

Autism Speaks Summary

Prepared by: Goodwin Procter LLP
As of November 12, 2010

This information is intended to provide a general overview on certain limited topics and responses to certain frequently asked questions from a national perspective. The information was prepared as of November 12, 2010, is not updated or reviewed periodically, and no obligation to do so is undertaken. This is not intended as legal advice. Answers to your questions and courses of action will depend not only on the federal laws referenced, but on state and local laws, rules, regulations, customary practices, policies and procedures, and actual recommendations and courses of action will need to be based on your specific factual circumstances and locale. While this is intended to provide an general overview, you are strongly encouraged to speak with an experienced lawyer in your locale about your specific circumstances.

I. Adults with Autism Spectrum Disorders

a. Determining “Adult” Status Under Federal Law.

i. Education and Non-Financial Services. If an individual is entitled to financial assistance, education and other benefits and services under the federal Individuals with Disabilities and Education Act (IDEA), then these benefits and services are available through the age of 21.

ii. Financial Assistance. For purposes of receiving certain types of federal government financial assistance, such as Supplemental Security Income (SSI), an individual will be treated as an adult at age 18.

b. Transition Services Available To Individuals Under the IDEA. The IDEA sets forth specific transition services that are required to be provided to young adults with autism spectrum disorders, please see Section II(a)(iv)(H) for more information.

c. Financial Resources Available to Adults with Autism Spectrum Disorders. There are a number of government financial resources that may be available to adults with autism spectrum disorders or to fund programs that such adults may participate in, including Supplemental Security Income (SSI), Social Security Disability Income (SSDI) and state Medicaid Home and Community Based Services (HCBS) waivers. For more information on these resources, including eligibility requirements, see Section III for more information.

d. Living Arrangements for Adults with Autism Spectrum Disorders. A number of different living arrangements for adults with an autism spectrum disorder may be available and decisions should generally be based on the needs and abilities of each individual. Financial assistance, such as SSI, SSDI and HCBS waiver may be available to fund the living expenses of an adult with an autism spectrum disorder. Some of the more common living arrangements, each of which may be government and/or privately funded, include:

- i. Transitional models which are generally intended to be short-term options and may provide behavioral evaluation and treatment, intensive life skills programs or college support programs.
- ii. Supported living provides for individuals to primarily live independently and receive limited assistance (such as for personal finances, managing government benefits, etc.). This limited assistance is generally provided by a family member or a professional agency.
- iii. Supervised living provides for greater assistance than the supported living model, but does not rise to the level of group home living. Generally, support is available 24 hours per day and adults may live with or near a number of other adults with autism spectrum disorders.
- iv. Individuals may live in a group home option, which generally provides for small groups of individuals (less than 8) to live in apartment-style housing with varying levels of assistance (based on each individual's capabilities) provided by a professional staff. The level of assistance may range from assistance with day-to-day activities (meal preparation, personal care, etc.) to more autonomous day-to-day living with several weekly check-ups.
- v. Farmstead programs allow for a group of individuals to live and work on a working farm.
- vi. Some families elect for an adult with an autism spectrum disorder to remain living at home, in which case certain government funding (in the form of SSI, SSDI or, in limited cases, HCBS waivers) may be available.
- vii. A long-term care institution may be an appropriate alternative to consider if an individual needs intensive, constant supervision.

e. **Employment Resources For Adults with Autism Spectrum Disorders**

i. **General Assistance and Resources**

- (A) Each state has a Department of Vocational Rehabilitation and the purpose of this department is to provide various employment assistance for adults with disabilities. The department may provide services such as assessment and diagnosis, counseling, job search assistance, assistive technology and on-the-job training. Also, because the Department of Vocational Rehabilitation is associated with the Department of Education transition services are often provided for high school students, which will generally focus on integrated employment, post-secondary education, independent living and community participation. For more information, individuals should contact their state Department of Vocational Rehabilitation or discuss transition services in connection with their IEP program.
- (B) A number of private resources may provide information or assistance, such as the ASPE, which is a non-profit organization focused exclusively on integrated and career advancement for individuals with disabilities or certain websites or blogs may also be helpful, such as jobs4autism.com.

f. Common Employment Models

i. Some individuals may be able to participate in a customized employment program which involves an active negotiation with an employer to modify an existing job to be appropriate for a particular individual's needs, interests and abilities.

ii. Individuals may be able to participate in a supported employment model, which are generally funded by Medicaid waivers, including those highlighted below:

(A) Individual job placement consisting of an individual receiving on-site job training with a job coach. As the individual's skill set and competency increases, the involvement of the job coach will decrease. This option is appropriate for high functioning, less resource intensive individuals.

(B) Small groups of individuals working together at a location in the community and receiving support from a job coach.

(C) Mobile work crews consisting of a small number of individuals that provide a certain service at various locations within a geographic area.

(D) Day habilitation programs and sheltered workshops provide for a collective environment primarily focused on life skills training. These options are the least socially integrated and offer individuals the most significant support.

g. Legal Guardianship.

i. In most states when an individual turns 18 the individual will be considered an adult. Prior to age 18, families need to determine if it is necessary to be able to continue to make medical and financial decisions for a family member with an autism spectrum disorder. Based on this determination, a family member will need to apply for either limited or full guardianship and/or to be a conservator of such individual.

ii. To become an individual's legal guardian or conservator, contact the Office of Public Guardian in the applicable state. Typically the process will include completing an application and all parties (i.e., the family member seeking guardianship and the individual) attending a hearing represented by separate legal counsel.

