

DISABILITY RIGHTS PENNSYLVANIA MONTGOMERY COUNTY GUARDIANSHIP PROJECT:

TWO YEARS OF PROGRESS TOWARDS REFORM

MAKING SYSTEMIC CHANGE, ONE CLIENT AT A TIME

A fundamental aspect of adult life is the autonomy to make our own decisions. Sometimes those decisions are good, sometimes not. In any event, most people enjoy the freedom to make decisions and control the direction of their lives as a natural transition to adulthood. However, this freedom is sometimes taken away from people with disabilities through guardianship when there is a concern about their ability to manage their own financial resources or to meet essential requirements for their physical health and safety. Fortunately, in Pennsylvania, the law recognizes that people who may need help in making decisions can avoid guardianship by taking advantage of less restrictive alternatives. Such alternatives help people with disabilities continue to make their own choices about where to live, how to spend their time, who they spend their time with, what services to receive, and health care.

Disability Rights Pennsylvania (DRP), with generous funding from the Pennsylvania Interest on Lawyers' Trusts Accounts (IOLTA) Board, is supporting the effort of the Montgomery County Court of Common Pleas (Court) to prevent and reduce the number of unnecessary guardianships of people with intellectual disabilities, autism, brain injury, mental illness, and similar disabilities through direct legal representation and targeted outreach and education about effective guardianship alternatives. This Report highlights the collaborative work between DRP and the Court towards this end, as well as the successful results of this work on behalf of individuals with disabilities from July 2019 through June 2021.

SHIFTING TO A NEW PARADIGM

As society has moved away from almost automatic institutionalization and segregation of people with disabilities, most now live their entire lives in their own homes and communities. Community living is not merely a placement; it is premised on the foundation that individuals with disabilities should be fully integrated into community life and participate in society to the greatest extent possible. Accordingly, full integration and participation of people with disabilities in community life includes their right to make their own decisions. Yet, there may be situations in which individuals, due to the nature of their disabilities, lack the legal capacity to make certain types of decisions. In the past, guardianship was the only option available to address a person's lack of legal capacity to make decisions. However, because guardianship allows "substitute decision-making" by the guardian, it significantly impedes the autonomy and independence of the person with a disability.

Today, there are many alternatives to guardianship, rendering it unnecessary in most cases. For instance, Pennsylvania law allows family members to act as "health care representatives" who can make health care decisions -- without the need for guardianship -- for persons who lack capacity to do so [1]. "Representative payees" can be designated by the Social Security Administration to handle a person's Social Security benefits, which often are the only source of income for people with disabilities [2].

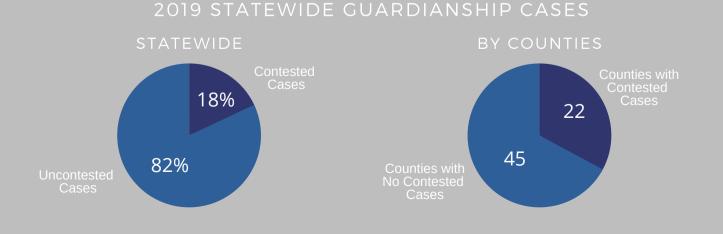
^{[1] 20} Pa.C.S.A. § 5461. For additional guidance on health care decision-making by health care representatives and others, see Pennsylvania's Department of Human Services Office of Developmental Programs (ODP) Bulletin "<u>Procedures</u> for <u>Surrogate Health Care Decision Making</u>" and <u>Annex A</u> at ; <u>www.dhs.pa.gov</u>. See also DRP's publication "<u>HEALTH</u> <u>CARE DECISION-MAKING WITHOUT GUARDIANSHIP – THE ROLE OF HEALTH CARE REPRESENTATIVES</u>" at <u>https://www.disabilityrightspa.org/</u>.

^[2] For more information about the Social Security Administration's Representative Payee Program, see <u>https://www.ssa.gov/payee/</u>.

In addition, family, friends, and advocates can act as a "supported decisionmaking network" to facilitate the individual's own decision-making ability on an array of decisions [3]. Each of these alternatives is less onerous for the individual with a disability and their family and is less intrusive on individual liberty than guardianship. Nevertheless, families still undertake legal proceedings to become guardians over their adult children with disabilities, often based on erroneous advice from schools, service providers, or doctors telling them that guardianship is mandatory or the only way to protect their loved ones.

