

# Living on the Autism Spectrum: Legal Issues Over a Life Span

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Research suggests that more than 3.5 million Americans are living with a neurological condition known as autism. More individuals have been diagnosed with autism in recent years than were previously diagnosed with this developmental disability. Known rates of autism are higher now than ever before. As a result, academic interest in autism has increased significantly.

In response to this growing interest, the University of California at Los Angeles (UCLA) has been offering an undergraduate class on the topic of autism. It is titled “Current Perspectives on the Autism Spectrum and Neurodiversity.” Each week a different theme is chosen to examine issues involving autism from that perspective.

For the past few semesters, Dr. Nora J. Baladerian and I have been invited to speak during the week when “legal issues” is the designated theme. Dr. Baladerian has addressed the issue of disability, abuse, and victimization. I have focused on legal issues involving capacity to make decisions – issues which arise in adult guardianship and conservatorship proceedings.

While dysfunctional state guardianship systems adversely affect many adults on the autism spectrum, and legal reform of those systems deserves academic attention, there are a wide range of other legal issues that arise over the course of a life with autism. Along with problems associated with decision-making capacity, myriad other legal issues deserve mention as well. Therefore, the focus of my presentation at the autism perspectives class in the 2017 fall semester includes an overview of a wide range of legal issues.

My presentation looks at legal issues that may arise during the life span of someone on the autism spectrum – as a child, a teenager, and an adult.

Many of the issues are the same or similar to what a neurotypical person would experience, although others are more unique to people with developmental disabilities. Hopefully, by identifying the various legal issues autistic people may encounter during their lifetimes, students will have a better understanding of the difficulty autistic Americans have in securing equal rights and living an independent life.

## **Childhood Years**

Children are born with legal rights – not legal responsibilities. The philosophical foundation for the legal rights of American children is the Declaration of Independence, the preamble of which recognizes that they are created equal to everyone else. Among the legal rights inherent in personhood – a status that arises at birth – are life, liberty, and the pursuit of happiness.

Whether autism is inherited or developmentally generated, an autistic child is a “person” entitled to equal protection and due process of law under the United States Constitution.

These fundamental rights are important to children with autism since these protections restrict the manner in which they may be treated by federal, state, and local government entities. Children with autism, like children generally, may not be treated in an arbitrary or irrational manner by government regulations or public benefits programs.

Because they have special needs that neurotypical children do not, government agencies may be more involved in the lives of children with autism than children in general. Thus, the constitutional protections of equal protection and due process may have greater significance in their lives.

Even though children with disabilities will not themselves raise constitutional objections to unfair treatment by government agencies, others, such as their parents, can raise these issues for them. Therefore, anyone wanting to understand legal issues in the life of people with autism should remember that they start off life and continue throughout life endowed with fundamental constitutional rights.

This principle forms the foundation for the statement of rights in the Lanterman Act – landmark legislation enacted decades ago by the California Legislature recognizing the right of people with developmental disabilities to dignity, respect, equal treatment, and essential services.

The Lanterman Act declares: “Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the United States Constitution and laws and the Constitution and laws of the State of California.” The Lanterman Act is frequently cited in disability rights and disability services litigation.

The life of a child – any child – generally involves home, neighborhood, school, relatives, and perhaps a church or other religious institution. A child interacts with the world in a multitude of roles – as a son or daughter, sibling, student, friend, and consumer. Each role has a legal dimension.

When it comes to school, most people do not think of this setting in legal terms. However, for autistic students there is an entire body of special education law that comes into play. There is a federal law – Individuals with Disabilities Education Act, known as IDEA – that confers the right to a free appropriate public education to students with autism and other disabilities. Thus, there may be IDEA-related legal disputes between parents and schools over an Individualized Education Plan (IEP).

Some children with autism need specialized care or personal services outside of a school setting. A combination of federal and state funds – plus private insurance – may be used to secure these services.

Parents have to navigate through a bureaucratic and legal maze of regulations to find and obtain the necessary care for their autistic child. Although the child may be unaware of the details, he or she may go through childhood hearing terms such as “Medicaid Waiver,” “IEP,” or “IPP.” The latter is a term used in California for an Individual Program Plan through which an agency known as a regional center coordinates disability services for a client with developmental disabilities.

While the life of a neurotypical child is complicated enough in contemporary society, the life of an autistic child has extra layers of complications due to legal, financial, and medical needs and concerns that children without disabilities do not experience.

Add to all of this laws regarding victimization. Children with disabilities are more likely to be victims of abuse than generic children. By the age of 18, a majority of children with disabilities may have been victims of abuse – whether emotional, physical, or sexual. Some of this rises to the level of a crime, so many children with disabilities – including those with autism – may have to interact with the criminal justice system.

Unfortunately, many victims with disabilities do not report the abuse out of fear or because they think they will not be believed. When a report is made, often nothing happens – there is no arrest or prosecution. So the interaction of an autistic child with law enforcement officials may be a frightening and often unproductive experience.

Being a victim of abuse or neglect also may involve family court or juvenile dependency court. Parents may battle over custody and visitation in family court – legal skirmishes that can last for years. If both parents are responsible for the abuse or neglect, juvenile dependency proceedings may be used to find foster care, create a guardianship, or promote parental rehabilitation and family reunification.

Navigating the legal waters of family court or dependency court is emotionally disturbing enough to a neurotypical child, so one can only imagine how

difficult it is for an autistic child.

Childhood years are idealized by society as a time of innocence and carefree living for children – and sometimes that is the case. But for an autistic child, being part of a family system that deals with IEPs, IPPs, Medicaid waivers, and the like – and sometimes experiencing disturbing legal proceedings – can add a degree of aggravation to the complications inherent in autism itself.