II. Education: Individuals With Disabilities Act (IDEA) and the Individualized Education Program (IEP)

a. General Information. The Individualized Education Program ("IEP") originates from Section 1414 of the Individuals With Disabilities Education Act ("IDEA"). Section 1414 of the IDEA discusses the procedures of evaluations and reevaluations, parental consent and rights, eligibility determinations, educational placements and setup and monitoring of individualized education programs. The IEP governs the educational and other support a child with disabilities will be given for an upcoming school year. The IEP also sets the specific goals and milestones for the child with a disability. The formation of an IEP is

discussed and agreed upon by the child's parents, teachers and local educational agency representatives.

i. Initial Evaluations, Procedures and Requirements

- (A) A State educational agency, other State agency or local education agency is responsible for conducting a full and individual evaluation with the child in question before any special education services or provisions may be implemented. Either the parents or guardians of a child or the State or local agency may request that an initial evaluation take place. In general, the State or local agency has 60 days to determine if the child has a disability from the date of parental consent.
- (B) The State or local agency is required to provide notice to the parents of a child with a disability that describes any evaluation procedures the agency plans to conduct. In conducting the evaluation, the agency shall use a variety of assessment tools and strategies to gather relevant functional and developmental information (including information from the parent). This evaluation may assist in determining whether a child is a child with a disability and the content of the child's individualized education program, including enabling the child to be involved in and progress in the general education curriculum.
- (C) The evaluation process shall be selected so as not to discriminate on a racial or cultural basis; administered in the language most likely to yield accurate information on what the child knows and can do academically, developmentally and functionally; and administered by trained and knowledgeable personnel.
- (D) Upon completion of the evaluation, the determination of whether the child is a child with a disability shall be made by a team of qualified professionals and the parent. A copy of the evaluation report and the documentation of determination of eligibility will be given to the parent.

ii. Parental Consent. The general rule is that in order to have an evaluation performed there must be parental consent. However, parental consent for an evaluation shall not be construed as consent to any receipt of special education services or any related services. Before performing any special education services, the agency seeking to perform the services must receive informed consent from the parent.

iii. Reevaluations.

- (A) Reevaluations generally occur when either the educational agency determines that the educational or related services needs of the child warrants a reevaluation or if the child's parents or teachers requests a reevaluation. Reevaluations shall not occur more than once per year unless the educational agency and the parent agree otherwise. Reevaluations shall occur at least once every 3 years, unless the parent and the local educational agency agree that a reevaluation is unnecessary.

(B) Reevaluation of a child may be based, in part, on the following existing data: evaluations and information provided by the parents of the child, current classroom-based (or other) assessments or observations, or observations by teachers and related service providers. Based on that initial review and input from the child's parents, the following additional data, if needed, will be identified: whether the child continues to have a disability and such educational needs, the present levels of academic achievement and related developmental needs of the child, whether the child continues to need special education and related services, and whether any additions or modifications to the special education and related services are needed to enable the child to meet the measurable annual goals set out in the IEP of the child and to participate, as appropriate, in the general curriculum.

iv. Individualized Education Program ("IEP").

(A) General Description. IEP means a written statement for each child with a disability that is developed, reviewed and revised in accordance with the following: (1) a statement of the child's present levels of academic achievement and functional performance; (2) a statement of measurable annual goals, including academic and functional goals; (3) a description of how the child's progress towards their annual goals will be measured and when periodic reports on the progress the child is making towards the annual goals will be provided; (4) a statement of the special education and related services and supplementary aids and services to be provided to the child or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided for the child; (5) an explanation of the extent, if any, to which the child will not participate with nondisabled children in the regular class and in regular activities; (6) a statement of any individual appropriate accommodations that are necessary to ensure the academic achievement and functional performance of the child on State and districtwide assessments; and (7) the projected date for the beginning of the services and the projected frequency, location and duration of those services and modifications.

(B) IEP Team. The IEP team is a group composed of the following: (1) the parents of a child with a disability; (2) not less than one regular education teacher of the child (if the child is participating in the regular education environment); (3) not less than one special education teacher (or at least one special education provider); (4) a representative of the local educational agency who is qualified to provide/supervisor specially designed instruction to meet the needs of children with disabilities and is knowledgeable about the general curriculum and is knowledgeable about the availability of resources of the local educational agency; (5) an individual who can interpret the instructional implications of evaluation results (may be the same person as any of 2-4); (6) at the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child; and (7) where appropriate, the child with a disability.

