ASSESSMENT OF CHILDREN WITH CHARGE

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Editorial Comments by Sandra L.H. Danvenport, M.D.

> Assessment should be driven by what questions the educational team and the parents have about the child. It should be used to guide the I.E.P. process. It should be a holistic process and not a tool that condemns the child to a perceived inability to learn.
>
> Assessment does not require standardized measurements. Often, a "Portfolio Assessment" is far more helpful. The portfolio may include review of records, review of current developmental milestones, review of progress toward goals, and functional assessments of vision, hearing, etc. No standardized tests exist which can accurately assess children who have multiple sensory impairments. *A. standardized test score is like a drive-by shooting.*
>
> Because in assessment drives the I.E.P. process, facts should be stated in the organized manner. In addition, it is extremely important that useful and valid recommendations be made as well.
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> *"Is it possible to accurately assess a child who does not see or hear, who has had so little exposure to intensive language stimulation that his or her primary means of communication is nonspeech vocalizations, body expression, and approximately 20 manual signs? Are there clues that would tell you he could learn given the right approach? Is it possible that the use of totally inappropriate assessment tools has added significantly to the attitude that this is not only an untestable child, but an unteachable one?"* (Wolf-Schein, 1998).

What is important to know about assessment of children with CHARGE?

The first thing to note is that children with CHARGE are more different than they are alike. There is no "normal level of functioning" for this group of kids. There are adults with CHARGE who attend college and graduate school with minimal or no support, and there are adults with CHARGE who use one-on-one support personnel for all activities of daily living and work. It seems that some of the variation depends upon how much vision and hearing the child with CHARGE has. In a study on CHARGE and developmental delay (Hartshorne, 1999), I found that children with CHARGE who had better hearing and vision scored higher, overall, on a scale of adaptive behavior skills. I also concluded,

> At present, there is no valid and reliable method for estimating the range of cognitive abilities for children with CHARGE, or for any subgroup within the deaf-blind population. However, because of these results, we can be relatively confident that the intellectual abilities of these children are routinely underestimated, due to other disabling factors.

We are able to accurately assess the intelligence levels of some children with CHARGE in traditional ways because they have little or no sensory impairment. However, there are many children with CHARGE for whom the use of traditional assessment procedures is grossly inappropriate. A child with limited hearing and vision will not do well on a traditional IQ test. If this method is used, it is likely to result in an underestimate of the child's true abilities, and inaccurate labeling. (See drive-by shooting quote, above.)

So, what should assessments look like for these kids?

First and foremost, the primary purpose of assessment should not be to place a label on a child based on test performance. The primary purpose should be "to properly describe children's current level of performance in order to point the way to the best intervention possible" (Wolf-Schein, 1998). The assessment should drive the IEP or IFSP. Having said that, assessments should address all of the following areas: (Anderson, Chitwood, & Hayden, 1998)

- Movement
- Communication
- Social Relationships
- Independence/Self-Concept
- Perception/Senses
- Thinking Skills
- Learning Style

In addition, assessments of children with CHARGE should include an evaluation of functional hearing, functional vision, and functional communication skills. How does the child hear, see, and communicate in different contexts?

When possible, assessments should include observation of the child working in familiar environments, with familiar persons. This can provide a wealth of information on learning style, communication, social skills, behaviors, and abilities.

Portfolio assessment can sometimes be an appropriate option for use with children with CHARGE. This can include review of records, interviews with professionals and parents, review of current developmental milestones, and review of progress toward goals.

What should assessment reports look like?

Because children with CHARGE have such complex and multiple needs, assessment reports should state facts and findings in an organized manner. In addition, it is critical that reports include useful recommendations for service providers and parents. These should include recommendations about functional skills and activities in which the child engages.

Functional skills are those that enable a child to function independently in natural environments. Ask yourself, "Is this a skill this child needs to learn in order to function as an adult?" For example, a child could practice the cognitive skill of categorizing by color in many ways. A non-functional way would be to have the child place colored blocks into containers for the sole purpose of the task itself. A functional way to practice this skill would be to have the same child sort construction paper into drawers or files for someone to use at a later time. A child learning one-to-one correspondence could do so by inserting pegs into a pegboard. The same child could learn the same skill if she were passing cookies out to her classmates. It is essential that that the assessment itself, the results, and the recommendations address skills that will be functional for the child in his or her natural environment.

