Autism and Conservatorships:

Protecting Civil Rights and Providing Access to Justice

Presentation to UCLA Class on "Current Perspectives on the Autism Spectrum and Neurodiversity"

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By Thomas F. Coleman
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According to statistics from the Department of Developmental Services, regional centers provide services to 80,000 autistic clients. About 20,000 of them are adults, some of whom are living under an order of conservatorship.

About 3,300 regional center clients will turn 18 this year. By 2024, that number will increase to more than 4,000 annually. A significant number of these young adults will find themselves involved in probate conservatorship proceedings because their parents or an agency such as the public guardian believe they lack the capacity to safely manage their finances or health care needs or are not able to make decisions regarding their place of residence, educational endeavors, vocational interests, social contacts, or sexual activities.

This presentation provides UCLA students with a basic understanding of what autistic adults face when someone petitions the court for an order of conservatorship. To understand the situation better, students should know what substantive rights an autistic adult has prior to a conservatorship, the procedural rights that should be afforded to them in a conservatorship proceeding, and the practical reality of how these proceedings actually operate. Because there is a significant divergence between theoretical procedural protections and actual practices, major reforms are needed to bridge this gap.

Legal Rights

Everyone makes decisions. As children, we are allowed to make minor choices in our life. When it comes to the major decisions, however, the legal authority to make these choices is vested in parents or guardians. When an individual reaches the age of majority and becomes an adult, the child is emancipated from parental authority and has the exclusive right to make his or her own decisions.

Substantive Rights

The constitution prohibits the government from unreasonably interfering with an adult's right to make decisions regarding where to live, where to travel, whether and how to vote, social, recreational and sexual activities, what job to hold, whether to go to school or not, and how to spend money. State and federal statutes regulate the extent to which private individuals and businesses may interfere with the choices of adults in such matters.

The protections of the federal constitution apply to all individuals. There is not an exception for people with disabilities. The same is true for protections under the California Constitution.

The state's Lanterman Act clearly explains that constitutional and statutory rights apply to individuals with intellectual and developmental disabilities. However, just as it is for everyone else, the rights of people with disabilities are not absolute.

Sometimes the rights of an individual must be balanced with the rights of other individuals or with society's duty to protect those who are vulnerable. Thus, states have created systems to protect adults who are seriously at risk of abuse, neglect, or exploitation. Some states call it a guardianship system. California calls it conservatorship.

Autistic adults may find themselves as involuntary participants in such legal proceedings. This occurs when someone petitions a court to intervene in their lives due to apparent functional incapacities that allegedly interfere with their ability to take care of their own personal or financial needs.

Procedural Rights

The Fourteenth Amendment to the United States Constitution declares that the government may not deprive an individual of life, liberty, or property without due process of law. The California constitution has a similar provision.

When a parent, relative, government official, or other individual files a petition with the superior court to place an adult under an order of conservatorship, the adult's liberty is placed at risk. Any or all of the decision-making rights mentioned above can be taken away in a conservatorship proceeding. The individual, therefore, is entitled to due process protections as those issues are being decided.

But what process is due? The law recognizes two types of due process: constitutional and statutory.

Constitutional due process requires that court proceedings that place basic liberties at risk must use procedures that are fundamentally fair.

For example, constitutional due process requires that the burden of proof in a conservatorship proceeding is higher than that in an ordinary civil proceeding for money damages. Conservatorships require clear and convincing evidence that an adult lacks the functional capacity to take care of his or her basic needs.

In ordinary civil proceedings for money damages the appointment of counsel is not required for indigent litigants. However in proceedings that substantially affect liberty interests, such as criminal, juvenile delinquency, juvenile dependency, child welfare, civil commitments, and conservatorships, constitutional due process requires the appointment of counsel for those who cannot afford one.

Statutory due process is another matter. It requires procedures to be followed that the law declares as mandatory for a particular type of proceeding.

In conservatorship proceedings, for example, the petition must be verified. It must be served on the proposed conservatee. A court investigator is supposed to meet and evaluate the individual. Counsel must be appointed if requested or if the court determines an attorney is necessary to protect the interests of the proposed conservatee.

A hearing must be held to: (1) inquire into the individual's capacities; (2) determine whether the burden of proof has been met; (3) ascertain if a less restrictive alterative to conservatorship would suffice to protect the individual from harm; and (4) decide who should be appointed as a conservator if one is necessary.