Many guardianship proceedings in Pennsylvania are uncontested. Uncontested means that there was likely no hearing, and it also means that the person subject to guardianship likely did not have legal counsel. Pennsylvania law does not mandate court-appointed counsel for alleged incapacitated persons in guardianship cases and most individuals subject to those proceedings have little, if any, money of their own or the ability to find and retain independent counsel. Data reported to the Unified Judicial System in Pennsylvania show that in 2019, less than 18% of guardianship cases processed statewide were contested. Fortyfive (out of 67) counties reported no contested cases. Consequently, guardianship is largely happening in Pennsylvania to people with disabilities without a trained and knowledgeable lawyer who can help identify viable alternatives to guardianship that will effectively protect their health, safety, and finances.

[3] The Pennsylvania Supreme Court has held that a court should not appoint a guardian if it finds that there are sufficient supports and services in place, including the support of family and friends, so that guardianship is not necessary regardless of the respondent's capacity. In re Peery, 727 A.2d 539, 541 (Pa. 1999).



PAGE 05

WORKING TOGETHER FOR JUSTICE AND LASTING CHANCE

In 2018, the Honorable Lois Murphy of the Orphans' Court Division of the Montgomery County Court of Common Pleas approached DRP about assisting individuals with disabilities involved in guardianship proceedings. Judge Murphy sought to expand access to legal representation for such individuals (especially young individuals) through the appointment of DRP and other private counsel in initial guardianship proceedings. She also wanted to provide information to would-be guardians and previously appointed guardians about guardianship alternatives. DRP subsequently applied for and received an IOLTA grant to help Judge Murphy's vision become a reality beginning in July 2019 through our "Promoting Autonomy for Montgomery County Residents with Intellectual and Similar Disabilities Project" (Project), which initially focused on assisting individuals with intellectual disabilities and autism and then expanded to include representation of people with other disabilities too (e.g., mental illness).

Through continued IOLTA funding, DRP has used the following tools to bring guardianship reform in Montgomery County:

 Direct Legal Representation – DRP accepts assignments to represent alleged incapacitated persons in initial guardianship proceedings and guardianship review hearings. DRP's expertise in working with clients with intellectual and similar disabilities, our knowledge of guardianship law and alternatives to guardianship, and our commitment to the rights of people with disabilities assure that we provide our clients with excellent legal representation.

- Technical Assistance to Attorneys Along with providing education and training on guardianship alternatives to many attorneys with a guardianship practice in Montgomery County, DRP has also made itself available to attorneys to provide individualized advice, support, or assistance in guardianship cases that raise unique or challenging issues.
- Incentives for Pro Bono Attorneys DRP participates in the Pennsylvania Supreme Court's Continuing Legal Education Board's CLE Pro Bono Pilot Program (currently scheduled to end in 2021), which enables pro bono attorneys to earn CLE credits. Attorneys who participate in this program can earn CLE credit while we monitor and support them through the process of representing alleged incapacitated persons in Montgomery County.
- Educating Guardians or Individuals Considering Guardianship DRP provides counseling and education services (directly and/or through the distribution of appropriate publications) to family members and others who contact us about guardianship for adults with disabilities. We explain effective alternatives so that they understand all potential options. DRP also provides these services to persons currently serving as guardians so they can evaluate whether continued guardianship is needed.
- Educating Schools and Providers Parents of young adults with disabilities are often misinformed by schools, health care providers, and/or disability service providers (such as supports coordinators or other case managers) that guardianship is essential when their children turn 18. DRP reaches out to school districts, health care providers, and disability service providers that serve Montgomery County residents to offer our education services and/or publications about alternatives to guardianship.

DEVELOPING LEGAL EXPERTISE AND GROWING COMMUNITY SUPPORT



Attorneys Receiving CLE Credits for Pro Bono Representation of Alleged Incapacitated Persons in Guardianship Cases



Instances of Technical Assistance Provided to Attorneys in Guardianship Cases 98

137

Attorneys Who Received Trainings/Information about Guardianship and Alternative

Guardians, Health Care Personnel, and School Personnel Who Received Trainings/Information about Guardianship and Alternatives

SUCCESS BY THE NUMBERS

In many of our cases, DRP was able to work collaboratively with the Court and Petitioners' counsel to find a court-sanctioned alternative to guardianship.

