

A Parent's Guide to Neuropsychological Evaluations

by Lucy Berrington

What key ideas and issues should parents keep in mind when choosing a neuropsychologist, and how should they use the neuropsychological report to get the best possible services for their child or teen?

The fall 2009 issue of the **AANE Journal** included the article “Guidelines for Neuropsychological Evaluations for Children and Teens: Neuropsychological, Educational, & Legal Perspectives,” based on interviews with many trusted professionals in the AANE community, who generously shared their experience. This guide collects, summarizes, and adds to the most important tips for parents that were highlighted in that article.

Selecting a neuropsychologist

When choosing a neuropsychologist, aim to find someone you can work with over the long term, preferably all the way through your child's schooling. The better a neuropsychologist knows your child, the more helpful and persuasive their reports will be to parents, educators, and (if your case ever becomes litigious) hearing officers.

Contact AANE for recommendations of neuropsychologists known to work effectively with children and teens who have Asperger Syndrome (AS) and other closely related autism spectrum conditions (High-Functioning Autism, PDD-NOS, or Nonverbal Learning Disorder).

Note: some clinics and hospitals offer multidisciplinary team evaluations. Their reports are collaborative efforts involving a neuropsychologist, a speech and language pathologist, an occupational therapist, a special education teacher and so on. If you go this route, make sure all of the evaluators are willing to testify in any legal process that may arise. Some legal experts argue it is better to assemble your testing team from different practices. If the evaluators are all from one practice, they may be assumed to be more likely to agree with each other; several independent evaluators reaching similar conclusions may carry more weight. Also, some neuropsychologists warn that multi-disciplinary reports may be fragmentary and not well-integrated.

In your initial contact with a neuropsychologist you are considering hiring, ask questions such as the following: (Note that some of the services listed below might entail an additional fee.)

- Tell me about your training and professional qualifications. (Look for a licensed psychologist with a full-time post-doctoral fellowship of one to two years in pediatric neuropsychology.)
- What age patients do you serve in your practice? (A practice limited to children and teens offers more relevant expertise and wider experience.)
- Do you have a special interest or particular experience working with children with Asperger Syndrome and other autism spectrum disorders?
- Have you had any prior experience with my school district or current private school (or one the child may attend in future)?
- Can you guarantee the report will be available by our deadline—four weeks before our team meeting on _____ (fill in the date)? (Some school districts take the position that they are entitled to ten school days to consider an independent evaluation report. Parents also

need time to review it and request changes if there are inaccuracies or areas of disagreement.)

- How will you gather information about my child from educators? Will you send out questionnaires? Will you interview educators? Will feedback from educators influence what tests you administer or what issues you address?
- If requested, can your report incorporate your personal observations of the child in a setting other than your office, such as a home, school, or community setting? (This usually entails an additional fee but can be very valuable to educators, mediators, and hearing officers.)
- Do your reports include educational recommendations? (A report without recommendations is incomplete. Avoid working with a neuropsychologist who would refer you to an educational consultant for this purpose.)
- Are your recommendations customized to the child's individual profile, or based more generically on the diagnosis? (Look for the former.)
- Does your evaluation cover social skills, executive functioning, anxiety and other emotional issues, vulnerability to bullying and teasing, and readiness for the transition to independence?
- Do you routinely, or could you, attend a team meeting yourself (as opposed to referring me/us to an educational consultant)? If this is impossible, can you or an associate be available by phone (e.g., to explain the educational recommendations to the child's school team)?
- If the educators at my child's school should question or reject your findings and recommendations, would you be willing and able to work with educational advocates or lawyers and/or attend hearings?
 - This is especially important if you think the case might become adversarial. Even if you are not expecting legal action, bear in mind that it might become necessary in the future.
 - Before working with a neuropsychologist, you can check the Bureau of Special Education Appeals website (<http://www.doe.mass.edu/bsea/decisions.html>). Search for the name of the neuropsychologist, see if he or she has testified before, and read the cases. Did the hearing officer(s) give weight to this person's testimony? If the neuropsychologist has testified several times and hasn't been found credible, look for someone else. Note, however, that many competent neuropsychologists have not given evidence at hearings. (This site is also useful for researching specific issues; e.g., eligibility for year round programming that includes summer services.)

At the intake meeting

- Prior to administering any tests to your child, the neuropsychologist is likely to ask you to provide information about your child through written questionnaires and documents (e.g. past testing, school records, or IEPs) and a face-to-face interview. At this meeting, be as specific as you can in articulating your concerns. For example, in what ways do your child's social problems present?
- Try to articulate what you see as the goal of this evaluation. For example, you may want the evaluation to help you and the educators identify and understand your child's learning style or social struggles, or to assist with school placement decisions.
- Ask the neuropsychologist to consider issues that might not yet be dominant in your child but which are associated with his or her functioning and apparent deficits. Services must be put in place even though some difficulties (such as anxiety) aren't yet very obvious, because without support they will probably become more obvious, typically from late elementary school years onwards. (If there are *no* current needs in a particular area, the district isn't legally required to provide services.) Also ask the neuropsychologist to articulate in the report

how the transition to independence can be built into the goals of the IEP from a young age, leading to stronger transition skills through high school and beyond.

