

**Diagnostic Center, Southern California**

# **Delivering the Hard News Well: Your Child Has Mental Retardation**



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## Components of the Hard News Conference

The difficult task of informing families about intellectual disability (mental retardation) is best addressed by developing a systematic individualized protocol for each family. The protocol will serve as a guide to staff members who will be delivering the hard news. The following eleven documents have been prepared to assist staff in this process:

1. Introduction to Delivering the Hard News Well: Your Child has Mental Retardation
2. Delivering the Hard News of Intellectual Disability Well: A Meta-Message Checklist
3. Pacing a “Hard News” Session: Key Concepts for Communicating a Mental Retardation Diagnosis
4. Using Visual Supports to Communicate Development Patterns
5. Graphic Displays
6. Cultural Considerations in Discussing Mental Retardation
7. Reasons to Accurately Identify Intellectual Disability
8. Rationale for Delivering the Hard News: A Case Study
9. Educational Definitions
10. AAIDD Definition of Intellectual Disability
11. Family Support Recommendations

## Part 1:

### **Introduction to Delivering the Hard News Well: Your Child has Mental Retardation**

*Diana Browning Wright, M.S. and Nancy Gronroos, M.S.*

Your child has mental retardation. Saying these words for the first time to a family is probably one of the most dreaded responsibilities for school psychologists and special educators.

The term “mental retardation” has become so painful that there is now a strong movement to change the terminology. For example, the American Association on Mental Retardation (AAMR) officially changed its name to American Association on Intellectual and Developmental Disabilities (AAIDD) in 2007. “Intellectual disability” is becoming widely accepted and is often preferred by families and professionals alike.

Even though the label applied may change, the significance for parents and children will not. Delivering and receiving the message will remain a painful experience.

Informal discussions with our colleagues suggest a need for additional training devoted to the issues, techniques and communication strategies necessary to skillfully give this message. Although school psychologists and special education teachers learn the technical skills for making the diagnosis in university training programs and through mentorship on the job, there also remains a need for research and systematic training on best practices in actually communicating the diagnosis and necessary supports. (See: American Association on Intellectual and Developmental Disabilities (AAIDD) for clarification of environments and supports.)

In our reading and discussions with colleagues, these questions have repeatedly arisen: How do we effectively deliver the message? When should we do it? Do we really have to do it? What is the fallout from doing it well versus doing it poorly? Through dialogues with families who have received the message in skillful ways, and with those for whom years of accumulated rage and pain have ensued following poorly delivered messages, working tenets have emerged that are embodied in the following articles. They have been many years in the making as the writers have struggled with the issues of honesty, compassion, skills, and background knowledge necessary to perform this critical service. They are offered here not as solutions, but rather as beginning points to stimulate discussion with your peers and supervisors, self-reflection and the desire for further study.

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## Part 2:

### Delivering the Hard News of Intellectual Disability Well: A Meta-Message Checklist

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'Delivering the 'hard news' of intellectual disability (also known as mental retardation) requires the informant to be fully present. This experience may, in retrospect, come to be a peak experience for better or worse for this family, remembered in detail all their lives. Scripts to aid in this process can be helpful, but more importantly the following core values, the 'meta-messages' underlying the body language, voice tone and actual words of the informant, must ring loud and clear throughout the session. The following affirmations can be helpful to review immediately before beginning a meeting in which family members are informed of the child's mental retardation.

- I respect *your* right to hear this news in private, not in a large impersonal meeting, and to express however *you* feel about this openly with me.
- I care about *your* child – this is hard for me to say and I know, hard for *you* to hear.
- I know the delightful human being *your* child is, and can give *you* examples from my experience.
- I know the limits of prediction and will neither over or under play what I know.
- I will make the news comprehensible to *you* and *your* family, with concrete examples of why I believe the diagnosis is correct, and I will not bury the news in jargon or euphemisms or metaphors to pretend the significance is less than it really is.
- I will make myself aware of cultural, ethnic, racial and social and economic differences between myself and *your* family and will seek to communicate in ways that bridge those differences with sensitivity and compassion.
- I honor *your* right to be overwhelmed by this message, and to express grief, anger, denial and even despair without being overwhelmed myself by *your* feelings.
- I can handle *your* reaction and will not break my compassionate stance no matter how *you* respond.
- I respect *your* right for a 'second opinion' and will not alter my compassionate stance because *you* ask for one.
- I know *you* may have questions, and I have time or will make time to answer them non-defensively.
- I know *you* exist in a context and I am available, if *you* ask me to help *you* problem solve how or if *you* tell others about this.
- This is the same child-before this news as well as after this news and I promise to remind us of this fact before the session is over.
- Your child is a human being to cherish and support.
- Your child can learn, make *you* proud of accomplishments and bring *you* happiness.
- Your child can be a great teacher for *you* and all who meet *you* and *your* child.
- We can work together, hand in hand, to help *your* child achieve maximum independence and quality of life.

## Part 3:

### **Pacing a 'Hard News' Session: Key Concepts for Communicating a Mental Retardation Diagnosis**

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#### **Prepare to Deliver the News**

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1. **Prepare to embody the core meta-messages** from the attached checklist in all that you convey.

*Under stress, people read your underlying intent more than the words themselves.*

2. **Don't speak fast**, or convey your need to “hurry up.”

