rather than creating a negative association - for example, “Whoa, that was a big crash! That was so cool, are you ready to stand up again?” Having to manage losses of balance without physical assistance allows the student to improve their eccentric control and to reinforce cause and effect relationships. Consider the student’s need for visual supports during balance challenges, such as increased lighting and contrasting colors on the edges of surfaces, to support their low vision and decrease the visual demand for an activity with a high physical demand.
The student will benefit from seating across their school environment(s) that provides them with adequate posture support and sensory feedback. Ideal positioning includes neutral pelvis alignment, hips and knees at 90°, feet able to be planted in neutral on the floor or, if needed, a footrest, a high back, and, depending on sustained sitting endurance, they may benefit from arm rests.
The student will benefit from position changes approximately every thirty minutes to support their posture and in the setting of their globally low muscle tone (Girardi, 2016). Position changes can include sitting in a desk chair or a more supportive chair like a bean bag chair, standing, increasing the height of the work surface to minimize the need to bend or hunch forward, prone or modified prone on a wedge, and lying on a mat or the floor. The student’s school activities should be planned out to be incorporated into these different positions - for example, while prone on a wedge to receive support throughout the length of their body, the student could have a school task in front of them on the floor to work on.

Recommendations
The student will benefit from a functional strengthening program that emphasizes increasing muscle performance and endurance of the shoulder complex, abdominal muscles, and pelvic girdle in activities that are meaningful and motivating for the student. This could include playing games in quadruped or supported quadruped (over a peanut ball, with their belly on a swing) or activities that require reaching overhead and laterally outside of their base of support for preferred items. If music is motivating for the student, using a switch-activated speaker system with the switch positioned above their head could encourage them to reach overhead repeatedly to activate the switch in the “Timed” setting or to maintain their arms above their head to activate the switch in the “Direct” setting.
The student will benefit from activities that provide them with strong proprioceptive input - this will increase the somatosensory information available to be integrated into their balance system to help compensate for their low vision and the impairments of their vestibular system that are characteristic of CHARGE syndrome. Additionally, it will help to compensate for the globally decreased information from their muscle and joint receptors that is the result of low muscle tone and possible skeletal abnormalities consistent with individuals who have CHARGE and may improve their motor coordination.
The student will benefit from consistent monitoring by medical doctors who specialize in the musculoskeletal system, such as orthopedics and physiatry. Their low muscle tone, postural impairments, and possibility of congenital skeletal abnormalities increase their risk of joint contractures, scoliosis, and chronic pain. Consistent follow-up with a specialist will help to monitor their musculoskeletal development, provide ongoing assessment of their need for bracing or postural support, and to improve their quality of life in the long-term.
The student will benefit from increased opportunities for practice and repetition across all of their physical activities. CHARGE syndrome limits the somatosensory, visual, auditory and vestibular input that their body receives, leading to gross motor delays and impaired motor coordination. Providing the student with increased repetitions compared to a typical peer to practice a particular skill allows them the opportunity to improve their coordination, rate of success, and confidence. Additionally, physical activities should be designed with an emphasis on function, intrinsic reward of the task for the student, and generalizability of the activity benefit them in performing other similar skills.