Quality Indicators and Desired Outcomes of Evaluations of children with CHARGE

Mar (1998) identifies the following as indicators and outcomes of quality evaluations for children who are deaf-blind. These indicators are also appropriate when evaluating children with CHARGE. A quality psychoeducational evaluation should:

- identify educational/psychosocial concerns;
- use meaningful and relevant tasks;
- use multiple procedures;
- use multiple observations of communication behaviors and social interaction skills in natural routines;
- describe degree of participation in tasks, not failures and inabilities;
- focus on how the student acquires information rather than on test scores;
- involve parents, teachers, and other service providers in information gathering;
- assess pragmatic, functional home and community skills.

A quality evaluation for these children should result in these outcomes:

- positive outcomes for student, parent, team;
- increased understanding of communication behavior;
- a description of competencies, difficulties, progress, and environmental factors affecting performance;
- a description of behavioral concerns and recommendations for supports and services;
- avoidance in use of jargon, technical language, unnecessary references to scores or age levels, and comparisons to the “norm”;
- a description of social interaction skills, involvement with peers, and participation in school and community, and recommended strategies to increase these;
- a description of goals the student might be expected to attain and general strategies to help the student attain them;
- a discussion of strategies for dealing with problem behaviors using positive support such as reinforcers, preferred activities, redirection, and communication training;
- suggestions for age-appropriate and meaningful materials and activities.

Finally, Mar (1998) has developed a “Consumer Test” of assessment outcomes. This is perhaps the most useful set of questions to consider when evaluating a child with CHARGE.

CONSUMER TEST OF ASSESSMENT OUTCOMES

- Will the evaluator be able to describe sufficiently my competencies and the ways that I best communicate?
- Will the assessment indicate what progress I have made?
- Will the assessment be used to determine my needs, desires, choices, and interests in everyday situations and settings?
- Will the assessment help my family, teachers, and schoolmates to interact with me better?
- Will the assessment lead to interventions that make sense to me?
- Will the assessment identify the services and help I really need?
- Will the assessment help other people who work with me?
- Will the assessment contribute to the long-term plan?

References

Anderson, W., Chitwood, S., & Hayden, D. (1997). Negotiating the Special Education Maze: A Guide for Parents and Teachers, 3rd Edition. Bethesda, MD: Woodbine House

Hartshorne, N. (1999) The prevalence of mental retardation in CHARGE Association. Paper presented at the 4th International CHARGE Syndrome Conference for Families, Houston, TX.

Mar, H. (1998). Psychological Evaluation of Children who are Deaf-Blind: An Overview with Recommendations for Practice. DB – LINK: The National Information Clearinghouse on Children Who Are Deaf-Blind.

Wolf- Schein, E. (1998). Considerations in assessment of children with severe disabilities including deaf-blindness and autism. International Journal of Disability, Development and Education, 45, 35-55.

PSYCHOEDUCATIONAL EVALUATION OF CHILDREN WITH CHARGE SYNDROME

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"Is it possible to accurately assess a child who does not see or hear, who has had so little exposure to intensive language stimulation that his or her primary means of communication is nonspeech vocalizations, body expression, and approximately 20 manual signs? Are there clues that would tell you he could learn given the right approach? Is it possible that the use of totally inappropriate assessment tools has added significantly to the attitude that this is not only an untestable child, but an unteachable one?"(Wolf-Schein, 1998).

Under special education law, all children must have an appropriate evaluation in order to be identified as eligible for special education services. The evaluation also serves to identify a child's learning difficulties. During the evaluation process, information will be obtained about a child's present abilities. This information will assist the school team to understand how the child learns, and to plan for his or her educational program. This evaluation should drive the goals and objectives included in the Individualized Education Plan (IEP) or the Individualized Family Service Plan (IFSP).

The Individuals with Disabilities Education Act (IDEA) requires that the assessment be conducted by a Multidisciplinary Team. This means that individuals with different areas of expertise should be involved. The team is often led by a school psychologist. Testing procedures used by schools must meet the following requirements (Anderson, Chitwood, & Hayden, 1997):

- The tests and evaluation materials are administered in your child's native language and primary means of communication.
- The tests must be professionally approved for the specific purposes for which they are used.
- The tests must be given by trained professionals according to the instructions of the publishers of the tests and materials
- Tests and evaluation materials that assess a wide range of educational and developmental needs and capabilities should be used in addition to tests designed to provide a single general intelligence quotient.
- Tests should be selected and administered so as to ensure that they accurately assess the child's aptitude, achievement level, or other factors they are designed to measure, rather than reflecting the child's disabilities.
- The evaluation should be undertaken by a team or group of persons from several professional backgrounds, including at least one teacher or other specialist with knowledge in the area of your child's suspected disability. Your child should be assessed in all areas related to the suspected disability, including, where appropriate, health, vision, hearing, social and emotional status, general intelligence, academic performance, communication skills, and motor abilities.