*Time spent now can reduce or eliminate future family/school discord.*

*This is likely to be a profound experience, remembered by the family all their lives.*

3. **Watch your body language:** Lean forward, sit side-by side or within touch if sitting at a table. If appropriate, touch the parent gently on the shoulder or hand at least once during the session (bear in mind gender differences/similarities, cultural, ethnic and economic disparities that influence comfort levels and formality/informality needs). Remember to hug, or use a firm, two handed handshake for closure if you perceive that the parents are receptive.

*Appropriate touch can convey connection and compassion which allows the listener to attend to the message more completely.*

4. **Use the parents' and child's names** throughout the session after soliciting input on how they would like to be called (do not assume you know whether formality or informality is most comfortable).

*Personalization leads to a sense of connection, making the message easier to hear.*

5. **Try to get both parents at the conference** if at all possible.

*This message will be very hard for one parent to convey to another at a later date.*

6. **Prepare yourself.**

*Be ready to be fully present, undistracted, empathic and compassionate. Remember, you are in some way contributing to the death of their hopes and dreams for their child. Simultaneously, remember that mental retardation is only one feature of this child; other individual characteristics and strengths also need to be discussed. The purpose of telling the family this news is to prepare them for full participation in the on-going designing of supports for their child in a variety of environments. You don't want to over dramatize this label, but you want to be sure the family knows all that you know about this child and his or her needs for supports.*

7. **Never deliver hard diagnostic news in IEP meetings with large numbers of people,** or in meetings in which the parent(s) are suppose to choose programs, attend to goals and objectives or plan for the future of their child.

*A lack of sensitivity conveyed by delivering hard news in large groups will haunt you, the family, and the district/family interactions for years to come. Ongoing discord can often be traced to this meeting if insensitivity characterized the encounter.*

8. **Remember what you are trying to do: Give parents information about what we know about the child that is compassionately delivered, comprehensible by them and respectful of current and future adult/child mutual attachment issues.**

It is important for parents to hear that their child will continue to learn and acquire more skills, although their thinking will not be fully mature. Point out the qualities their child has that support participation in home and community life, e.g., being responsible, working carefully. The term “intellectual disability” may be introduced. This term has gained wide acceptance and is often preferred by families and professionals alike. It may be used in the discussion once it is clear that the parents understand the nature of their child’s disability and the need to carefully plan for supports in a variety of current and future environments. (See: American Association on Intellectual and Developmental Disabilities (AAIDD) for clarification of environments and supports.)

Encourage parents to ask questions. Ask them whether the diagnosis is surprising to them, but do not argue with parents who disagree with the diagnosis. Point out that regardless of the diagnosis given, the child they are taking home is the same one that they know and love. Mention comments the parents have made or interactions observed that show their current awareness and sensitivity to the needs of their child. Indicate that the important thing is for their child to have the educational and emotional support he or she needs, and that adults respect the pace of their development. Parent support groups and Regional Center services are usually mentioned. For parents who are ready for contact with them, addresses can be given before they leave the session.

### Beginning the Session

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- Friendly greeting** of the parent

**Sample script:** *“Come on in! I am so please you were able to come to this meeting. May I get you a cup of coffee?”*

- Tell something endearing** about the child that occurred during the assessment process. The family will be 'hearing' your degree of connectedness to the child, and your degree of appreciation of the child's unique and loveable characteristics. This message is hard to receive if the family does not believe you know and care for this child.

- Briefly summarize** the assessment process, reminding the family of the information they gave for the adaptive behavior scales. Compare and contrast adaptive behavior results with what you saw (behavioral observations during assessment, in the classroom, in the home, etc.) and results you obtained during testing or structured observation.

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## Transition to the 'Hard News'

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Not all parents need to be prepared for the gravity of the diagnosis you are about to discuss, having already raised the issue. Other families benefit from a clear transition message before beginning the "hard news." This decision is often based on the informant's sense of the parents' awareness of their child's functional skills in comparison to age mates. The informant has likely gauged the degree of preparation to hear this news from information given by the parents during the adaptive behavior interview. If it appears the parents have not yet realized the implications of their child's skills in relation to their peers, use of a transition message before discussing the diagnosis can be helpful. If you elect to use a transition message, some informants have found it helpful to set the message clearly apart from the previous discussion in order to prepare the family.

The key underlying message, however you phrase it is: **Something of gravity is coming that I don't take lightly and don't expect you to take lightly either.**

*"Mr. and Mrs. Owens, I have something to talk with you about now, that I have not looked forward to saying, and I imagine will be hard for you to hear. But I don't feel it is 'ok' for me to know something about Oliver that I do not share fully with you. We all need to have the same information to be able to do our best future planning for Oliver's education."*

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## Now: Deliver the Hard News Well

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- Next, give the implications** of the test results/adaptive behavior/information you just finished talking about. (This step follows the summary of the assessment process, or if you have elected to give a transition message, immediately after that message.)

**Sample script:** *"So, Jane and Roger," we see that Tiffany has some real strengths, and some real weaknesses in her skills that she demonstrates at home in your family, in the community, at school with her classmates, and when she takes formal tests. Overall, you stated that she seems like a child of about 5 to you when compared to other children you know. The assessment team saw her as having approximately 4 year old skills overall. We are all pretty close. We are in agreement that she is progressing at a much slower rate than her classmates in all areas. The implication of this is important for us to talk about now, Jane. (Lean forward with supportive eye contact) Tiffany is a little girl who we can say has intellectual disability. The more common term for this is 'mental retardation.'"*

- Present the diagnosis** as it contrasts with other less exact terms.