## **Teenage Years**

When an autistic child becomes a teenager, another set of legal issues emerge in his or her life. Some of this stems from the social dynamic of wanting to fit in and to be liked by neighborhood kids and school mates. While it may vary from individual to individual, peer pressure may exist in the teenage life of someone with autism.

Sexual urges and raging hormones create biological impulses for all teenagers – regardless of disability status. Autistic teenagers are not exempt from the biological transformation from child to adult.

Many states set the age of sexual consent at 16. In New York, the age is 17. In California, it is set unrealistically high at 18. It may be as low as 14 in some states – if the sexual participants are both within three years of age.

Sex with anyone below the age of 14 is a crime in all states. Factual consent is irrelevant. In California, even if both partners factually consent to sex, if one of them is under 18, it is a crime.

Sex in public places is also criminalized. In some states public sex is automatically illegal, even if it is not seen by someone who is offended. In California, the law is more nuanced. Sex in a place that is technically public, but is not exposed to the eyes of an offended viewer, may not be a criminal act.

Not only is sex education essential for autistic teens – just so they understand why they have biological urges – but it is important for them to learn “the

rules of sex” as part of that education. Failure to learn the rules of sex – and to adhere to them in real life – can result in an autistic teenager being arrested and placed in custody. A juvenile detention center is not where any teen – much less one with autism – would want to be.

Teens with developmental disabilities may be more easily led astray than those without. Peer pressure can get them in trouble with the law if they are convinced by an overbearing individual to engage in conduct that is criminal – perhaps stealing something from a store or transporting drugs.

Parents and others in a position of authority need to explain to autistic teens what is against the law – above and beyond sexual conduct – and how to stay out of trouble. They need to be encouraged not to give in to peer pressure.

In places such as California, all students – including those on the autism spectrum – have a right to be safe at school. They have a right to be free from harassment or bullying. Autistic students need to be told of this statutory right and the need to complain if they are verbally or physically mistreated by anyone at school. There are administrative procedures in place to process such complaints if and when they are filed.

Parents also need to encourage an autistic son or daughter to report abuse that occurs at school to them – particularly if the perpetrator is a school employee. School-related abuse – especially if it is physical or sexual – can give rise to a lawsuit against a school district. As more people with disabilities and their families speak up, such lawsuits are becoming more frequent.

## **Adult Years**

When someone with autism turns 18 and thus becomes an adult, a wide range of complex legal issues must be dealt with by the individual and by responsible adults in his or her life. These include: voting, finances, housing, health care, sex, marriage, education, and employment.

Once a person with autism turns 18, he or she has the legal right to vote and to make all major and minor life decisions, including in the areas mentioned above. The parent or guardian who previously had been making such decisions, no longer has the legal authority to do so.

Unless and until a court enters an order of guardianship or conservatorship on the grounds of “incompetency” or mental disability, an autistic adult remains in charge of all aspects of his or her life. The adult has sole authority to decide where to live, whether to vote, when to have sex with a consenting partner, whether to get married, what school to attend, whether to seek a job, and what doctor and what medical services to have.

Turning 18 and becoming an adult confers on all individuals – with or without disabilities – all of the rights and responsibilities of adulthood. The hybrid adult/child interim teenage years are over.

An autistic adult can voluntarily defer to the wishes of others, but it must be voluntary. Transporting an adult to a place where they don’t want to go is kidnaping. Making an adult stay in place against his or her wishes is false imprisonment. Requiring someone to have medical procedures he or she objects to is battery. Adults in the life of someone with autism must make a major mental adjustment when that someone turns 18. Either the autistic adult has to be given the final say over what happens, or the parent or other authority figure must take legal action to give them authority to make decisions for the individual.

If a petition is filed in court for a guardianship or conservatorship, the fundamental right to make major life decisions is placed in jeopardy. These legal proceedings are a huge intrusion into the life of an autistic adult.

Due process, the Americans with Disabilities Act, and state statutes require that a guardianship or conservatorship order be narrowly tailored to the specific needs of an individual whose mental competency is challenged. Decision-making capacity

must be assessed in each area called into question. An attorney should be appointed to advocate for and defend the rights of the individual. Less restrictive alternatives must be explored and used if they are feasible.

Unfortunately, many state guardianship systems employ assembly line justice and process cases without following constitutional and disability rights laws. Each year, thousands of Americans are placed under guardianship when other options – with the use of appropriate supports and services – would have more properly balanced the competing interests of freedom and protection.

In some cases, parents may bypass the guardianship process altogether by having their autistic adult child sign powers or attorney or supported decision-making agreements. Because such legal documents usually do not include a monitoring process and instead delegate carte blanche authority to a parent or third party, such an alternative to guardianship may increase the risk of abuse or exploitation.

Supported decision-making arrangements can be a good option – but only if they are safe and legal. Issues regarding capacity to sign these documents, undue influence, conflicts of interest, and monitoring for abuse must also be dealt with.

This is the tip of the iceberg. The theme of “legal issues” and autism is quite complex. It could easily be the subject of an academic course all of its own.



Thomas F. Coleman is the legal director of Spectrum Institute – a nonprofit organization sponsoring a Disability and Guardianship Project and a Disability and Abuse Project.

For more information about supported decision-making, go to: <http://spectruminstitute.org/sdm/>. For a comprehensive set of commentaries and reports on guardianship and conservatorship and the need for reform, see: <http://spectruminstitute.org/library/>.