Depending on the child's age and overall level, assessment can take place in the home, school, or both. Assessment at home may take the form of the examiner making general observations, and asking questions of parents, or the examiner may enlist help from parents to administer test items, so that the best performance possible may be obtained from the child.

One alternative way for examiners to evaluate students with more severe disabilities is through the use of "portfolio assessment". This may include review of the child's records, review of the child's current developmental milestones, and review of the child's progress toward current goals. It will include teacher and parent interviews. Also included may be functional assessments of vision, hearing, and communication.

General Tips for Parents:

- Ask for an evaluation meeting with the team prior to the assessment to determine the focus of the evaluation. Evaluation should be driven by questions the educational team has, and not by "what seems like the best test battery to use". Once the team decides what questions they want answered, finding appropriate ways to get these answers during the assessment is much easier. Assessments need not be tests that yield standardized scores. More often than not, IQ testing for a child with CHARGE will be inappropriate, because of vision and hearing losses. An IQ score that is inaccurate tells you nothing about how the child learns, and may lead to an unnecessary and inaccurate label of mental retardation. *"A standardized test score is like a drive-by shooting."***--Whose quote is this???**

- When you can be present during the evaluation, be sure to watch for your child's fatigue and stress levels. It will help if you can give your child some time to become familiar with the examiners. If allowed, observe the assessment session. Note how well you think your child did, and let the examiner know what you see. You know your child best, and this information will be valuable to the assessment.

- Contribute to the assessment process as much as you are comfortable. Information you provide about your child's abilities, temperament, and medical issues will help the examiners to make sense of assessment information. The examiners may have specific questions for you or evaluation instruments for you to fill out on your child.

- Ask the examiner about his or her familiarity with CHARGE, with vision and hearing impairments, and with deaf-blindness, if appropriate. It may be helpful to connect the examiner with the CHARGE Syndrome Foundation, or with your state's deaf-blind technical assistance center.

- Mar (1998) has developed a "Consumer Test" of assessment outcomes (see next page). This is perhaps the most important set of questions to consider when your child is evaluated. It is from the child's viewpoint. It may be useful to share this list with your child's evaluation team.

CONSUMER TEST OF ASSESSMENT OUTCOMES

1. **Will the evaluator be able to describe sufficiently my competencies and the ways that I best communicate?**
2. **Will the assessment indicate what progress I have made?**
3. **Will the assessment be used to determine my needs, desires, choices, and interests in everyday situations and settings?**
4. **Will the assessment help my family, teachers, and schoolmates to interact with me better?**
5. **Will the assessment lead to interventions that make sense to me?**
6. **Will the assessment identify the services and help I really need?**
7. **Will the assessment help other people who work with me?**
8. **Will the assessment contribute to the long-term plan?**

For more information on psychoeducational evaluation and assessment, consult the following references:

Anderson, W., Chitwood, S., & Hayden, D. (1997). Negotiating the Special Education Maze: A Guide for Parents and Teachers, 3rd Edition. Bethesda, MD: Woodbine House

Hartshorne, N. (1999) The prevalence of mental retardation in CHARGE Association. Paper presented at the 4th International CHARGE Syndrome Conference for Families, Houston, TX.

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Wolf-Schein, E. (1998). Considerations in assessment of children with severe disabilities including deaf-blindness and autism. International Journal of Disability, Development and Education, 45, 35-55.

INDIVIDUALIZED EDUCATION PROGRAMS (IEPs)

INDIVIDUAL FAMILY SERVICE PLANS (IFSPs)

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By law, through the Individuals with Disabilities Education Act (IDEA), any student receiving services through special education must have an IEP or IFSP. These are plans developed by the educational or early intervention team serving the student. Parents must be included in this team, and in all decisions made about the child's education, by federal law. IEPs will include the following components:

- A description of the student's present levels of performance in several areas
- Annual goals for the student and short-term objectives to help them meet those goals
- A description of the specific special education services and related services the student will receive and where and when they will take place
- When the services will start and how long they will last
- How the student's progress on the goals and objectives will be evaluated

An IFSP is written for infants and toddlers and their families, and will include goals and objectives for both the child and the family to assist the child with early development, as well as a plan for transitioning to school-based services after age 2. This plan should always be developed in a family-centered way, meaning professionals make certain the family's priorities come first. For a child with CHARGE, assistance with case coordination (coordinating between medical and educational personnel) may be a high priority. The following components are included in an IFSP:

- A description of your child's development
- Your family's concerns and needs
- What your family hopes and dreams for your child
- What services your family needs to realize these dreams
- In what environment will the services be delivered?
- What other services are needed by your family?
- When will these services begin, and how long will they last?
- Who will coordinate the services?
- What is the plan for transition to school-based services?