**Sample script:** *"Sometimes we hear people using other words to describe 'mental retardation.' You may have heard some: developmental disability, developmental delay, having significantly below average cognition, and so forth. I prefer the term 'intellectual disability' because there aren't as many preconceived beliefs about it as with the term 'mental retardation.' The term 'delay' makes it seem like the child will someday catch up, which isn't accurate."*

- ☑ **Ask for clarification. "What does the term 'mentally retarded' mean to you?"** Don't assume parents are aware of the impact of the diagnosis, degree of needs or future issues. You need to probe the parents' understanding and feelings about the diagnosis. Answer questions with clear conveyance that you know the limits of prediction.

**Sample script:** *"Mrs. Jones, when you hear the words, 'intellectual disability' or 'mental retardation,' what do they mean to you?"*

**Sample clarifying script:** *"Kiko, although we don't have a crystal ball, here's what I know in my experience, and in all that I have read or heard: Yu-kun is 9 years old, yet has skills similar to 5 year olds. We have never seen children of his age, with this rate of progression 'catch up' to his classmates in the way he problem solves and reasons about the world around him. I would of course be thrilled if it ever occurred. But what we do know is this: Yu-kun needs us to think very seriously about what goals we have for him, and what the next steps are to teach him the skills he needs to be as independent as possible in the future."*

- ☑ **Clarify and contrast: what it does NOT mean with what it DOES mean.**

**Sample script:** *"Brendan can and will continue to learn and add to his skills. But, from what we know about how children develop, we believe Brendan will not understand the world and solve problems in a fully adult way. He can love and be loved, and we do expect he will be able to have a job and contribute to the world around him. However, Brendan is likely to need additional support for certain activities and in certain environments. In some environments, he may need a lot of adult support, whereas for other situations he may need very little help. The supports he needs, will depend on the demands placed on him in a specific environment. You may wish to make use of community or public agencies that are out there to help Brendan, in addition to resources in the school district. Our goal is to help Brendan be as independent as possible as an adult."*

- ☑ **Use person-first language throughout the session.** This entails always appending the term; for example, rather than saying "mentally retarded child" or "intellectually disabled child," say "child with mental retardation" or "child with intellectual disability." This distinction is important. Mental retardation or intellectual disability are descriptors of the person and do not in any way summarize who this person is, nor define him or her totally. Families are very sensitive to this issue, as well they should be.

**Sample script:** *"Children with intellectual disability often require supports when..."  
"Adults who, like Johnny, have intellectual disability have successfully..."*

- ☑ **Reference causation** and lay to rest any ideas about "who is to blame" if, in this case, it is possible.

**Potential Script:** *"Some parents I know tell me the first thing they thought about when hearing about their child having intellectual disability is, 'I caused this.'" (WAIT FOR RESPONSE.) What we know from years and years of research is that this can happen in any family, and most often we can not find any cause. Sometimes we can figure out what happened to cause a child to not develop normally, but most often we can't. It isn't something you did, or didn't do, Maria."*

- ☑ **Use “active listening skills.”** Wait, wait and WAIT. Allow the parent to lead the discussion forward. Do not be defensive or undone by the responses: grief, denial, shock, anger, guilt. Your job is not to force acceptance, your job is to continue to use active listening, conveying confidence, competence and compassion. Your job is to be honest and compassionate, focusing on the unique characteristics of the child, not over emphasizing this label.

**Sample Script “for anger and denial”:** *“Mr. and Mrs. Chen, I know this is hard to take in. I have had quite a bit of experience working with children like Philip (or if you are a beginning psychologist: I have had quite a bit of training on how to make this determination), but no one can deny you know your child better than anyone. You can take this information I needed to tell you and put it away for now. That’s okay. For some families, that is the best next step. If you find out later your child needs extra services, you’ll know about agencies and services that can help him. He is such a wonderful little boy and we do so enjoy working with him. You have provided such a warm and loving home for him.”*

- ☑ **Bring up the family context.** *“Are there people you want to tell about this: grandparents, family friends, aunts/uncles, brothers/sisters? Can I help you in any way with this process?”* Convey understanding that telling, or not telling others is equally valid.

**Sample script:** *“Some families tell me that one of the hardest parts of hearing this news is figuring out what, if anything, they want to say to grandparents, aunts, uncles, neighbors, people in the grocery store, and so forth.”* WAIT FOR RESPONSE.

- ☑ **Give some ideas of the future.** Some families may ask for even very distant future predictions, even in very young children (employment, driving, where the child “must” attend school, marriage, independence, etc.) Remember, understanding of the impact may require clarification. Do not make assumptions. Allow parents to lead, giving them the information they seek. Do not offer more than they request.

