

CHAPTER 4

What's the Score?

Everybody gets tested and not many people like it. For families with children with Down syndrome, testing began at birth and never let up. When our children were born, one of the first questions we asked was, "What's the Apgar score?" Maybe before we even knew our child had Down syndrome, we might have fallen right into the testing trap. While some of us may have had a prenatal diagnosis, most of us wanted a score and we wanted to compare that score with the perfect score of 10. It is the rare infant with Down syndrome who gets the perfect score.

The testing continued relentlessly, with many tests comparing our child's development with typically developing children: the Bayley Scales of Infant Development, The Differential Ability Scales, Wechsler Preschool and Primary Scale of Intelligence, Wechsler Intelligence Scale for Children, Stanford-Binet: Fourth Edition, Woodcock-Johnson, Kaufman Test of Educational Achievement, Peabody Picture Vocabulary Test, and other measures.

We don't have to like it, but we do have to live with it. Everybody gets measured—with weekly spelling tests, math quizzes, final exams. Some of our children are judged by the SAT or ACT. During the transition years, some new tests and assessment tools may be used to test our children with Down syndrome. These tests will be used to determine eligibility for adult services, and, perhaps, to determine what kind of services your son or daughter receives.

Why Test?

I personally never liked it when my son was tested. It always served as another reminder that he had Down syndrome and was behind in some measure. It could be his height, head circumference, mean length of utterance, or even his ability to pick up Cheerios.



I knew he was delayed, yet I hated the endless reminders that the tests brought to my attention.

The cynic in me also knows that testing is a business. People make a living producing, administering, and interpreting tests. There are many types of tests and sometimes there are only small differences among them. There are many professionals licensed to give these tests—among them are psychologists, neuropsychologists, school psychologists, developmental psychologists, social workers, and others. The tests themselves are considered proprietary. That means that the product is owned by an individual or a company and is protected by trademark or patent. What that actually means to a family, with few exceptions, is that unless you are qualified to administer the test, you are not allowed to see it.

In fairness, however, there are several very important purposes for testing transition-aged students with Down syndrome. They are to determine:

- eligibility for services;
- level of services needed;
- career interests and abilities;
- readiness for postsecondary education or college.

Testing to Determine Eligibility for Services

As your child prepares to leave the school system, the state adult service agency will, in most instances, require her to undergo eligibility determination to see whether she qualifies for adult services. These services can include residential supports, employment supports, transportation, day programs, and service coordination. Even if your child received services as a child, from the very same agency (the Department of Developmental Disabilities, for example), she will most likely be required to undergo eligibility determination again.

For families of children with Down syndrome, this seems a little ridiculous. The extra chromosomes are still there, she still has Down syndrome, and many of you are thinking, “why can’t I just send a picture?”

The reality is that each state has criteria to determine eligibility. While some states determine eligibility once, usually when the individual first requests services, many use different eligibility criteria for children than for adults. Some states are more lenient in determining childhood disability than they are for determining adult disability. This is due to the wider eligibility for services under IDEA, in some cases.

The other reality is that some students make enough gains and progress in school that they no longer need services as adults. This is the basic premise for providing special education in the first place—so students receive the help needed to master the skills necessary to be successful as adults.

Since there are no separate eligibility criteria for individuals with Down syndrome, you can expect that your child will undergo an eligibility determination for

adult services. You should inquire with the appropriate state agency or with your school district as to the age this occurs in your state. In many states, it is at age 18. Test results from when your child was younger will not be considered in most situations, so don't bother getting your child tested at the earliest possible age in hopes you will somehow minimize the waiting for adult eligibility.

Although the overwhelming majority of people with Down syndrome will qualify for adult services, some of the most "high functioning" of our children may not be eligible. Eligibility usually is based on three factors:

1. Some states quantify it with an actual IQ score (usually below the 68-70 range), and other states use an "IQ score that is two standard deviations below the norm." Since the norm is 100, both definitions mean much the same.
2. The limitations in intellectual functioning must be accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-direction, functional academic skills, work, leisure, health, and safety.
3. The onset must have occurred before the individual's 22nd birthday.

This is meant as a general guide. Eligibility criteria may vary and you must check with your state.

Denial of Eligibility

If your child is denied eligibility for adult services, you may want to appeal that decision. If so, you will want to make a written request for her file and any supporting materials that were used in reaching the decision. It will be important to understand the process and how the decision was reached. You can either manage the appeal yourself or hire an attorney who has experience with the adult service agency's regulations and policies.

There is usually only one reason why someone with Down syndrome would be deemed ineligible for adult services, and that is if she did not meet the disability criteria. If her IQ is over 70 and she has demonstrated that she does not have any significant deficits, she might not be eligible. While I have never personally seen an individual denied adult eligibility, I have seen many families who do not seek adult services.