The proposed conservatee has the right to demand a jury trial. During the hearing, the proposed conservatee has a right to present evidence, call witnesses, and challenge the evidence of the petitioner. In preparation for the hearing, the proposed conservatee can ask that experts be appointed to help bolster portions of his or her case or to rebut aspects of the petitioner's case. In other words, state statutes afford a proposed conservatee a toolbox filled with procedural devices to test the validity of a petition or contest a conservatorship.

These constitutional and statutory protections theoretically seem awesome and appear to be plentiful. In practical reality, however, they are often more illusory than real.

Functional Realities

Parents are accustomed to making major decisions for their autistic children as they are growing up. Schools, doctors, and service providers look to the parents for guidance or direction on educational, medical, and financial matters. But as a child is about to reach adulthood, everyone knows that the legal authority to make these decisions will shift from the parent to the child the day the child turns

18 and becomes an adult. But is the individual really capable of making major decisions? Is the individual at risk of harm, either self-harm or from others when parents will no longer have the legal authority to manage the life of their loved one?

Sometimes the functional inability of an autistic adult to navigate through a minefield of major decisions in life is clear. Sometimes the functional ability, with proper supports and services, is also clear. Other times, the parents, young adults, and third parties are operating in a gray area where capacity to make major decisions is in doubt.

Service providers want clarity. They do not like operating in a gray zone where they could be sued for allowing parents to make decisions when the adult has the legal right to do so. They also want to avoid situations where they are unsure if an adult truly understands a situation and is giving informed consent. An order of conservatorship provides such clarity. The conservator has the authority. But constitutional rights are not to be taken away for the sake of clarity. There must be a necessity for a conservatorship – a necessity that less restrictive alternatives will not solve.

For many young autistic adults, there is pressure placed on the court to provide the clarity that the parents and service providers want. But the constitution and statutes call for a tempered approach, one that pushes back against this pressure and tests whether such incapacity exists for all decisions, whether there is capacity for some areas of decision-making, and whether less restrictive alternatives to conservatorship are feasible.

Such testing is contemplated by state laws. Statutes call for the appointment of an attorney to represent the proposed conservatee. Without an attorney the individual will not be able to take advantage of the procedural safeguards provided by law. Reading and understanding the petition and other legal papers are one matter. But what about filing a motion to appoint an expert to evaluate the individual's capacities? What about demanding an expert such as a social worker to evaluate less restrictive alternatives? What about insisting on a hearing at which objections are made to hearsay statements and reports? What about calling favorable witnesses and cross-examining the petitioner's witnesses? Filing an appeal? None of these procedures are practically available to a proposed conservatee who does not have an attorney.

In a significant number of cases, judges are not appointing attorneys to represent these litigants. And when attorneys are appointed, many of them are not properly trained to effectively communicate with autistic clients. Judges also put pressure on appointed attorneys to settle the cases in order to get them off their dockets. Many attorneys succumb to this pressure because the judges control a portion of their income stream. The judges can decide their fees in a specific case and whether the attorneys get future appointments to cases.

Then there are attorneys who feel it is their role to advocate for what they, the attorneys, believe is best for their clients rather than advocate for what the client wants.

When autistic litigants do not have an attorney, or when the attorney surrenders rights rather than defends them – which is what happens in many cases – the system lacks accountability. There are very few appeals to a higher court because the litigant lacks the ability to process such an appeal on his or her own. And the attorney is not going to file an appeal to challenge the judge who sets the attorney's fees or to challenge the attorney's own ineffective representation. As a result of these procedural realities, the appellate courts are not seeing the big picture of how dysfunctional the conservatorship system really is and they are unable to issue rulings directing these flaws to be corrected.

The protections of the constitution and the mandates of statutes are technical safeguards. But generally these protections remain illusory because of the lack of accountability in the conservatorship system. That is why a growing number of individuals and organizations are demanding reforms. Among these organizations are Spectrum Institute,

the Autistic Self Advocacy Network, the Arc of California, and TASH.

Necessary Reforms

Spectrum Institute has become the primary organizational proponent for conservatorship reform in California. As its legal director and head of the Disability and Guardianship Project, my advocacy has included doing research, writing reports, filing complaints, and submitting briefs arguing that as it operates in practice, California's probate conservatorship system violates due process, ignores the mandates of the Americans with Disabilities Act, and fails to follow the directives of state statutes.

These pleas for reform have been made to the Governor, Supreme Court, Chief Justice, Judicial Council, legislative leaders, and civil rights enforcement agencies. Until very recently, the responses mainly have been avoidance, denial, or rejection.