**Sample script:** *“I want to tell you what we have learned about Billy’s strengths, as well as the supports we think he needs. Your delightful son needs us to carefully consider both how to use his strengths and what supports will help him learn best and be successful, now and in the future. We want him to have what he needs for a high quality life.”*

**Sample script:** *“Does this mean an automatic special school or class for Fletcher?” “No it does not. We will all meet together at the IEP meeting and decide what Fletcher is ready for next. He can stay with the group he is with now, or we may all decide it’s time for us to look around for other services and places to meet the goals we all want to focus on to help Fletcher achieve. You will always maintain your role: helping us understand Fletcher better. We’ll work together, Alison, just like we have in the past.”*

- ☑ **Allow the family to continue leading the discussion,** talking out their understanding of what they heard. Use your “active listening skills” to extend the conversation and promote the parent as the acknowledged leader of this interaction.

## Transition to Conference Ending

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### Tell what comes next:

1. **Going home** (It is critical at this step to refer to the fact that the child is no different than before the message and to let the parents know you are available by phone.)

**Sample script:** *“When you get home, Mrs. Jones, and you think back on all we’ve talked about, there is something you may wish to remember that another mother told me. She tells me that she was very overwhelmed later at home, but her little boy came up and climbed on her lap and said, ‘Can you play yet, Mom?’ At that moment she says she realized something very important: her son was the same son she had always known. He hadn’t changed; she had just come to a new understanding of what he might need in his life. ‘If you think of something you want to talk about, you’ve got my phone number. Please just give me a call.’”*

2. **Coming back** (Let the family know that the upcoming IEP meeting is to collaborate and plan next steps, not to repeat this session.)

**Sample script:** *“At the IEP meeting in two weeks there will be myself and... (State who and their positions) I will need to tell them all briefly about Billy’s assessment results. You will hear me use the terms ‘mentally retarded or intellectually disabled range’ or once or twice as I share what we know. But then, we will immediately start talking about next learning steps we feel Billy is ready for. We will ask your advice on what you would like to see next for Billy, and we will share with you what we think should be next. Together we will make decisions about our teaching goals for him. Please, Mrs. Wright, if you think of any questions, jot them down, or anything you would like us to know. Remember, you can bring anyone you would like with you. Some families choose to bring a friend, a parent, a brother or sister. This is fine. Some people choose to make an audio (or video) recording about the meeting so they can share it with family members who weren’t there. This is fine as well. Just let us know in advance so we can plan room arrangement, etc.”*

3. **Give a general idea of what you will contribute** (ideas on next-step goals, agencies and information sources family may wish to pursue)

**Sample script:** *“Arturo, by the time you come back for the IEP meeting, I can have a list of resources you may wish to keep in mind for Miguel. There are books, websites, parent groups and agencies that can be of help to you and Miguel as he progresses. We will also tell you about the Regional Centers. These are California agencies for persons who have developmentally disabilities. They provide a lifetime of support opportunities for children they determine to be eligible. They can provide help getting a job, help finding living arrangements, and, in general, help the person be as independent as possible...” (Mention respite, in-home behavior management, funding for diapers, estate planning or any other of the services you think the family will want to know about).*

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## Ending the Session

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- ☑ **Stand up, then** contrast hearing these findings unprepared, in a meeting with lots of people, with what has just transpired. This can be very helpful in forming a good future working relationship with the family, regardless of the reaction of the parents when they heard the news. If you used a transition phase to delivering the hard news, **restate** how hard this was to say, and to hear.

**Sample script:** *"Mr. and Mrs. Sanchez, I'm glad we had the opportunity to meet together before the upcoming IEP. I wouldn't want you to hear this for the first time at that meeting. Thank you so much for coming in today. (I know how hard this meeting must have been for you. I know this was certainly hard for me to tell you."*

- ☑ **Physical closure:** Offer a two-handed handshake, hug, or very brief physical touch if appropriate to the relationship you have established, recognizing the cultural, ethnic and other boundaries that may need consideration.

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## Final Note

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The above pacing guide is based on years of delivering this message on a nearly weekly basis to families with different characteristics. Bear in mind: no one script will work for all families; what would be appropriate for some would not work well with others. The most important thing to remember is the meta-messages. If you believe these tenets, you will find the words and develop the pacing that works best for you.

This guide was developed to assist you, the reader, in finding or clarifying your own "best practice." It can not be employed mechanistically, or by memorizing scripts. To do so would violate the tenets that are the underpinnings of this process.

We wish to acknowledge Deborah Holt, Diagnostic Center Director, who has generously supported and encouraged all our efforts, and justly deserves commendation for her leadership and emphasis on treating families with dignity, respect and sensitivity. The authors are indebted to Dr. Bonnie Kraemer, San Diego State University, for her insightful comments and critique of the process described in this paper. Additionally, we would like to acknowledge our colleagues at the California Department of Education, Diagnostic Center, South who have generously shared their experiences and helped develop this process. This protocol was first presented for a California Association of School Psychologist (CASP) Convention in 2001 which included: Judi Burkhartsmeier, Nancy Gronroos, Diana Browning Wright and our former colleagues Harvey Gurman and Brenda Steele.

## Part 4:

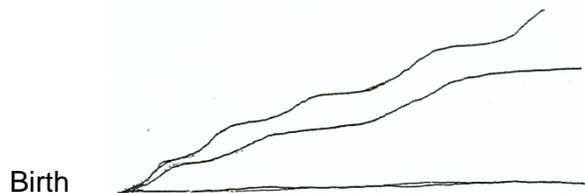
**Using Visual Supports to Communicate Developmental Patterns***Nancy Gronroos, M.S.**California Department of Education, Diagnostic Center, South***Discussing Discrepancies between Age Expectations and Actual Functioning**

A simple summary chart showing functional levels across several domains is often helpful when parents are unaware of how their child's development compares to that of age peers or the pervasiveness of the discrepancies. When results are reported as functional ages, it is important to keep in mind the normal age variation among children in acquiring specific skills. Sample graphic displays used in Simi Valley Unified School District with parents of infant and preschool children are attached.