Adults with Down syndrome might also be declared ineligible for adult services if they apply in a state other than the one where their parents live (whether or not their parents are their guardian). This sometimes occurs if the person with Down syndrome has attended a school or postsecondary program outside her home state. You and your child may decide that staying in the new state makes sense—she has friends, there are job opportunities, or some other reason. You figure that by making her a resident, she will then be eligible to apply for adult services in that state. This is like having a typical child try to establish residency in another state so she can be considered a resident and pay in-state tuition.

States that have many special education schools or programs that attract students from out of state have regulations that make it difficult or impossible for people from other states to receive adult services. In reaching a residency determination, the state will consider who paid for the student to attend the special education school or program. The state will almost always be able to trace funding to an out-of-state source (either the family or school district). I have seen families spend over \$80,000 to fight this decision. Some have been successful, but others still did not get services for their adult child with Down syndrome.

TYPES OF ASSESSMENTS

INTELLIGENCE TESTS

After the administration of IQ testing, the psychologist shared with me an exchange she had with Jon during the test. As I recall, she showed him the parts of an engine and asked him to put it together. He replied, "I guess if I knew how to build a car, I would know how to do it." Jon's answer demonstrated some thoughtfulness, but the strict scoring requirements of the IQ test meant that he received no credit for his answer. In the real world, this kind of strategy would be very helpful to Jon. But, IQ tests are not very real to me.

Intelligence tests that determine an intelligence quotient (IQ) are considered norm referenced tests. This means that the scoring is determined by testing a very large sample of individuals and assigning scores based on the performance of the very large group who took the tests. Generally, a score of 100 is considered "normal" on these tests. These tests have tremendous implications for individuals with Down syndrome and related disabilities because intelligence testing is required in determining who is eligible for adult services and may also be used for admission to some postsecondary programs.

To qualify for adult services, an adult with Down syndrome generally needs to meet the criteria for intellectual disabilities (mental retardation), or whatever term is being used to refer to people whose cognitive limitations result in a score that is generally 70 or below. Some people with Down syndrome might also qualify for services from the state agency that supports people who are deaf, hard of hearing, or blind. However, the agency that supports individuals with intellectual disabilities generally has the expertise, service models, and resources to best assist people with Down syndrome.

The following are fairly standard ranges for scores on intelligence tests. Depending on the test, the ranges may differ slightly.

- 130 and above Very Superior
- 120-129 Superior
- 110-119 High Average
- 90-109 Average
- 80-89 Low Average
- 70-79 Borderline
- 69 and below Range of Mental Retardation

There are various assessment tools used to measure cognitive intelligence. Among them are:

- Wechsler Intelligence Scale for Children - Fourth Edition (WISC-IV)
- Wechsler Adult Intelligence Scale—Fourth Edition (WAIS-IV)
- Stanford-Binet Intelligence Scales—Fifth Edition (SBS)
- Kaufman Assessment Battery for Children—Second Edition (KABC-2)
- Woodcock-Johnson III Tests of Cognitive Abilities (WJ-III)
- Differential Abilities Scale (DAS)
- Naglieri Test of Nonverbal Intelligence
- Comprehensive Test of Nonverbal Intelligence (C-TONI)

The Year Your Child Takes a Test Can Affect Her Score

A 2003 Cornell University study found that the year that an individual takes an IQ test can greatly affect the score she achieves. The variability is enough to have serious consequences. Since IQ scores tend to rise 5 to 25 points in a generation, the test is corrected and made more difficult every 15 to 20 years so the mean score can be reset to 100. According to The Cornell News, the researchers found that the number of children recommended for special education services with mild mental retardation tripled during the first five years after the new test was released compared with the final five years of an old test, even though there were no real changes in underlying intelligence.

Standard IQ tests measure verbal skills (such as the ability to define words or explain how two or more concepts are similar), nonverbal skills (such as the ability to copy patterns or predict what shape comes next in a sequence), short-term memory (such as the ability to repeat back a string of numbers, either forward or backwards), and processing speed (such as the ability to look at shapes that are keyed to numbers and write down the corresponding number).

In the past few decades there has been considerable attention to other forms of intelligence. The concept of emotional intelligence by Daniel Goleman and the multiple intelligence theory of Howard Gardner suggest that there are other parts of intelligence that matter that are not captured by standard intelligence tests. Although these ideas are fairly popular, they have had very little impact on the use of traditional intelligence testing.

DRAWBACKS OF INTELLIGENCE TESTS

Most parents of children with Down syndrome believe that traditional intelligence tests have marginal use in their children's lives. Our children perform better than their test scores indicate, and the tests fail to capture their special talents. I think low scores on IQ test can also demonstrate lack of access to the education that typical children receive.

Most people agree that intelligence testing is flawed. While improvements have been made, the tests often fail to take into consideration cultural and racial differences, and they are not very good at determining learning disabilities. They can be valuable, however, in suggesting useful interventions and learning strategies.