- (C) IEP Meeting Attendance. A member of the IEP Team shall not be required to attend an IEP meeting if the parent and the local education agency agree that the attendance of the member is not necessary. A member of the IEP Team may be excused with consent of the parent and the local education agency provided said IEP Team member submits, in writing, input into the development of the IEP prior to the meeting.
- (D) IEP for child ages 3 through 5. In the case of a child with a disability aged 3 through 5, the IEP Team shall consider the individualized family service plan and the individualized family service plan may serve as the IEP of the child as long as it is consistent with State policy and agreed to by the child's parents and the educational agency.
- (E) IEP for child who transfers school districts. In the case of a child with a disability who transfers school districts within the same academic year in the same State, the local educational agency shall provide services comparable to those described in the previously held IEP until such time as the local educational agency adopts the previously held IEP or develops, adopts and implements a new IEP. In the case of a child with a disability who transfers school districts within the same academic year in a different State, the local educational agency shall provide services comparable to those described in the previously held IEP until such time as the local educational agency conducts an evaluation (if determined to be necessary) and develops a new IEP.
- (F) Development of IEP. In developing each child's IEP, the IEP Team shall consider the following: (1) the strengths of the child; (2) the concerns of the parents for enhancing the education of the child; (3) the results of the initial evaluation or the most recent evaluation of the child; and (4) the academic, developmental and functional needs of the child.
- (G) Review and revision of IEP. The local educational agency shall review the child's IEP periodically, but not less frequently than annually, to determine whether the annual goals for the child are being achieved. The IEP can be revised based on the following: any lack of expected progress toward the annual goals and in the general curriculum, the results of any reevaluation, information about the child provided to, or by, the parents, the child's anticipated needs, or other matters.
- (H) Transition Services. Under the IDEA, certain transition services are required to be provided in connection with an individual's IEP.
- (1) By age 14 the "transition services needs" of each individual should be identified and discussed. This should occur in connection with the annual IEP meeting. Identifying "transition services needs" will generally involve developing a multi-year description of coursework to achieve an individual's post-school goals.

- (2) By age 16 each young adult must have a “statement of needed transition services,” that should address such young adult’s instruction, related services, community experiences, development of employment and other post-school adult living objectives, and if appropriate, acquisition of daily living skills and functional vocational evaluation.
- (3) In addition, a “statement of the interagency responsibilities” must be prepared to identify which government agencies will be responsible for the provision or funding of the needed transition services.
- (4) The participants in the process described above should include the young adult, the parent(s), a special education teacher or related service provider, a regular education teacher (if appropriate, based on the young adult’s coursework) and representatives of the appropriate agencies.

b. Frequently Asked Questions

Q: What must occur during the 60-day time period after the public agency receives parental consent for an initial evaluation?

A: An initial evaluation must be conducted within 60 days of receiving parental consent for an evaluation or, if the State establishes a different timeframe within which the evaluation must be conducted, within that timeframe. The IDEA 60-day timeline applies only to the initial evaluation. Public agencies are not required to make the eligibility determination, obtain parental consent for the initial provision of special education and related services, conduct the initial meeting of the IEP Team to develop the child’s IEP, or initially provide special education and related services to a child with a disability during the IDEA 60-day initial evaluation timeline.

Q: How must a public agency document that the IEP Team members have been informed of changes to the IEP?

A: In making changes to a child’s IEP after the annual IEP Team meeting for a school year, the parent of a child with a disability and the public agency may agree not to convene an IEP Team meeting of the purpose of making those changes, and instead may develop a written document to amend or modify the child’s current IEP. The regulations only require that the child’s IEP Team is informed of the changes to the IEP, not the specific manner in which it is documented.

Q: Must the assessments and other evaluation used to determine special education eligibility include a doctor’s medical diagnosis (particularly for children suspected of having autism)?

A: There is no requirement (under the IDEA) for a medical diagnosis when determining special education eligibility. However, the information that is gathered in determining eligibility may include a diagnosis by a medical professional. Also, while a medical diagnosis may prove informative in determining if the child is a child with a disability and/or the appropriate educational program for the child, there can be no one factor that establishes whether or not the

child has a disability. Like all other information that is obtained in an assessment, any medical diagnoses must be documented and carefully considered for eligibility purposes.

Q: Which members of an IEP Team may be excused from an IEP Team meeting?

A: The following IEP Team members may be excused from an IEP Team meeting by written agreement between the child's parents and the educational agency: the regular education teacher(s) of the child (if the child is, or may be, participating in the regular education environment); the special education teacher(s) of the child; a representative of the educational agency; and an individual who can interpret the instructional implications of evaluation results.

Q: Is there a specific timeline in which public agencies must notify parents of a request to excuse an IEP Team member from attending an IEP Team meeting?

A: There is no regulation in place that dictates a timeframe in which an agency must notify parents of a request to excuse an IEP Team member from attending an IEP Team meeting. Also, there is no regulation of how far in advance of an IEP Team meeting the parent of a child with a disability and the educational agency must agree in writing to a IEP Team member excusal. Note that no matter when the educational agency requests an excusal of an IEP Team member the parent of the child with a disability must agree to the excusal in writing.

Q: How may an IEP be modified without convening an IEP Team meeting?

A: In making changes to a child's IEP after the annual IEP Team meeting for a school year, the parent of a child with a disability and the educational agency may agree not to convene an IEP Team meeting and instead may develop a written document to amend or modify the child's current IEP.

Q: Must an educational agency provide a parent of a child with a disability with prior written notice about changes or proposed changes to an IEP?