**Explaining Declining Scores**

Earlier test scores may not have reflected intellectual disability, especially for young children. The decline in scores may arouse fears that the child is losing skills. If there is no evidence to support these fears, a simple diagram can help parents understand why the discrepancy often occurs, although there has been continued growth.

The rough drawing below illustrates the apparent similarity during infancy between typically developing children and those with disabilities, and the growing discrepancy with age. At birth and during the sensorimotor period, a child with a mild to moderate disability may function much like typically developing children of the same age. During the early childhood years, delays in the use of language are usually noted and the child may be considered communicatively handicapped. If standardized tests are used at this time, the child with a mild disability may perform within normal ranges, especially on perception-based nonverbal instruments. The normal developmental sequences are followed, but the child tends to acquire the skills associated with each developmental period at a slower rate, and to have more difficulty elaborating and applying them flexibly. Thus, over time, the widening gap is reflected both in test scores and day to day functioning. At some point, the child's reasoning style does not appreciably mature, but he or she continues to learn specific skills.



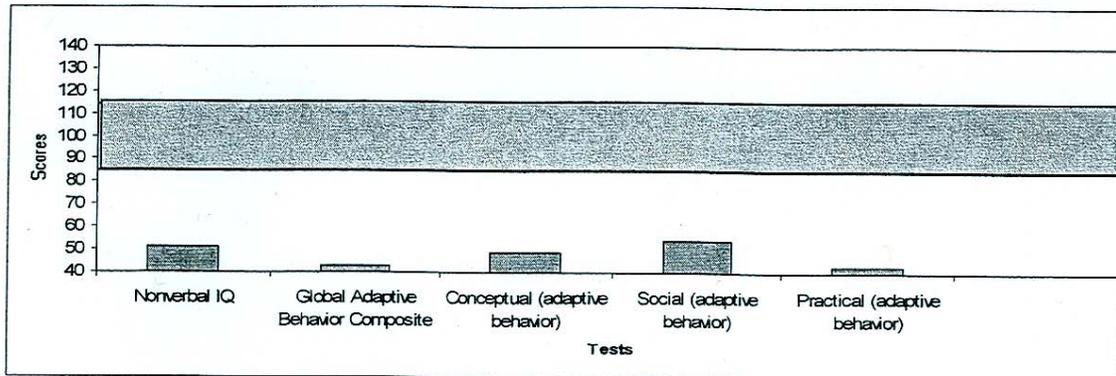
Discussion of the diagram and test results is somewhat different for a young child functioning in the mild range than for a child of eight or nine years or a more severely disabled child.

- For young children who appear to have mild retardation or intellectual disability, parents need to know that tests are not as reliable in predicting eventual functioning as they will be when their child is around eight or nine years of age. Their child's current learning rate, the way they understand the world, and their practical skills are like those of children with mild range intellectual disability. The gap between their age and expected functioning may decrease, increase, or maintain with time. By early elementary years, if there are not complicating factors such as a sensory disability or cultural/linguistic differences, it may be stated that most children do not "close the gap" with those whose development is following a typical course.
- For older children or those who clearly have intellectual disability, it is important for parents to understand that their child will continue to learn new skills throughout their lifetime, although at a slower rate. Their child's understanding of the world and problem solving will not mature to the level of typically functioning adults.

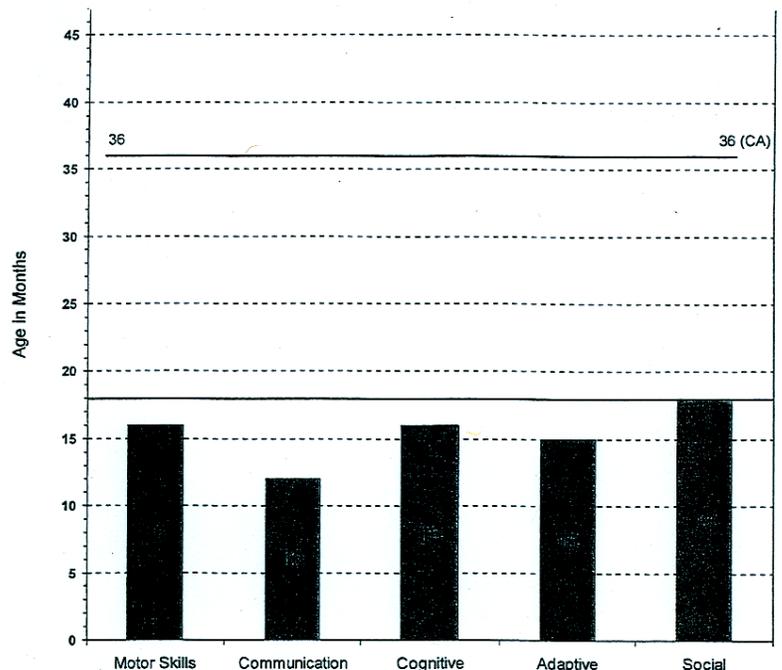
Part 5:

**Graphic Displays**

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Graphic display of standardized IQ score, Global and Domain scores for Adaptive Behavior for an elementary age student with mental retardation. Average range is noted by dark band.