Some slight movement toward reform has recently occurred. The Supreme Court is reviewing its first appeal from an autistic conservatee. The Court of Appeal reversed a conservatorship order because the autistic conservatee never once appeared in court. The Judicial Council has expanded mandatory training requirements for court-appointed attorneys. Officials at the California State Bar have inquired about how they can improve their complaint system. The Fair Employment and Housing Council has welcomed suggestions on how to strengthen disability rights regulations that apply to judicial proceedings. A state senator has introduced a bill to clarify that the role of counsel appointed for proposed conservatees with developmental disabilities is to advocate for the expressed interests of the client. A county supervisor in Northern California held a forum focusing on conservatorship deficiencies and is facilitating an ongoing dialogue between reform advocates and government officials.

Slight movement toward reform is better than none at all. But much more needs to be done.

The United States Department of Justice should investigate complaints alleging violations of the Americans with Disabilities Act (ADA), both systemic and in individual cases, by courts in conservatorship cases. The state Fair Employment and Housing Department should do the same. DFEH has authority to enforce the ADA in California.

The Department of Developmental Services should provide guidance to and oversight of regional centers as they perform their statutory role to evaluate whether a conservatorship is necessary for a client and whether less restrictive alternatives may be feasible.

The Supreme Court should clarify that the Code of Judicial Ethics prohibits judges who hear conservatorship cases from controlling, directing, or coaching attorneys for proposed conservatees through the power to appoint these attorney and pay them in individual cases. Another agency should be handling this administrative function. Judges should decide cases, not manipulate outcomes.

The Judicial Council should work with the Legislature to create a new system for recruiting, training, appointing, paying, and monitoring attorneys appointed to represent clients with disabilities in probate conservatorship proceedings.

The Legislature should enact a right-to-counsel bill that would mandate the appointment of attorneys for all proposed conservatees, clarify that their role is to advocate for the client's wishes and to defend the client's rights, and direct the State Bar to develop performance standards for these attorneys.

These are just a few of the measures that would ensure that the rights of autistic adults and other proposed conservatees are truly protected. We must bridge the gap between the theoretical rights enshrined in law and the reality of how the conservatorship actually operates in practice. ◊◊◊

Thomas F. Coleman is the legal director of Spectrum Institute. He may be reached by email at: tomcoleman@spectruminstitute.org

Autistic Conservatees: Young Men and Women Denied Access to Justice

Case Studies

Gregory

Gregory has autism. His mother filed a petition for a limited conservatorship when Gregory turned 18 so that she could continue to make important decisions for him pertaining to health care and financial matters. The court appointed an attorney to represent Gregory as is required by law in a *limited* conservatorship proceeding.

Since the mother did not ask the court to remove Gregory's right to make his own social decisions, the order granting the limited conservatorship did not transfer that power from Gregory to his mother when she was appointed as conservator.

Unfortunately, because his court-appointed attorney did not object, the judge removed Gregory's right to vote. This was done without regard to Gregory's desire to vote or the level of his understanding of the voting process. The judge and the attorney assumed that Gregory would not be capable of voting. No evidence existed to support that unwarranted assumption.

Research by Spectrum Institute conducted in 2014 revealed that about 90% of conservatees were routinely being stripped of their voting rights. In many cases, court-appointed attorneys were actively participating in the disenfranchisement process.

When Gregory started to object to visiting with his father, Gregory's mother asked the court for instructions and Gregory's first appointed attorney supported Gregory's wishes. The court said it would allow Gregory to decide himself. When the father objected, the court appointed another attorney who then recommended mandatory visitation every Sunday. The court agreed to this.

Rather than pressuring her son to have forced visits, the mother resigned as conservator and agreed to be replaced by a professional fiduciary. Then the battle began all over again when the new conservator also wanted to respect Gregory's wishes. The father asked the court to remove her and to appoint new co-conservators who would enforce the mandatory visits. Once that occurred, the new co-conservators pressured Gregory to visit with the father.

Throughout the proceedings, Gregory did not have an attorney to defend his right to make his own social decisions. Caving in to pressure from the father – and from the judge who wanted this ongoing visitation battle to end – Gregory's attorney agreed to the every-third-weekend arrangement.

Gregory's caregivers then asked an attorney interested in disability rights to help Gregory fight the order. The superior court refused to allow this. The attorney then represented the mother pro bono and through her he vicariously raised the constitutional violations of Gregory's rights in an appeal.

Rather than addressing the merits of these arguments, the Court of Appeal dismissed the appeal on the ground that only Gregory could complain on appeal. However, Gregory was not a party to the appeal because his attorney had walked away from the case when the visitation order was entered.