A: Yes. An educational agency must provide written notice to the parent of a child with a disability a reasonable time before the educational agency (1) proposes to initiate or change the identification, evaluation or educational placement of the child; or (2) refuses to initiate the identification, evaluation or educational placement of the child.

Q: May an educational agency pursue an initial evaluation even if a parent refuses to consent to the initial evaluation?

A: Yes. If a parent of a child enrolled in or seeking to be enrolled in public school does not consent to an initial evaluation or fails to respond to the request for consent, then the decision to use consent override procedures is up to the educational agency. In the case of a reevaluation, if the parent of a child with a disability fails to respond to the request to a reevaluation, then the educational agency may conduct a reevaluation of the child without invoking the parental consent override procedures (if the educational agency can demonstrate it made reasonable efforts to obtain parental consent for the reevaluation).

Q: What recourse is available to a parent of a child with a disability who agree to most of the child's IEP, but disagree with a particular service or services in their child's IEP?

A: When there is a disagreement with a particular service between the parent and the educational agency, the parent and agency should work to informally achieve agreement. While

the parent and agency attempt resolution, the rest of the IEP services should be provided to the child with a disability. If ultimately the parent and the agency cannot come to an agreement, the parent may pursue remedies such as mediation or due process procedures and should strongly consider consulting an experienced lawyer.

Q: What services can be provided to a child with a disability under the related services provision?

A: Related services can include the following: transportation, developmental services, corrective services, supportive services, artistic services, cultural services, art, music or dance therapy. There is no exhaustive list as to what may be provided to the child, but determinations are made in light of each child's unique abilities and needs about what may assist the child in benefiting from special education.

c. Helpful Websites

- i. U.S. Department of Education IDEA website: <http://idea.ed.gov/>.
- ii. U.S. Department of Education IDEA website for Part B (ages 3-21): <http://idea.ed.gov/explore/home>.
- iii. U.S. Department of Education IDEA website for Part C (ages birth-2): coming soon.
- iv. Information regarding Individualized Education Program (IEP): <http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalArea%2C1%2C>.
- v. Updated Questions and Answers regarding IEP's: <http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CQaCorner%2C3%2C>.
- vi. Questions and Answers on the National Instruction Materials Accessibility Standards (NIMAS): <http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CQaCorner%2C5%2C>.
- vii. Information regarding Early Intervening Services (EIS): <http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalArea%2C8%2C>.

III. Financial Resources Available to Individuals with Autism Spectrum Disorders

a. Government Financial Resources. A number of governmental financial resources may be available for individuals with autism spectrum disorders, including:

- i. Supplement Security Income. Supplemental Security Income (SSI) is a federal government financial assistance program administered by the Social Security Administration that provides financial assistance to individuals that meet certain qualifications with low income or limited resources who are 65 and older or blind or disabled. To be eligible for SSI assistance prior to age 18, an individual must (i) not be working and earning in excess of a specified wage (\$1000 per month as of 2010), (ii) have a physical or mental condition that results in "marked and severe functional limitations" (i.e., seriously limit the individual's activities) and (iii) such condition must last or be expected to last at least 12 continuous

months. In addition, for individuals under 18 the income and resources of family members living in the individual's household will be considered. If an individual has been receiving SSI benefits prior to age 18, during the one year period after such individual's 18th birthday his or her SSI benefit eligibility will be re-evaluated based on the adult disability rules and such individual's income. If an individual was unable to receive SSI benefits prior to age 18 due to the individual's family income or resources, such individual may qualify for SSI benefits at age 18 based on such individual's independent income and resources. To encourage young adults with disabilities to work, a large percentage of the income of an individual under age 22 applying for SSI may be excluded. Determining whether an individual meets the eligibility requirements (both before and after age 18) will be a fact specific analysis based on the individual's medical diagnosis and such diagnosis impacts his or her daily life activities and work capabilities. Please see the Social Security Administration, Electronic Booklet: Children With Disabilities at <http://www.ssa.gov/pubs/10026.html> for more information.

ii. Social Security Disability Insurance. Social Security Disability Insurance (SSDI) is a federal government financial assistance program administered by the Social Security Administration that provides financial assistance to individuals who have a disability that began before age 22. SSDI financial assistance is paid based on a parent's Social Security earnings record and are available if one of the parents (i) is receiving Social Security retirement or disability benefits, (ii) has died and worked for a sufficient amount of time under Social Security or (iii) if the disabled adult received "dependents benefits" on the parent's Social Security earnings prior to age 18. The disability determination for SSDI benefits will be based on a determination by the Disability Determination Services agency in the individual's state and will generally take into consideration the individual's medical diagnosis and how the individual's medical diagnosis impacts his or her daily life activities and work capabilities. Please see the Social Security Administration, Electronic Booklet: Children With Disabilities at <http://www.ssa.gov/pubs/10026.html> for more information.

iii. Medicaid Home and Community Based Services Waivers. Medicaid Home and Community Based Services (HCBS) waivers are available through many state's Medicaid health care programs. Generally, HCBS waivers allow states to provide funding for a variety of home and community-based services for individuals with developmental disabilities. HCBS waivers are state-specific and require additional research to determine what assistance may be available, the eligibility requirements and the process. Medicaid waivers are available in many states to fund home or community based services (i.e., nursing services, minor home modifications, counseling and therapies, supervised living, day habilitation, etc.) and a limited number of states provide autism-specific waivers. Generally, HCBS waivers fund programs and related services and are not intended to go directly to individuals, however, certain states have started Self Determination Initiatives which allow individuals to select, purchase and direct particular services.

b. Applying for Government Financial Assistance. To begin the application process for SSI or SSDI payments and get additional information regarding eligibility for such payments, please access the online application system, call the Social Security Administration offices directly or visit a local Social Security Administration office. HCBS waivers are state-specific, therefore, to get more information contact a local Medicaid office.

c. **Additional Financial Resources to Consider.** In addition to government financial resources, other financial resources to consider include health insurance and grants or other financial support available from public or private non-profit organizations.