Scores falling 50% below chronological age, or more, represent functioning that is severely delayed.

Graphic display of functional age scores from Team Assessment for preschool age child with mental retardation. Chronological age is noted by solid line, and 50% of child's CA is also noted by a solid line.

## Part 6:

### **Cultural Considerations in Discussing Mental Retardation**

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Working with parents who have different cultural traditions presents additional challenges. The school psychologist may not be familiar with the manners, expectations for professionals, values, and assumptions that are dominant in the parents' culture, especially in districts with great diversity.

#### **Working with a Translator**

When a second language is involved, a translator familiar with both the culture of the family and that of American educators can be invaluable. The translator can explain the expected courtesies in interacting with the parents, how mental retardation is likely to be viewed, and other cultural factors that may be significant during assessment and when discussing a diagnosis of mental retardation. Sometimes the parents offer to bring their own translator to the meeting; however, using a translator from the district is recommended. The parents may not anticipate a diagnosis of mental retardation. Having a family member or a person from their community hear this diagnosis may be humiliating.

Before speaking to the parents about the diagnosis, dialogue with the translator about the possible implications for the family, and how best to give the message with clarity and compassion. Discuss the importance of confidentiality regarding the child's diagnosis. The translator may dread having to convey to the parents that the child has mental retardation. Explore these feelings and any reservations and give support. Anticipate problems that may occur and possible responses. Practice what will be said when explaining the diagnosis to the parents. Emphasize the importance of an unembellished translation without interpretations or omissions. Parent comments should also be translated as precisely as possible. After meeting with the parent, discuss the translator's impressions of how the message was understood and received and whether follow-up contact with the parents prior to an IEP meeting is advisable.

#### **Visiting the Home**

If the parents are willing, including a home visit in the assessment process can help establish a positive relationship. The visit is evidence of desire to elicit the child's best performance by observing him or her in a comfortable, familiar setting. It permits the parents to show what their child can do, provide background information, and, in their own surroundings, discuss their concerns and hopes for the child. The psychologist can better assess the degree to which the child is meeting family expectations, the type of support caretakers use to elicit performance, and the stimulation offered in the environment.

#### **Recognizing Individuality**

Individuals do not always share the values and traditions associated with their ethnicity or nationality. As in the United States, values and traditions may vary due to factors such as religious beliefs, membership in subcultures, education, awareness of other cultures, and relative interest in assimilation versus maintaining one's own traditions. Some of the dimensions to be considered when establishing a relationship with parents of any ethnicity, including parents born and raised in the United States, include:

- Comfort with informality. The parents may regard being addressed by their first name as disrespectful. In some cultures there are rules about who should be greeted first and who may propose dropping formal titles. Casual dress may also lead to questioning of the examiner's professionalism.

- Amount of eye-contact that is considered to be courteous, and the degree of proximity and touching that is comfortable.
- Pacing. Many Americans tend to introduce the main issue rather quickly and directly. This approach may feel abrupt and even rude to people accustomed to conversing or leading up to issues indirectly.
- Comfort with self-revelation. Personal questions are considered intrusive by people of many cultures, here as well as abroad. Some districts use questionnaires designed for a medical/research model. Questions on parental behavior that will neither clarify the diagnosis nor lead to differential interventions should be omitted.
- Comfort with dialogue and joint decision making. Some parents expect professionals to make recommendations based on their specialized knowledge and are not comfortable with the degree of parent participation encouraged in most districts. Disagreement or reservations may not be openly expressed, but may be the basis for lack of follow-through. The advice and support of the extended family or community leaders may be more important than that of the assessment team.
- Showing emotion. Some parents may suffer deeply without outward emotional display. Stoicism does not necessarily mean the message was not understood.

### **Possible Outcomes**

Cultural factors influence the outcomes for the child that may not be anticipated or under the control of the assessment team. Some of these factors are:

- Belief in the cause of the child's disability. Attributions may include an accident of nature; genetic predisposition; the consequence of one or both parents' behavior; divine punishment for sins of parent(s), extended family members, or an ancestor; or even demon possession. Alternative viewpoints can be offered, but are not likely to change deeply held beliefs; professionals need to respectfully work with the parents, regardless. Some beliefs may work to the child's advantage. For example, parents who believe in divine punishment may also believe that caring for the child well will earn divine forgiveness.
- Belief in potential for change with interventions. Some parents may spurn offers of special education, believing in tutorial or religious interventions. Others with limited financial or emotional resources may commit them to their children without disabilities.
- Impact of child's disability on the family's standing in their cultural community. Because the marriageability of siblings may be affected, parents may reject services which would make it clear to others that their child has a disability.

Because of factors such as these, it is especially important to speak in terms of the support that the child is likely to need to maximize his or her future independence and of the educational and community resources available. The assistance of a translator should be offered to help the parents work with relevant public agencies. The phone number of a parent from the same culture who has a child with a similar disability and agrees to be a resource may be helpful. Psychologists will need to be informed about parent support groups offered in the parents' language. Possible resources are the offices of state and national organizations, and community service providers for children and adults with developmental disabilities.