These plans are written to assure that each child with a disability will receive a *Free Appropriate Public Education (FAPE)*. This means that public schools are required to provide special education services to a child with disabilities, even if the child attends a private or residential school. Appropriateness is decided upon by the educational planning team, which includes the parents. This team of people designs an individualized plan for the child, based upon the child's needs. This plan is written in the IEP or IFSP document. Related services are also available to students with disabilities, based upon educational need. Related services can include the following, and any or all of these should be considered for a child with CHARGE:

- assistive technology
- audiology
- counseling
- occupational therapy
- parent training
- physical therapy
- psychological services
- recreation
- school health services
- social work services
- speech and language therapy
- transportation
- vision or hearing services
- orientation and mobility

For children under age two, services may be a bit different, and may be provided by an agency other than the school system, such as health departments. However, you and your child will be served through these agencies by specialists in the area of infant and toddlers development.

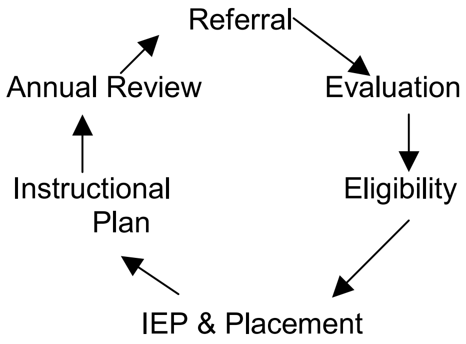
IDEA also requires that students be served in the *Least Restrictive Environment* (LRE). This means that students with disabilities are guaranteed equal access to education, and must receive education where they are least restricted from peers without disabilities. Each IEP team determines how much time the child will spend being educated alongside peers without disabilities. “Students are to be educated in a separate classroom or school only when the nature and severity of their disabilities makes it impossible to meet their educational needs in a less restrictive environment.” (Anderson, Chitwood, & Hayden, 1997). This part of the law is what has led to the recent movement toward inclusive education for children with disabilities.

At age 16, a student’s IEP must include a plan for transition. This can be devised and included as early as age 14. This is most easily accomplished through the use of person-centered-planning techniques. These are a set of activities centered around the student, which take into account the student’s needs, preferences, and interests when planning for the future. Desirable outcomes of a good transition plan can include:

- post-secondary education
- vocational training
- integrated employment (including supported employment)
- continuing and adult education
- adult services
- independent living (including supported living)
- community participation

It is important that a student’s program be written before a placement decision is made. It is somewhat typical of school districts to automatically group students into classrooms that match the students’ labels. For example, a child with autism could be placed in a classroom for children with autism, based on the label, instead of looking at that child’s specific needs, first, and then deciding upon where those needs can best be met. It is important to keep in mind that the label placed on your child should never solely determine their classroom placement. The school team must look at your child’s individual needs, first.

Anderson, Chitwood, & Hayden (1997) refer to the “school system’s cycle” for special education services. In general, it works like this: The cycle begins with **referral** of a student for special education services. The student then undergoes **evaluation** to determine if he or she meets **eligibility** requirements to receive services. If eligible, an **IEP** convenes, and **placement** decisions are made. From the IEP, **instructional plans** are made and carried out during the school year. Each year, an **annual review** IEP must be conducted to review the student’s progress on goals and objectives, and to revise the instructional program. Every three years, a re-evaluation of student eligibility and needs takes place. This is generated by a new **referral**.



Due Process
IDEA grants each child with a disability the right to legal “Due Process.” More specifically, the following steps are required of school districts:

- Provision of A Free Appropriate Public Education (FAPE) is provided for all children with disabilities between the ages of 3 and 21 in most states
- Children are educated with their peers without disabilities to the maximum extent possible
- Specially designed educational and related services, designed to meet the unique needs of the child, must be written in the IEP
- Parental consent must be obtained before an initial evaluation or a first placement in a special education program takes place
- Reasonable notice must be given to families before an evaluation, placement, or change of placement takes place, or when the school district refuses to carry out these actions
- Evaluations must be carried out by a multi-disciplinary team, including one specialist knowledgeable in the area of the student’s suspected disability
- Tests used for evaluation must not be discriminatory
- Parents may inspect and review all records
- If parents disagree with evaluation results, the school district must pay for an independent evaluation if requested
- If parents believe their child’s rights have been violated, an impartial due process hearing may be requested

Your child’s Due Process rights can empower you to advocate for your child’s best interests.