IV. Legal Protection and Rights / Discrimination

a. **Employment Discrimination.** The Americans with Disabilities Act (the “ADA”) prohibits discrimination on the basis of real or perceived mental disability. Individuals with autism are protected individuals under the ADA.

i. What conduct constitutes discrimination?

(A) The most significant protection of the ADA is that it prevents employers from either terminating or refusing to hire an individual because of his or her mental condition. As long as the individual is able to perform the essential functions of the job, with reasonable accommodations, the employer cannot consider the employee or potential employee’s mental condition in making hiring or firing decisions.

(B) Additionally, the ADA prohibits employers from asking about mental conditions prior to giving a job offer. Employers may ask whether an applicant has a disability that would prevent him or her from effectively filling the position, but only if the employer asks that question of all potential employees. What the employer may not do, under the ADA, is meet an individual, observe their behavior, and then ask whether they have a disability on the basis of the employer’s observations.

(C) Just as important for many people with autism, the ADA makes the employer responsible for harassment or mistreatment of a protected individual in the workplace. If other employees tease or make jokes at the expense of someone on an ongoing basis because of his or her autism, the employer can be held responsible for this behavior. This is true even in a workplace where all the employees tease each other.

ii. What constitutes reasonable accommodation? In determining what constitutes a reasonable accommodation, considerations like cost and inconvenience to the employer may be taken into account, but it is still ultimately a subjective and fact-specific determination. Examples of reasonable accommodation are changes in supervisory methods, changes in workplace procedures, and restructuring a position to move minor tasks that the employee cannot perform to other employees.

iii. Am I still protected from discrimination if my autism is managed and does not affect my performance at work? The Americans with Disabilities Act also protects individuals with a record of having an impairment and individuals who are perceived to have an impairment. Even if your autism does not affect your job in any way, if your employer or co-workers discriminate against you because they believe you to be autistic, you may have a claim under the ADA.

iv. Should I disclose my condition to my employer or potential employer?

- (A) Disclosure of a condition is not obligated unless your disability would pose a direct threat to the health or safety of others. For the purposes of autism-spectrum disorders, this means that disclosure will most often be a personal decision.
- (B) If as a candidate or employee, you decide not to disclose your condition, then you would not be entitled to reasonable accommodation, as described above and provided for under the ADA. An employer is not expected to provide reasonable accommodation for an impairment unless the employer knows of the condition. If you will require reasonable accommodations to perform your basic job functions, then you will need to disclose your condition.
- (C) However, if you decide not to disclose your condition, and can perform your job functions without accommodation, you will still be protected by the ADA. If, because of your autism, you are repeatedly mistreated, teased, or harassed by your coworkers or actions are taken against you by your employer, whether because you are perceived as having an impairment or because your employer or coworkers discovered your impairment other than by your disclosure, then this treatment will likely still give rise to a claim of discrimination under the ADA.

v. Can my employer retaliate if I complain about discrimination or insufficient accommodations? The ADA prohibits retaliation against an employee for complaining about or opposing his or her employer's alleged discrimination. Courts have recently also extended these protections under the ADA to parents, children, spouses, close relatives, and friends of employees who work in the same environment, even though those individuals did not themselves engage in the protected conduct. Therefore, if you complain about discrimination or mistreatment because of your autism, and your employer retaliates by firing one of your friends or relatives, this may also be sufficient to make a claim for retaliation under the ADA.

vi. What do I do if I believe that I have been discriminated against because of my autism? A helpful first step for an individual who believes he or she has been discriminated against is calling the helpline run by the Equal Employment Opportunity Commission (EEOC). Their job is to review discrimination complaints against employers and to assist individuals who have received discriminatory treatment, and they can often point you in the right direction. Additionally, an individual who has been discriminated against cannot pursue a claim in court against his or her employer unless he or she has first filed a complaint with the EEOC or a comparable state agency. In addition to the ADA, there are many state statutes prohibiting employment discrimination, and agencies like the EEOC enforce these provisions at a state level. In addition to contacting the EEOC, contacting the agency in your state that deals with employment discrimination can be helpful.

b. Housing Discrimination.

i. Like the ADA, the Fair Housing Act prevents the discrimination in housing on the basis of mental disability, and as under the ADA, autism is considered a mental disability

for the purposes of discrimination. Reasonable accommodation for individuals with disabilities is required in the housing setting, just as in the employment setting.

ii. If you believe you have been refused housing because you or someone in your household is autistic, a helpful first step is to contact the U.S. Department of Housing and Urban Development. They will be able to either help you in filing a complaint or should direct you to someone who can help you.