Once the appeal was dismissed and the case returned to the trial court, the judge decided to resolve the constitutional issue by removing Gregory's social rights completely. He appointed a new attorney for Gregory. This lawyer may have been selected outside of normal rotation in order to ensure cooperation with this plan. And that is exactly what the selected lawyer did.

Despite strong evidence of Gregory's ability to make his own social decisions, the lawyer ignored the facts and instead argued what she thought was best for Gregory, namely, that the co-conservators should control Gregory's social life and contacts.

As a result of this lawyer's advocacy against her client's wishes and because of her decision to ignore favorable evidence, the judge removed Gregory's social decision-making rights.

The co-conservators then affirmed the every-third-weekend arrangement. Therefore, during the past several years Gregory has been forced to visit with his father and attend church services despite his objections to both. Gregory's freedom of association and freedom of religion have been violated because his court-appointed attorney did not advocate for his stated wishes or defend his rights.

Spectrum Institute filed a complaint in Gregory's case with the U.S. Department of Justice for ADA violations by his attorney. The case is still pending.

Stephen

Stephen has autism. When Stephen turned 18, his mother petitioned the court for a limited conservatorship so that she could continue to make medical and financial decisions for him. However, she did not seek to control Stephen's social decisions.

The court appointed an attorney to represent Stephen. When the attorney came to Stephen's home, the attorney focused all of his attention on the mother, essentially ignoring Stephen. This occurred despite the mother informing the lawyer that even though Stephen was nonverbal, he could communicate through a method known as facilitated communication. The attorney ignored this information and communicated solely with the mother, acting as though Stephen was not there.

Among the questions the mother asked the attorney was whether Stephen would be able to vote. She advised the lawyer that her son wanted to participate in the upcoming presidential election. The attorney informed the mother that voting was inconsistent with an order of conservatorship.

As in Gregory situation, Stephen had good reasons for not wanting to visit with his father. The mother believed that would not be a problem since she was not seeking control of Stephen's social life and contacts. However, when the father entered the conservatorship case, the father used a pressure tactic to force visitation with his son. The father said he would object to the mother being appointed conservator, unless the mother and the attorney for Stephen would agree to Stephen having regular visits with the father. This would include extended stays in New York where the father lived.

Rather than fighting for Stephen's right to vote and resisting the father's demand for extended visitation with Stephen, the appointed attorney filed a report recommending that his client be disqualified from voting and agreeing to the visitation arrangement. This was completely contrary to Stephen's wishes.

When Spectrum Institute learned of this case, we became involved. At our urging, the appointed attorney advised the court that Stephen should keep his right to vote and should not be forced to have in-person visits with the father. However, at the last minute the attorney diverted from this course of action and without consulting Stephen suggested to the court that internet visits on Skype should occur periodically.

Stephen did retain is right to vote, but only due to the intervention of Spectrum Institute. The Skype visits occurred for a while, but since Stephen retained the right to make social decisions, he eventually adopted a practice of not answering a Skype call or ending it when he wanted to.

Access to justice, including having an attorney who advocates for the client's wishes, should not depend on intervention by an advocacy organization. Effective legal representation should be occurring routinely in every case. However, that is not the situation in most conservatorship proceedings.

Olivia

Olivia has autism. When she was about three years old, her mother decided she could not handle a special-needs child. So the mother placed Olivia in the home of Olivia's great grandmother. Olivia was raised in that home throughout her childhood, having occasional visits with the mother.

When Olivia was a senior in high school in Santa Barbara County where she lived, she and her mother had disputes about the classes Olivia was taking. The great grandmother gave considerable deference to Olivia in terms of educational decisions. In contrast, the mother wanted to have total control of the school situation.

To gain such control, the mother filed a petition for conservatorship. She wanted authority to make decisions in her 19-year-old daughter's life, especially educational decisions. The mother wanted Olivia removed immediately from the great grandmother's home so that she could move Olivia to Orange County where the mother lived.

Olivia was in 12th grade. Despite the fact that she would not have enough credits to graduate for another year, the school was going to allow Olivia to walk with her fellow students at the upcoming graduation. This was a big deal to Olivia.

Olivia did not want to move to Orange County. She liked Santa Barbara where her great grandmother, cousins, and friends lived. Because of the strained relationship with her mother, Olivia knew the move would upend her life.

The court appointed a public defender to represent Olivia. Despite having 300 open cases of various sorts to deal with – an unrealistic and unconscionable burden – the public defender vigorously advocated for Olivia. The case went to trial. However, the judge, who had nostalgic notions of a mother-daughter reconciliation, ignored evidence favorable to Olivia staying in Santa Barbara and entered an order appointing the mother as conservator.