## Part 7:

### **Reasons to Accurately Identify Intellectual Disability**

*Deanna Johnson, NCSP  
School Psychologist, Temecula Valley Unified School District*

Intellectual disability appears to be under-identified for various reasons, but probably mostly due to the significant stigma of the label. As an example of this, only 8 to 10 percent of students referred to the Diagnostic Center of Southern California are identified as having intellectual disability, while up to 40 percent, including students with autism, are ultimately determined to have that disability. Some reasons for giving an accurate diagnosis follow.

#### **Appropriate Expectations**

- Developing realistic IEP goals that can be achieved is important for both the student and for relationships between educators and the family.
- Having appropriate expectations for academic progress is beneficial for a student's self concept, and results in better adjustment and reduced behavior problems.
- The diagnosis helps educators understand a student's emotional functioning, attention span, and social needs.
- Addressing functional and social skills development is educationally essential but may be overlooked without accurate identification.
- Understanding the diagnosis may dispel anger and "blame" for the student's difficulties and allow collaborative planning to go on.

#### **Accessing Resources**

- Planning for vocational and independent living opportunities can occur earlier.
- Access to lifelong services from state agencies requires eligibility determination prior to age 18.
- Parents can more effectively advocate for their child's needs when they have this information.
- Having a diagnosis allows parents access to a wide range of support groups, websites, and other information sources.
- The diagnosis can facilitate appropriate treatment in the juvenile and adult justice systems.

#### **Professional Responsibility**

- Communicating accurately and completely with families is an ethical responsibility.
- Assessment of intellectual disability is the responsibility of school psychologists and can not simply be referred to medical practitioners for this purpose.

## Part 8:

### Delivering the Hard News: A Case Study

*Deanna Johnson, NCSP  
School Psychologist, Temecula Valley Unified School District*

As a psychologist working with secondary students, I have had countless experiences with identifying older students as having intellectual disability (also known as mental retardation). As with students at all ages, thorough assessment to identify a broad set of needs is essential. Many times students have been previously identified as having a learning disability, language impairment, or health impairment, rather than intellectual disability. Sometimes students have not received any special education or related services because they did not meet criteria for a learning disability due to a low IQ score, and no further assessment (such as consideration of adaptive behavior) was conducted.

The case of “Katie”, who was age 13 when first identified as having intellectual disability, illustrates the problem of using only a nonverbal score with a limited range of items to rule out mental retardation. In the younger age range, items on this type of test require mostly skills in matching to attain an average score; thus the tests do not capture broad measures of reasoning and problem solving ability.

#### Previous Assessments:

Note: Standard scores have a mean 100 and a standard deviation of 15 points.  
T-scores have a mean of 50 and a standard deviation of 10 points.

2003 ***Comprehensive Test of Nonverbal Intelligence (CTONI)***  
Standard Score: 86

Scores from the language assessment were extremely low

2006 ***Wechsler Intelligence Scale for Children, 4<sup>th</sup> Edition (WISC IV)***  
Full Scale Standard Score: 69

***CTONI***  
Standard Score: 80

#### Assessment of 2008:

Katie was referred for behavior problems such as agitation in class, hyperactivity, and social problems with peers in her Special Day Class

#### Cognition

***WISC IV***  
Verbal Comprehension Standard Score: 50  
Perceptual Reasoning Standard Score: 71

***CTONI***  
Standard Score: 68

#### ***Comprehensive Test of Phonological Processing (CTOPP)***

<i>Subtest</i>	<i>Standard Score</i>
Phonological Awareness	61
Phonological Memory	82
Rapid Naming	61

## Adaptive Behavior

### ***Behavior Assessment System for Children, 2<sup>nd</sup> Edition (BASC-II)***

Teacher Rating Scale	T-score: 40
Parent Rating Scale	T-score: 35

Significant for anxiety and depression

### ***Adaptive Behavior Assessment System, 2<sup>nd</sup> Edition (ABAS-II)***

General Adaptive Behavior Standard Score

Teacher Form	67
Parent Form	72

## Language measures

### ***Comprehensive Assessment of Language (CASL)***

Standard Score: 64

### ***Clinical Evaluation of Language Fundamentals, 4<sup>th</sup> Edition (CELF-4)***

Standard Score: 46

## Achievement

### ***Wechsler Individual Achievement Test, 2<sup>nd</sup> Edition (WIAT-II)***

<i>Subtest</i>	<i>Standard Score</i>
Reading	47
Word Reading	40
Pseudoword	67
Comprehension	40
Math/numerical Operations	61
Math reasoning	47
Spelling	60
Written expression	80

## **Conclusion:**

With comprehensive assessment it was clear that Katie's difficulties were much more pervasive than a language based learning disability. Comprehensive assessment included not only Katie's scores on traditional measures of cognitive ability, but also the degree of supports she needs in adaptive behavior for activities of daily living and community access. In spite of a few spikes in some areas, she was found to have an intellectual disability functioning within the range of intellectual disability. When her needs were properly addressed and expectations were based on her overall functioning, Katie's anxiety and depression began to resolve, as did her behavior issues. Parents, peers, and Katie herself observed positive educational results following the diagnosis and altered education programming.

## Part 9:

### Educational Definitions

#### **Federal CFR 300.8**

*Mental retardation* means significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.

#### **California 5 CCR § 3030**

(h) A pupil has significantly below average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affect a pupil's educational performance.