Finally, here are a few useful tips to consider when preparing for your child's IEP:

- Take a photo of your child with you and place it on the table at the meeting where everyone can see it. This will help to keep the focus on your child as an individual.
- Take an advocate or friend with you. IEPs can be intimidating to parents, with many professionals with professional opinions sitting around a table telling you what they think is best for your child. Just having a friend along to sit next to you and help you listen or take notes can give you more confidence to say what is on your mind and advocate for your child's needs and rights. Alternatively, ask another parent of a child with a disability who has "been there" to attend the meeting with you, and to speak up when they feel advocacy is needed.
- Be assertive, but not aggressive. Repeat yourself concerns if you feel they are not being heard. As difficult as it is not to become very emotional during these meetings, try not to lash out in anger at the team. You are going to have a long-term relationship with these people, who will be teaching your child. It is better to calmly state your concerns, know your rights, and remember that you are the utmost authority on your child. You know your child better than anyone!
- Trust yourself. Trust your instincts. As a parent of a child with CHARGE, you have a wealth of knowledge and are the person most invested in your child's future.
- If, after discussion and advocacy, you do not agree with what is being written in the IEP, you may, on the document itself, indicate your disagreement and either request further discussion, mediation, or a due process hearing.

To read more about IEPs, consult this excellent and user-friendly resource:

Anderson, W., Chitwood, S., & Hayden, D., (1997). Negotiating the Special Education Maze: A guide for Parents and Teachers. Bethesda, MD: Woodbine House

DOS AND DON'TS FOR EDUCATORS

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HOT plus DOG does not equal HOTDOG

DEAF plus BLIND does not equal DEAFBLIND

DO build a relationship with the child. The child that does not trust you cannot learn from you.	DON'T assume that what works for other children will work for this child.
DO celebrate progress, however small.	DON'T underestimate child's ability to learn.
DO help the child develop a positive outlook on life and love learning.	DON'T get so focused on what the child can't do that you fail to see what the child is can do.
DO remember that ***ALL BEHAVIOR IS COMMUNICATION***. (See: "Behavior as Communication")	DON'T assume a child has to speak or sign words in order to communicate. Body language, facial expressions and gestures can speak volumes. In fact, an infant' s understanding of spoken words is based on reinforcing naturally occurring babbling like "mama" or "dada." Likewise, a deaf child's naturally occurring gestures like the thumb of a flat open hand touching the chin or forehead are also reinforced to mean "mama" or "dada."
DO work with parents as partners. Enlist the help of parents to get at the likes and dislikes of the child so the entire team can build on naturally occurring communication.	Don't ignore the parents or belittle their contributions and observations.
DO become familiar with both hearing and vision loss as well as the definition of deafblindness.	DON'T assume that a child with both vision and hearing loss can be served by adding the techniques suggested by the teachers of the deaf/hard of hearing to those by the teachers of the blind/visually impaired.

DO get on the child's "radar," i.e. be sure to communicate within the child's "communication bubble." (See Communication)	DON'T assume a child sees clearly just because he/she can follow movement or understand what you say just because he/she turned toward your voice.
DO understand the significance of medical problems.	DON'T let all the medical "stuff" hinder interaction with the child. These kids don't break. Let the nurse or personal care attendant worry about the whistles and buzzers.
DO teach functional skills.	DON'T teach skills in isolation.
DO teach experiences from beginning to end.	DON'T expect the child to get more too 10-15% by incidental learning. A child who is DeafBlind may think that people and objects appear and disappear by "magic."
DO help the child learn to anticipate what is coming using touch cues, object cues, calendar boxes, etc.	DON'T surprise the child by suddenly picking up the child, taking toys away, putting something in the mouth, suctioning, etc. without letting the child know what is going to happen.
DO find out what the child likes and does not like so they can learn about motivation.	DON'T always expect a child to learn what you want him/her to like.
DO let the child make choices, get messy and learn about consequences.	DON'T make all the decisions <u>for</u> the child.
DO encourage and facilitate social interaction with peers.	DON'T shield the child from hurt feelings. He/she needs to understand what other children think, too.
DO encourage consistent and fluent communication between the child and every person who is in constant contact including parents, nurses, teachers, siblings, interveners, etc.	DON'T assume the responsibility of communication <u>for</u> those people.

DO LOVE THESE KIDS BECAUSE THEY WILL LOVE YOU BACK!