iii. Not only do the federal housing laws prevent discrimination on the basis of mental disability, but nearly every state has a local statute and agency that deals with housing discrimination as well. Additionally, all states other than Idaho, Mississippi and Wyoming provide for some form of payment of attorneys fees under certain conditions. If you believe you have a claim for discrimination on the basis of mental impairment, the U.S. Department of Housing and Urban Development or your local state agency can help you approach the problem either federally or within your jurisdiction.

c. Discrimination in Places of Public Accommodation.

i. General Information. Thirty-seven out of fifty states have not only codified some sort of anti-discrimination provision on the basis of disability, including mental disabilities, but have also provided for attorneys fees under certain conditions. These laws have almost universally been interpreted to include autism. For instance, in February 2010, New Jersey amended its Law Against Discrimination to expressly include "autism spectrum disorders" in its definition of disability. These provisions prevent places of public accommodations like restaurants, movie theaters, and retail establishments from refusing services on the basis of real or perceived mental disability. Under the ADA and other state statutes, public establishments are required to do more than simply provide services. They are obligated to make reasonable accommodations, like under the ADA's employment provisions. For instance, a YMCA was required to make reasonable accommodations to allow for an eight-year-old boy with autism to attend daycare and classes provided to children at the YMCA. In another case, a retail clothing store was required to allow a 14-year-old girl with autism to be accompanied by a family member in the dressing rooms, against store policy because it constituted a reasonable accommodation. Both of these cases were dealt with by the local state agency.

ii. What do I do if I believe that I or my child have been discriminated against? Most states have a human rights or equal protection agency that is receptive to reports of discrimination. For instance, Minnesota has a Department of Human Rights, New York State has a Division of Human Rights, and Massachusetts has a Commission Against Discrimination. These agencies are receptive to reports of discrimination, and can either personally help you file a complaint or can direct you to someone who can, based on the details of your individual situation. If you believe that you or your child have been discriminated against, contact an agency in your state that deals with any kind of discrimination. Once you have established that they deal with discrimination, they can assist you in finding someone to talk to about discrimination on the basis of mental disabilities. If your state agency is not helpful, or you are not sure who to contact, the U.S. Department of Justice maintains a toll-free ADA information line, 800-514-0301. This

hotline can provide you with answers to specific technical questions, free ADA materials, or information about filing a complaint.

d. Protection From Improper or Abusive Care.

i. Individuals with autism are protected from improper or abusive care in publicly funded programs under the Developmental Disabilities Assistance and Bill of Rights Act (known as the “DD Act”). This federal law was enacted to improve service systems for individuals with developmental disabilities. The law states that developmentally disabled individuals have a right to appropriate treatment, services, and habilitation for their disability, and includes a requirement that the federal and state governments ensure that publicly funded programs meet certain standards such as:

- provision of care that is free of abuse, neglect, sexual and financial exploitation, and violation of legal and human rights
- provision of appropriate and sufficient medical and dental services
- avoiding the use of physical restraint or seclusion as punishment
- avoiding excessive use of chemical restraints or the use of such restraints as punishment
- provision for close relatives or guardians of developmentally disabled individuals to visit the individuals without prior notice

ii. Additionally, the law states that all programs for individuals with developmental disabilities should meet standards that are designed to assure the most favorable possible outcome for those served.

iii. The federal agency responsible for implementing the DD Act is the Administration on Developmental Disabilities (a division of the Administration for Children and Families). This agency, known as ADD, established protection and advocacy (P&A) systems in each state to protect the legal and human rights of developmentally disabled individuals. These individual state P&A Systems are monitored and reviewed by ADD to ensure compliance with the DD Act.

iv. If a family member with autism is not being properly cared for, you can contact the local State P&A Agency for the state in which the individual resides. Attached is a table listing contact information for each state, which is also available on the ADD website, at <http://www.acf.hhs.gov/programs/add/states/pas.html>. The P&A Agency will work to investigate complaints concerning the rights of the individual, and to resolve complaints through mediation, alternative dispute resolution, or litigation.

v. Additionally, some states have established regulations designed to investigate incidents of abuse of developmentally disabled individuals, and take steps to prevent such incidents from recurring. For example, in New York state, people who receive mental health services from the state’s Office of Mental Retardation and Developmental

Disabilities (OMRDD) are protected by regulations which require service providers to report incidents of injury or abuse. The reports are then investigated by an independent committee which provides steps for follow-up and prevention of further incidents.

vi. If you feel that a family member with autism is in danger and requires immediate intervention, contact your local law enforcement agency or 911 for assistance.

e. **Helpful Resources for Questions Regarding Legal Protection and Discrimination.**

i. <http://www.eeoc.gov/employees/charge.cfm>

ii. <http://www.neurodiversity.com/discrimination.html>

iii. Autism, Discrimination and the Law: A Quick Guide for Parents, Educators and Employers, by James Graham

iv. <http://www.mass.gov/mcad/forIndividualsEmployees.html>

v. http://portal.hud.gov/portal/page/portal/HUD/topics/housing_discrimination

vi. <http://www.eeoc.gov/policy/docs/retal.html>

vii. http://www.justice.gov/crt/housing/housing_coverage.php

viii. <http://www.ada.gov/>

ix. <http://www.acf.hhs.gov/programs/add/states/pas.html>.

