

Neuropsychological Testing at the PKU Clinic

Frequently Asked Questions

1. Who is tested?

All children are tested! We start testing at around age 3 years and continue testing approximately every three years into adulthood. We can test children under age 3 also, if parents or clinic staff have questions about early development.

2. What are the tests like?

We administer different tests depending upon the age of the child. For children under 2 ½, we typically administer the Bayley Scales of Infant Development-Second Edition. This test looks at fine and gross motor, language (speaking and understanding), object use, problem solving, and imitation skills. For children up to age 6, we administer the Differential Ability Scales Preschool Age Test Battery. This is an intelligence test that looks at the words a child knows, understands, and can use; visual-spatial problem-solving and imitation; visual and auditory memory; fine-motor development; and early mathematics skills. For children 6 to 17 years, we administer the Wechsler Abbreviated Scale of Intelligence, the Differential Ability Scales School-Age Academic Battery, and the Behavior Rating Scale of Executive Function, which measures neuropsychological skills such as planning, attention, memory, and organization. Depending on expressed parent or clinic concerns, each child's battery may differ slightly. For example, if a parent has questions about her child's reading development, we are able to complete a more comprehensive diagnostic reading battery in order to optimally address these questions and provide recommendations. Adults receive an individually selected battery of tests.

3. Why are children tested?

We know that children with PKU are at risk for learning difficulties. Early identification of developmental or neuropsychological deficits facilitates us in treating children medically and allows us to get early educational interventions to them when they need it and in a format most likely to be beneficial to learning.

4. What do the test results mean?

Performance on tests is scored in comparison to national norms obtained from children close in age to your child. Norm-referenced tests provide an index for evaluating change and/or growth over time. They also make it possible for us to measure the impact of remediation. Parents will be given individual feedback about their children's test results along with a written report. Standardized test scores are reported in a variety of ways. Depending on their statistical properties, they are named "T-scores," "scaled scores," "standard scores," etc. Scores used to measure intelligence are called standard scores. These scores are test composites—they take all of the subtests into account. These scores have an average of 100, with two thirds of children's scores falling between 85 and 115. For each test your child completes, we will provide you with the "standardized scores," the percentile rank



(average percentile score is 50, and two thirds of children's percentiles fall between 25 and 75), and a classification for easy interpretation (average, superior, etc.) compared to same aged peers.

Example:

| <u>Test</u> | <u>Standard Score*</u> | <u>Percentile Rank</u> | <u>Classification</u> |
|-------------|------------------------|------------------------|-----------------------|
| Verbal IQ | 88 | 21 | Low Average |

* Two thirds of children score between 85-115. Scores below 85 are considered to be below average compared to other children in this age group.

Note: Grade equivalent scores are determined by calculating the average score obtained by children in each grade. A grade equivalent is expressed in tenths of a grade (for example, 4.5 refers to average performance at the middle of fourth grade). "A grade equivalent *does not* mean that the student is performing at a level consistent with curricular expectations at his or her school. For example, a second grader who obtains a grade equivalent of 4.1 in arithmetic should not be said to be functioning like a fourth grader at the beginning of the school year."

5. What kind of scores should I expect?

Statistically speaking, the best guess about how a child will score is average. This means that you should expect your child to score anywhere between the 25th and 75th percentiles in all areas.

6. How accurate are the scores?

Instruments used at the clinic have been chosen for their statistical reliability and validity are quite good at predicting how well a child will perform academically at a typical school. *However, the younger the child, the less accurate are the obtained scores.* The test results for children under the age of 7 or 8 need to be interpreted with caution. For children over the age of 8 the test results become more reliable and more predictive of future academic achievement. The test scores are not 100% accurate—many children will struggle academically despite average test scores, while on the other hand, many children with low test scores will perform better than we would expect at school.

7. What if my child's test scores change after three years?

We expect children's standard scores to have some variability at each test administration—usually plus or minus about 3-6 points. We also expect that children's scores will move toward the average (100) as they get older and are tested again. So, for example, if a child at the age of 8 receives a standard score of 92 on the DAS, we could expect that child to score between 89 and 95 on the same test 3 years later. Statistically, it is more likely the child's score will inch up towards to 95. Similarly, for a child who received a score of 109 at the age of 8, we would expect a score between 106 and 112 at the time of the next administration, with chances slightly higher that the child's score will inch down towards the 106.



8. A percentile of 50 seems low to me. At school if my child received 50% on a test that would indicate failure!

A percentile rank score does not indicate the percent of correct items. It indicates the child's position in relation to other children of the same age, nationally. This is similar to the charts we use for your children's growth; remember that the vast majority of all children are average! Example: 78th Percentile Rank = Obtained score is better than 78% of children in the same age group taking the same test.

9. Can I have a copy of the test materials?

No. The tests we use are both "protected" and "copyrighted." This means that in order to protect their usefulness and scientific integrity, only credentialed psychologists or psychometrists have access to them, and no copies of the manual or test protocols may be made. This is similar to the rules for tests administered at school, such as the CTBS, the Iowa Basics, or the SAT.

10. How can I prepare my child for testing?

Children need to have a good night's sleep and be in good health during testing. If a child is tired, ill, or hungry, they will not perform well. Also, it is a good idea to explain to the child that all children with PKU have the opportunity to meet with the psychologist and work on some interesting tasks and games and that it is a lot of fun! We like to explain to the children that we are going to do fun or special work—puzzles, blocks, memory activities—to help us find out how they best learn. We also tell older children we will ask questions about words and have them do some reading, math, and spelling. We avoid use of the word "test." The amount of time the testing takes varies with the child's age, but we can always take breaks.

11. How can I find out more information or ask questions about school, development, the testing procedures, etc.?

You will have the opportunity to speak with the psychologist before and after the testing appointment. You may also call the PKU Clinic at 206-685-3015 or 1-877-685-3015 (toll free in Washington State) and ask to speak with the psychologist.