- The intake meeting provides a good opportunity for further discussion regarding the structure and content of the forthcoming report, e.g.:
 - Will the neuropsychologist integrate findings from previous evaluations with current findings?
 - Will the report include a summary or concluding statement that ties together all the information and paints a clear picture of the child's functioning?
 - Will the educational recommendations be collected in one section of the report and delivered in teacher-friendly language?
 - Will there be a statement of risk to the student, based on his or her neuropsychological profile, if the recommendations are *not* implemented?
 - Will the neuropsychologist comment on the appropriateness of the current or proposed IEP in the recommendations?
 - Will the recommendations specify the nature, frequency, duration and setting of service delivery, and the qualifications of the provider?
 - Will the recommendations be presented in terms of what the child *requires* in order to *make effective progress* (as opposed to what would be nice or ideal for that child, a concept that has no legal weight)?
 - Will the report contain recommendations about how parents and caregivers can best support the child at home?
 - Will the neuropsychologist refer parents to specific service providers (e.g. a private OT)?

At the feedback meeting

- It is good practice for the neuropsychologist to meet with parents to explain his or her findings. As you listen, ask yourself whether the report tallies with your understanding of your child. If not, discuss these areas of difference with the neuropsychologist, trying to understand what the evaluation shows and how the neuropsychologist is interpreting the information.
- Do not reject a diagnosis out of hand. Even though you may experience some pain or struggle in accepting a label for your child, the diagnosis can facilitate access to services that will help the child learn and grow to his or her full potential. If the report contains a diagnosis that is different from others your child has received in the past, ask the neuropsychologist to explain the criteria or reasons for it. Consider whether different terms are being applied to the same condition, or whether there is a substantive dispute about the nature of the condition.
- Make sure you understand the report—especially its recommendations.
 - Do the recommendations address *all* your child's key needs, at their actual level of severity?
 - Ask for concrete examples: e.g. what kind of intervention or support would this recommendation translate into in the classroom? How would I present this to my child's educational team?
 - If fully and well implemented, would these recommendations, taken altogether, really meet your child's individual needs?
- Use AANE's "Frame for Preparing for IEP Meetings" (www.aane.org/asperger_resources/parents_toolbox.html). The frame is designed to help families organize information, from the meeting with the neuropsychologist to the team meeting at school. It will help identify and track the most important issues, ensuring that they are discussed in the team meeting and incorporated into the IEP. The use of this frame

is taught in the parent workshop “Advocating for Your Child with AS in Public Schools” or “Advocating for Your Teen with AS in Public Schools.” (See www.aane.org or contact Children’s Services or Teen Services for workshop dates.)

- If your school lacks expertise in AS and related autism spectrum conditions, ask whether the neuropsychologist can supply attachments that will help educators understand relevant strategies and explanations. (Also see the educational articles on the AANE web site, or consult AANE staff.)
- Make sure the tone of the report is not argumentative and does not seem to have an ax to grind. An objective neuropsychological report carries more weight.

At the team meeting

- Make sure any independent neuropsychological report is available in advance (preferably about three weeks) to the special educator or administrator who will be facilitating the team meeting.
- You do not need to have a team meeting already scheduled in order to have an independent evaluation considered. The school is obligated by law to review an independent report and consider its recommendations at a team meeting within ten school days of receiving it.
- If the testing has been done in district, always make a written request that the testing results be available to you at least 48 hours before a meeting, so that you will have time to read and understand it. Do this as part of your initial request to evaluate. Without making this request you have no legal grounds to receive the report in advance.
- If there is no one on the team equipped to translate the report to the teachers, this role falls to the parents. Parents must understand the recommendations and how they will be put into practice in the classroom.
- Consider hiring your independent neuropsychologist—the person who did the testing and wrote the report—to attend the team meeting. When the neuropsychologist is present to answer educators’ questions (and to listen respectfully to their opinions and concerns), educators are less likely to dispute his or her findings, or misinterpret the recommendations. The neuropsychologist’s statements and responses will almost certainly carry more weight than a parent’s (however articulate and knowledgeable the parents are).

Will a school system pay for a neuropsychological evaluation?

Generally, neuropsychological evaluations, like any other evaluation, must be requested of the district first. Your child will be tested by a professional of the school’s choice. This could be someone on their payroll, usually a school psychologist, or with whom they have a contract.

If you are dissatisfied with the resulting report, or if you are requesting an evaluation in an area not assessed by the district, you may request in writing to have an Independent Educational Evaluation (a second opinion). The funding for independent testing is generally limited to “rate-setting rates.” Most neuropsychologists in private practice will not take those rates, so the independent evaluation will probably take place at a hospital. If you anticipate being in this situation, make the appointment for the evaluation as soon as possible. Hospitals often have long waiting periods. You may need to call months in advance to ensure that the hospital’s report will be available in time for a team meeting. It is far easier to make that appointment and cancel if it proves unnecessary than to get an appointment at short notice. A delay in testing will probably mean a delay in getting the services your child needs.