Under (j): (2) Intellectual ability includes both **acquired learning and learning potential** and shall be determined by a systematic assessment of intellectual functioning.

#### **34 CFR 300.304 Evaluation Procedures**

*Conduct of evaluation.* In conducting the evaluation, the public agency must—

(1) Use a variety of assessment tools and strategies to gather relevant functional, developmental, and academic information about the child, including information provided by the parent, that may assist in determining—

(i) Whether the child is a child with a disability under §300.8; and

(ii) The content of the child's IEP, including information related to enabling the child to be involved in and progress in the general education curriculum (or for a preschool child, to participate in appropriate activities);

(2) Not use any single measure or assessment as the sole criterion for determining whether a child is a child with a disability and for determining an appropriate educational program for the child; and

(3) Use technically sound instruments that may assess the relative contribution of cognitive and behavioral factors, in addition to physical or developmental factors.

### Resources

*Best Practices in Intellectual Assessment*, D. Reschly, & J. Grimes, Best Practices in School Psychology IV, Volume 2, p1337-1350, NASP Publications, 2002.

*Assessment of Children, Cognitive Applications, Fourth Ed*, J. Sattler, Sattler Publishing, San Diego, 2001.

*Contemporary Intellectual Assessment, Theories, Tests and Issues*, D. Flanagan, J. Genshaft & P. Harrison, Ed., Guilford Press, 1997.

## Part 10:

### AAIDD Definition of Intellectual Disability

Effective January 1, 2007 AAMR officially became the American Association on Intellectual and Developmental Disabilities (AAIDD). The American Association of Intellectual Disability is a professional organization that advances the knowledge and skills of individuals in the field of intellectual and developmental disabilities; strives to enhance the life opportunities of people with intellectual disabilities and their families; and to promote public policies, research, and services which advance individual choices and human rights.

**Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18.**

Intelligence refers to a general mental capability. It involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience. Although not perfect, intelligence is represented by Intelligent Quotient (IQ) scores obtained from standardized tests given by a trained professional. In regard to the intellectual criterion for the diagnosis of mental retardation, mental retardation is generally thought to be present if an individual has an IQ test score of approximately 70 or below. An obtained IQ score must always be considered in light of its standard error of measurement, appropriateness, and consistency with administration guidelines. Since the standard error of measurement for most IQ tests is approximately 5, the ceiling may go up to 75. This represents a score approximately 2 standard deviations below the mean, considering the standard error of measurement. It is important to remember, however, that an IQ score is only one aspect in determining if a person has mental retardation. Significant limitations in adaptive behavior skills and evidence that the disability was present before age 18 are two additional elements that are critical in determining if a person has mental retardation.

#### What is Adaptive Behavior?

Adaptive behavior is the collection of **conceptual, social, and practical skills** that people have learned so they can function in their everyday lives. Significant limitations in adaptive behavior impact a person's daily life and affect the ability to respond to a particular situation or to the environment. Limitations in adaptive behavior can be determined by using standardized tests that are normed on the general population including people with disabilities and people without disabilities. On these standardized measures, significant limitations in adaptive behavior are operationally defined as performance that is at least 2 standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, and practical skills.

#### Examples: Conceptual Skills

Receptive and expressive language  
 Reading and writing  
 Money concepts  
 Self-direction

Follows rules  
 Obeys laws  
 Avoids victimization

#### Social Skills

Interpersonal  
 Responsibility  
 Self-esteem

#### Practical Skills

Personal activities of daily living such as eating, dressing, mobility and toileting. Instrumental activities of daily living such as preparing meals, taking medication, using the telephone, managing money, using transportation and doing housekeeping activities.

Gullibility (likelihood of being tricked or manipulated)  
 Naiveté

Occupational skills  
 Maintaining a safe environment

## Part 11:

### **Family Support Recommendations**

Parents of newly diagnosed children need to know that there are good sources of information and support available to them. In addition to the address and phone number of the Regional Centers (California) or other providers (names will vary by state) that will directly give service to the family, contact information for local and national organizations is usually appreciated. Before passing on family service information, it is a good idea to check it, as organizations sometimes change names, contact information, or the nature of their services.

The following organizations offer information that is likely to be helpful to parents:

#### **American Association on Intellectual and Developmental Disabilities (AAIDD)**

444 North Capitol Street, NW  
Suite 846  
Washington, D.C. 20001-1512  
Telephone: 202/387-1968 or  
800/424-3688  
Fax: 202/387-2193

Web: [www.aaidd.org](http://www.aaidd.org)

This website will link to many valuable other sources of information.

#### **National Information Center for Children and Youth with Disabilities (NICHCY)**

P.O. Box 1492  
Washington, DC 20013  
Telephone: 1-800-695-0285  
E-mail: [nichcy@aed.org](mailto:nichcy@aed.org)

Web: [www.nichcy.org](http://www.nichcy.org)

This website will link to many valuable other sources of information.

[www.do2learn.com](http://www.do2learn.com)

Offers free and low cost computer learning games, picture cards for creating schedules and organizational tools, and suggestions for working with children with developmental disabilities.

[www.siblingsupport.org](http://www.siblingsupport.org)

Has articles of interest and listserves for both young and older siblings. Parents are welcome to monitor. On the homepage, click on Connect with Other Sibs, then SibKids Listserve for pre-adults or SibNet Listserve for adult siblings.