The mother immediately yanked Olivia from the home of the great grandmother and forced her to move to the mother's home in Orange County. The mother took away Olivia's phone and severed all contact between Olivia and her relatives and friends in Santa Barbara. Olivia was not allowed to attend the graduation ceremony with her classmates.

Fortunately, the public defender did what virtually never occurs. She filed an appeal for Olivia to challenge the order of conservatorship. With urging from Spectrum Institute, the Court of Appeal appointed an appellate attorney to represent Olivia in the appeal.

Despite strong arguments from the appellate attorney, the Court of Appeal affirmed the order of conservatorship. The judges decided not to closely scrutinize the proceedings in the lower court, ruling that appellate courts should give deference to trial court decisions in conservatorships. They ignored pleas from the appellate attorney to examine whether the trial court decision was supported by clear and convincing evidence – a heightened burden of proof.

The appellate court ruled that even though clear and convincing evidence is required in the trial court, that heightened standard disappears on appeal. They ruled that appellate judges should give no greater scrutiny to conservatorship orders that deprive adults of fundamental rights than they do to judgments for money damages in civil cases.

The appellate attorney petitioned the California Supreme Court to review the case. That court granted review. The issue is whether appellate courts should more closely scrutinize conservatorships than ordinary civil cases. Spectrum Institute filed a friend-of-the-court brief in the case. We are awaiting a date for oral arguments to occur.

Ashley

Ashley has autism. Now 26 years-old, she has lived with her mother most of her life.

Ashley does not like to be touched, is resistant to hygiene and self-care, and has had several psychiatric holds for Psychotic Disorder NOS, anxiety, post-traumatic stress disorder, depression, and intermittent explosive disorder.

In September 2018, Ashley's mother filed a petition to be appointed conservator so she could authorize medical care. Ashley had a painful tooth abscess but no dentist would treat her without a court order.

The well-intentioned petition initiated a downward spiral for Ashley and her mother when the court investigator recommended that the mother's petition be denied and that the Public Guardian be appointed as Ashley's conservator instead.

The court appointed the Ventura Public Defender to represent Ashley. Unlike the situation in Olivia's case where the public defender did a great job of advocacy, this lawyer did almost nothing – possibly due to his huge caseload. The lawyer never met with Ashley. Ashley never once appeared in court.

Despite the mother's protests about the Public Guardian being appointed as her daughter's conservator, and despite the judge never once laying eyes on Ashley, the court granted the conservatorship and appointed the Public Guardian to control all aspect of Ashley's life. The mother appealed.

Recalling how the Court of Appeal in Gregory's case had dismissed his mother's appeal because it was his rights, not hers, that were violated, Spectrum Institute urged the Court of Appeal to appoint an attorney to represent Ashley on appeal.

We argued that this was required by the Americans with Disabilities Act which requires public entities to ensure that people with disabilities have meaningful participation in the services they provide. Without an appointed attorney, there is no way that Ashley would have meaningful participation in the appeal.

The appellate court did appoint an attorney – the same one that had represented Olivia in her appeal. The attorney reviewed the matter and filed a brief in which he agreed with the arguments of the mother that Ashley's right to due process was violated because there was no evidentiary hearing and because Ashley never appeared in court. Fortunately, the Court of Appeal agreed.

The court's opinion, binding on trial courts throughout California, states: "A prospective conservatee who suffers from Autism Spectrum Disorder, regardless of the degree of mental impairment, has due process rights. The Legislature has provided protection for a 'special needs' person. Presence in court so that the trial judge may see and hear the person is a necessary component of the process."

Referring to Probate Code section 1825 which requires the presence of a proposed conservatee in court, the opinion adds: "Section 1825 is like the light switch to the courtroom and until it is turned on (i.e., satisfied), the trial court cannot truly see the big picture. It is precluded from ruling on the merits of a petition to appoint a conservator until it complies with section 1825."

This favorable result likely would not have occurred if an appellate attorney had not been appointed on appeal. This case calls attention to advocacy deficiencies that are likely to occur when public defenders have unreasonably large caseloads.

Adults with developmental disabilities such as Ashley are often shortchanged by appointed attorneys who provide minimal services that do not challenge the allegations in the petition or develop affirmative evidence to support the use of less restrictive alternatives to conservatorship.

For more information on this access-to-justice problem and how it adversely affects people with intellectual and developmental disabilities and other adults with cognitive challenges, watch the 34-minute documentary film produced by film maker Greg Byers for Spectrum Institute titled "Pursuit of Justice."