V. Divorce

a. **What is the proper way to help educate the court so that it understands the many facets of autism?**

i. In custody proceedings, a family court judge will generally hold an evidentiary hearing to get information about what is best for the child. Usually, this involves hearing from witnesses with personal knowledge of the child's life circumstances. The parents in a custody case usually will testify, and additional witnesses may include teachers, relatives, friends of the family or mental health professionals who have treated any of the parties.

ii. A parent testifying as a witness should be prepared to discuss every facet of their child's autism. A parent should be prepared to present to the court the care that the child needs on a day to day basis, including its financial costs and the role that each parent has played in the care in the past. Any documentation that the parent can provide as proof of their testimony should be prepared for introduction as an exhibit.

iii. While a parent is a good source of information regarding the individual circumstances of the particular autistic child, a mental health expert can be an extremely helpful and authoritative voice in explaining autism to the court. Many children with autism have already undergone and are continuing to receive treatment from a mental health

professional. In such situations, the mental health professional with prior knowledge of the child's circumstances is in the best position to describe autism as a general condition and its effect on the child's interest in this particular circumstance.

iv. If no professional with previous knowledge of the child is available, then the court could appoint an expert witness, such as a mental health professional or a social worker, to gather information about the child and parents' circumstances. Parents should be sure that such a professional is made aware of the child's condition and all facets of its impact. A parent may also hire an expert witness who is familiar with autism to help educate the court. Such a witness will be required in most courts to meet certain standards to qualify as a capable expert, including that his or her testimony is based upon sufficient facts, his or her testimony is the product of reliable principles and methods, and he or she has applied the principles and methods reliably to the facts of the case.

b. Can one divorced parent move forward with an evaluation if the other parent does not consent?

i. In many divorces, a parenting plan, custody order or other agreement will speak directly to the question of which parents can and must consent in certain situations, including the need for medical treatment and decisions regarding education. In situations where either or both parents are allowed to consent, these agreements often require notice to the other parent when any such decision are made.

ii. Where there is no explicit indication otherwise in an agreement between the parents, the consent of one parent is usually enough to initiate an evaluation. Schools are generally required to get consent of one parent to perform an evaluation, regardless of whether the parents are married or divorced. Either parent may provide the needed consent, unless a court order has been issued terminating that parent's right to make educational decisions.

iii. If one of the two divorced parents does not want an evaluation to proceed, he or she can typically do one of two things. First, the non-consenting parent could return to divorce court and ask the court to remove the consenting parent's educational decision-making authority. Second, the non-consenting parent could initiate a special education due process hearing by filing a due process complaint with the Office of Dispute Resolution. A Hearing Officer in the due process hearing will then decide whether the evaluation will go forward. However, initiation of a due process hearing does not negate the consenting parent's consent or prevent the district from moving forward with an evaluation pending the outcome of the hearing.

c. What is the best way to implement coordinated care between divorcing spouses so that the child has consistency?

i. The easiest, and possibly the most effective, way to implement coordinated care practices between divorcing parents is to come to an agreement on the proper care for the child prior to or during divorce proceedings. A useful tool to implement such practices in many states is a parenting plan. A parenting plan is a detailed description of the manner in which parents intend to continue caring for their child after divorce. It often includes

provisions related to custodial and visitation time allotted to each parent, scheduling, child support, education, medical care and resolution of disputes regarding child care. For parents of a child with autism, a parenting plan can be used to establish in a highly specified way proper care techniques, how to deal with certain medical and mental health issues that may arise, how costs of care will be shared and other concerns related to the child's condition.

ii. Parenting plans are often established through negotiation between the two parents. This is ideal because it is often the parents who know the child's needs and what will work for the individuals involved best. However, it is not uncommon for the parents to have difficulty agreeing on the parenting plan, in which case a mediator may be used to find a fair compromise. Some states require, and many states allow, a parenting plan to be submitted to the court during custody proceedings. Courts may also provide a mechanism, such as inclusion of the parenting plan in a court order, for making the agreement enforceable in the event that either parent fails to follow the care practices it contains.

iii. The proper approach for dealing with concerns about a parent who is not following proper care practices for a child with autism will vary by state. In states that allow the terms of parenting plans to be enforced, a parent can seek relief from the court for violations of a parenting plan. Courts may even hold a non-complying parent in contempt. Alternatively, a small number of states have passed laws enabling courts to order parenting coordination. Parenting coordination consists of appointment by the court of a trained mental health or legal professional to assist the parents in implementing coordinated parenting practices. The parent coordinator will often observe each parent's interaction with child and, if relevant, adherence to a parenting plan, give advice on how to improve and report back to the court with observations. In other states or where there is an absence of any sort of formal agreement on parenting practices, a parent may be able to get court assistance, such as the appointment of a professional to monitor visits with the non-complying parent, in the event the court is persuaded that the parent's behavior is harming the child.

iv. State laws regarding agreements on parenting practices vary widely. It is important to be aware of your state's laws on the subject and it will likely be helpful to consult an attorney familiar with these laws and the practices of the local family court.

d. How should divorced parents handle finances over the lifetime of a parent after divorce?

i. Financing Childhood – Child Support.