Assigning an IQ number to an individual with Down syndrome often has the chilling effect of labeling the person so that others do not see the strengths she has. In addition, intelligence tests are often administered by people who have little or no experience with Down syndrome. These professionals need to (but often don't) consider:

- speech patterns of our children;
- potential for hearing loss;
- the need to develop a rapport with the examiner;
- the effects of an unfamiliar testing environment;
- the ability to sustain effort for the test.

The good news is that after your child leaves high school and eligibility has been determined, the adult service system will have little interest in her scores on the in-

telligence test. The system is more concerned with outcome measures. Intelligence testing ceased to matter for me a long time ago. Regardless of any test result, I still loved my son the same.

Currently, there is no getting around IQ scores to determine eligibility for some services and benefits—just like there is no way around some kind of measure for college admissions, be it grades, test scores, or some combination of both. This is a change from the school years, when parents can refuse IQ testing and still get special education services for their child.

Jonathan was eight when I reluctantly agreed to IQ testing. I was totally opposed to it. I had long ago accepted his cognitive limitations and I did not see that there was anything to gain from intelligence testing. We knew he had Down syndrome and we knew how he learned best. What good could possibly come out of having a number assigned to him?

A few days after the test, the psychologist called me and shared with me some startling discoveries. During the subjective testing portion, where they looked at some emotional factors, Jon had provided some information that showed that he had seen or heard a sexually explicit event that he did not understand. The pieces all began to fall into place. Jon had been continually late getting to school even though he was picked up on time, his behavior had changed, he had experienced recent toileting accidents, and he had picked up new names for his private parts. Through the testing, we learned that the man driving Jon to school was sexually abusing him. After much therapy, Jon recovered and I had a new appreciation for IQ testing. I still hate the numbers, though.

Jon's first IQ score was pretty good. It was a high enough score for educators to see his potential, but just met the state cut-off for services. I think the testing people thought I was nuts because I actually said that it was the perfect score for those reasons. Two years later, the test was re-administered and his score was 10 points lower. I was not happy this time. I told the assembled professionals that if this trend continued, he would not have an IQ at all in another 10 years. They didn't think I was very funny.

GETTING THE "RIGHT" RESULTS

During the transition years, IQ testing can be used for two very different purposes: 1) as part of the admission process for a postsecondary program, and 2) as part of the determination process to qualify for Supplemental Security Income (SSI).

Here is where it gets a little tricky. If the IQ test is going to be used as part of the admissions process, you want your child to score as high as possible, since often a certain IQ level is required. In this situation, you want your child to be tested under the most favorable conditions. For example, you would want to make sure that your child is well rested, healthy, wearing comfortable clothes, and had a good meal and has snacks and a beverage available during the testing.

It may help to arrange a pre-meeting with the individual administering the test to go over the reason for the test (to get the highest score possible to gain admission to a postsecondary program) and to request breaks every 30 minutes if possible. You might stress that the written report reflect strengths that might not be apparent in the



test scores but would be helpful information to an admissions officer. You may also want to talk with the test administrator about the most appropriate test for your child. For example, would the WISC be more likely to show your child's strengths or the Stanford Binet? Would one of the nonverbal tests work better? In addition, you might consider paying for a private evaluation to make sure that testing conditions are optimal. You can also control who sees the results of the test when you pay for testing privately—which can be helpful if the results are not what you were expecting or hoping for.

If the purpose of the test, on the other hand, is to establish eligibility for SSI, it is not necessary to address the issues described above. You want to make sure that the Social Security Administration sees your child as having a clear disability as evidenced by her IQ score. Your child has to show evidence of disability, and the IQ test, along with medical support from her physician, is still considered the gold standard in determining disability. (See Chapter 6 for more on SSI.)

When Jon was a senior in high school, the school psychologist administered an IQ test to him. Although the narrative was right on the mark, the score was surprising low. The psychologist shared with me that he had never given the test to someone with Down syndrome and the last time he had even seen Jon was 10 years earlier.

Since Jon was applying to a postsecondary program that required an IQ score over a certain level, we privately paid for an independent evaluation. I found someone at a local pediatric hospital who had the experience I was looking for and I had an opportunity to share with her the reason for and importance of the test. The results of this test were much higher. Jon was admitted to the program of his choice, where he thrived and was very successful.

That other test? The one with the lower score? I submitted it with his application for SSI, which was approved.

SHOULD YOU ALLOW IQ TESTING BY THE SCHOOL?

Many parents prevent the school from doing IQ testing on their child, if at all possible, for fear that a low test score may lead to lowered expectations or fewer opportunities for inclusion. This is a personal decision. But as your child approaches the end of her high school career, it may be wise to consider IQ testing. If you don't have it done by the school, you will need to pay someone privately to do it to qualify your child for SSI and adult services. This can cost several thousands of dollars. While some of the expense may be covered by insurance, it can be expensive.

You will want to consider what you want to use the test score for and the experience of your school district in testing students with Down syndrome before going ahead with testing by your school. It may be prudent to consider having your school conduct IQ testing early in your child's high school career so you can determine your comfort level with using their testing to qualify your child for postsecondary education or adult services.