If your private insurance will fund the evaluation you may have more options. Some families go for an independent evaluation, paid out of pocket or through family health insurance, so that they can choose the neuropsychologist without restriction. Some school systems will agree in advance to accept an independent neuropsychologist's report in lieu of the district's performing its own psychological evaluation. If the district will not agree to this, the parents may still proceed with an independent evaluation, but in most cases will also need to consent to the district's performing its own psychological evaluation.

School systems are obligated to review and consider independent reports within ten school days of receiving them, but are not legally bound by them as they are to the results of the district's own testing. Some school systems might consider parents' choice of independent testing as demonstrating a lack of cooperation with the school system and attempt to use it against parents at hearings. In Massachusetts, special education regulations provide, however, that parents "may obtain an independent education evaluation at private expense at any time."

Working with the school over time to get the recommendations implemented

- All communications (such as requests for evaluations) should be submitted in writing and dated.
- Be aware of legal timeframes under federal and state law regarding testing and follow-up. See <http://www.fcsn.org/parentguide/pgintro.html> or <http://www.wrightslaw.com>.
- Excellent and frequent communication among educators and parents is key to ensuring implementation. Ideally a communication plan includes: a monthly face-to-face team meeting, a weekly check-in (by journal, email or phone—whatever will work for the designated educator), and as-needed/emergency communication (usually by phone or email) to make educators or parents aware of time-sensitive issues. See: http://www.aane.org/asperger_resources/articles/education/educational_interventions_asperger.html.
- Consider "enriching the team" (as Terri McLaughlin of the Federation for Children with Special Needs puts it). That is, bring in people with additional information and fresh viewpoints, e.g.: other people in the school who see the child in different settings, outside educational consultants with special expertise (such as AS, executive functioning, or social pragmatics), or an educational advocate.
- If you feel your advocacy is ineffective, contact the Federation for Children with Special Needs for expert support by phone, or the names of educational advocates who can assist you in person or at a team meeting, at your expense. (The Federation trains advocates who during their internships work with families pro bono, but their availability is limited.) Or contact AANE for information and training.
- At age 14 (in Massachusetts), a transition planning meeting should be held. This is a special meeting of the educational team devoted to deciding what services will be delivered during the high school years (beginning at age 15) to help the student achieve a realistic level of independence following high school graduation (or aging out of eligibility for Department of Education services). A neuropsych report evaluating a teen's current transition readiness provides a valuable foundation for this discussion and planning.

Beyond high school

- Children who are eligible for special education receive support either until they graduate with a state-standard high school diploma or turn 22 (whichever comes sooner). In Massachusetts, graduation now requires three things: earning credits mandated by the local educational authority, passing MCAS, and getting meaningful and substantial transition services in the high school years. See <http://www.fcsn.org/pti/topics/transition/index.html> and http://www.massadvocates.org/uploads/Uy/ri/Uyri2nnseo44kHuhX_wRlw/Implementation-Alert-Parent--FINAL-12-22-08-2.pdf.
- In the post-secondary setting, the neuropsych report is used to help define the student's needs and assess relevant accommodations in colleges. Colleges are obligated to provide reasonable accommodations, but they can define reasonable, so provision varies. The level of support is likely to be much lower than in high school. Students in higher education must request accommodations themselves and provide documentation of their disability. (The student's IEP is not relevant in college.)

Other helpful organizations

The Federation for Children with Special Needs, www.fcsn.org
Mass Advocates for Children, www.massadvocates.org

AANE thanks the professionals who generously shared their time and expertise for this guide and the original article. Call AANE staff for referrals to these or other professionals.

Joseph Moldover, Psy.D.; Sangeeta Dey, Psy.D.; Ann Helmus, Ph.D.; Lori Hodgins Brazell, M.S. Ed.; Lynne Mitchell, MSW; Natalie Labouchere, M.S., Ed.; Jean Stern, M.Ed.; Robin Lurie-Meyerkopf, M.Ed.; Terri McLaughlin, Federation for Children with Special Needs; Joan Tossaint, Advocate; Atty. Eileen Hagerty, Kotin Crabtree & Strong; Atty. Tim Sindelar, Hilton, Sindelar & Hahn; Atty. Julia Landau, Massachusetts Advocates for Children; Atty. Beth Simon, Massachusetts Advocates for Children and private practice; Atty. Mary Ellen Sowyrda, Murphy, Hesse, Toomey & Lehane.

Lucy Berrington is a writer from Newton, MA. Her journalism and fiction has been published in many newspapers, magazines and journals, including the Globe, the Herald, the Guardian, the London Times, and the New England Review. You can read her article about the movie **Adam** at http://www.aane.org/upcoming_events/Adam_Article.html.