(A) The financial costs of caring for a child with autism is generally shared by the parents after divorce. The custodial parent of a child is generally entitled to receive child support payments from the non-custodial parent to assist with the expenses of providing for the child. Child support is available regardless of whether the parents were ever married, the custodial parent is responsible for the separation or divorce or whether the custodial parent has the means to provide for the child alone. However, paternity must be admitted or proven in order for a

father to be required to make child support payments. In some cases, receipt of public assistance may affect whether and to what extent a parent can receive child support payments or whether such payments must be surrendered to the state. This will depend on state public assistance and child support agency rules.

- (B) Child support is determined by family courts in most states using a standard formula. The formula often considers the non-custodial parent's income, the custodial parent's income, the number of children being supported and each child's basic needs. Payments from a Special Needs Trust (see below) are not usually factored into the calculation of Child Support payments. Courts will authorize a subpoena for financial records of parents who refuse to provide their financial and income information or are believed to be lying about such matters.
- (C) State guidelines usually do not explicitly account for the additional expenses that raising an autistic child requires. However, many states' guidelines allow courts to deviate from the standard child support calculation if certain circumstances indicate that the standard calculation is insufficient. The special needs of a child is often one of these factors.
- (D) Parents should be prepared to educate the court regarding the nature of the child's condition and the expenses that the child's special needs entail. Many court's will appoint a mental health professional or other child specialist to evaluate the child. At the very least, a parent should be prepared to answer questions and provide documentation of prior evaluations and diagnoses that he or she received. A parent may want to consider getting help from an autism specialist to educate the court. A parent might consider addressing the costs and providing documentation of the following expenses and others: therapy, doctor bills, other practitioners, medications, equipment, supplies, caregiver training, special nutrition requirements, home modifications, special school costs, non-parental caregivers and transportation.
- (E) The custodial and non-custodial parents can negotiate a written agreement regarding child support. As long as the agreement meets any legal requirements imposed by state law, courts will generally enforce such agreements. It is often a good idea to get court approval of such agreements once signed. A court may require an agreement to show that the standard child support formula was considered and that deviations from the standard award are explained and acknowledged by both parties.
- (F) Custodial parents of children who have been identified as autistic after child support has been settled can move to have a child support order or agreement altered to account for the additional expenses that the diagnosis will entail. Many states require the parent seeking the change to make a motion with the court and provide evidence of the need for additional support amounts and of the non-custodial parent's ability to pay such amounts

ii. Financing Adulthood - Special Needs Trust.

- (A) In most cases, child support payments are required to continue until the child is a certain age (often 18 or 21) or is legally emancipated. A child with autism may not be ready to support or make decisions for himself or herself at the typical age of emancipation. In such cases, it is important that the child's needs be accounted for, including through the provision of continued child support. If possible, the possibility of continuation of support if the child is not self-sufficient at the time he turns the standard legal age should be addressed in the initial child support agreement or order. In cases where it has not been addressed, a court may order child support continued upon a showing that the child with autism is not self-sufficient and funds are needed to pay the child's expenses. The authority and willingness of courts to grant such continued support may vary greatly by state.
- (B) A Special Needs Trust is a trust to hold assets for a special needs beneficiary. Such Trusts can be used for a special needs beneficiary receiving public benefits, such as Supplemental Security Income or Medicaid, in order to supplement the beneficiary's income without impacting eligibility to receive benefits. There are generally two kinds of Special Needs Trusts:
- (1) a Third-Party Special Needs Trust is designed to hold property provided by someone other than the special needs beneficiary. A parent, custodial or non-custodial, or anyone else can put money in a Trust for the benefit of the special needs beneficiary. The person who sets up the trust has the right to determine where any money left in the trust will go after the death of the special needs beneficiary.
 - (2) a Self-Settled Special Needs Trust is designed to hold property belonging to the special needs beneficiary. As such, if the special needs beneficiary is a recipient of a state Medicaid program, the state program must be repaid out of the remaining funds upon the special needs beneficiary's death prior to distribution to those designated to inherit what remains.
- (C) A Special Needs Trust can ensure that money will be available for a child throughout his or her lifetime and that such money will not impact their access to means-tested benefits. A trustee, often the custodial parent, is designated to manage the Trust for the benefit of the special needs beneficiary. The trustee would be responsible for ensuring that payments from the Trust do not exceed the amounts that would render the beneficiary ineligible to receive benefit
- (D) Upon divorce, a parent may want to revise his or her will and change beneficiary designations on insurance and retirement benefits so that property and proceeds are diverted to the Special Needs Trust rather than directed to their ex-spouse or to the child directly. Because child support payments are viewed as belonging to the child, there is a danger that such payments could disqualify the child from means-tested benefits. In order to avoid this issue, a parent may want to assign some or all child support payments to a Special Needs Trust. In many states, child support obligations do not terminate at the death of the non-custodial parent and future support can be obtained from the deceased parent's estate. It may be

worth convincing the non-custodial parent to obtain life insurance and arrange for the proceeds to be deposited in a trust that continues to make the child support payments on his estate's behalf.