- DRP provided legal representation to 19 alleged incapacitated persons (AIPs) in initial guardianship proceedings:
 - 10 cases where petitioners agreed to entry of orders that AIPs do not need guardians and designating them as health care representatives and/or representative payees
 - 1 case where petitioners agreed to entry of order that AIP did not need a guardian of the estate and they could serve as health care representative and where AIP agreed to entry of limited guardianship of estate
 - 1 case where AIP did not contest guardianship and court granted guardianship petition
 - 1 case was transferred from another state and guardianship of the person was granted, though it will be reviewed
 - 6 contested cases. In only one contested case was the petition granted as filed.
 - 1 case where court ruled against petitioners finding AIP needed neither guardian of person nor estate
 - 1 case where court ruled against petitioners in part, holding that AIP did not need a guardian of the person but granting a limited guardianship of the estate
 - 1 case where petitioners withdrew request for guardianship of estate prior to hearing and the court granted plenary guardianship of person
 - 2 cases where court granted plenary guardianship of person but only limited guardianship of estate
 - 1 case where court ruled in favor of petitioners, granting plenary guardianship of person and estate
- DRP provided legal representation to 2 adjudicated incapacitated persons in guardianship review hearings and both guardianships were overturned.

RESULTS OF DRP REPRESENTATION IN INITIAL GUARDIANSHIP PROCEEDINGS



INDIVIDUALS DRP HELPED THUS FAR THROUGH THIS PROJECT

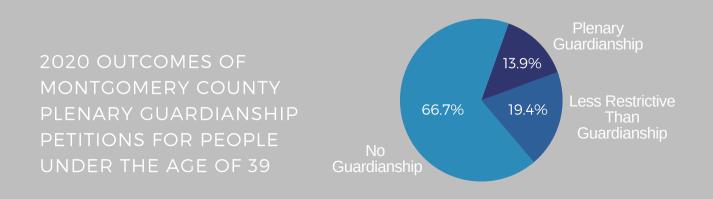
This is a sample of cases where our advocacy has resulted in positive outcomes for individuals with disabilities and their families.

- The parents of a 31-year-old woman with Rett syndrome agreed to an order recognizing them as her health care representatives in lieu of pursuing guardianship. Due to disability-related limits on her ability to hold a pen and sign documents, the order also indicated that the parents, as an accommodation for her disability, should be able to sign documents for her.
- The father of 18-year-old twins with autism agreed not to pursue guardianship and to entry of an order identifying he and their mother as their health care representatives and their mother as their representative payee. Afterwards, the father contacted DRP to express his gratitude for the outcome.
- DRP successfully contested in large part a guardianship petition filed by the parents of a 19-year-old woman with intellectual disability. We showed that she could understand a number of personal and financial matters but might need some support. At the court's request, we drafted a health care advance directive and financial power of attorney that the client could understand and execute. The court only appointed the parents as limited guardians of the client's estate with respect to handling contracts and legal documents.
- DRP successfully contested a guardianship petition filed by the parents of an 18-year-old with intellectual disability, autism, and bipolar disorder. The parents wanted guardianship in the event their son was subject to criminal justice involvement in the future, but we demonstrated that guardianship would not be necessary or helpful in that scenario.
- DRP successfully represented a 29-year-old man with mental illness and autism in a review hearing to remove his parents as his plenary guardians.

The client had been living independently with supports for five years and was able to meet his own needs (including paying his own bills and attending to his daily living activities). He received some supports from a Medicaid home and community-based waiver. Following an independent medical evaluation where the evaluator praised the client's abilities and determined he did not need a guardian, the parent-guardians advised that they would not contest the guardianship. Nevertheless, the court held an evidentiary hearing where we presented extensive evidence regarding the client's capacity. The court ruled that the client had sufficient capacity so that guardianship was not required and terminated the parents' guardianship.

 DRP worked with an attorney through the CLE Pro Bono Project who represented an 18-year-old woman with mental illness whose parents had petitioned for guardianship. Working with DRP's support, the client's attorney requested an independent medical evaluation and educated the client and her parents (through their counsel) about how a mental health advance directive could provide an effective alternative to guardianship. The client agreed to execute a mental health advance directive to allow her parents to help her with decision-making in the event of a crisis and the parents agreed to withdraw their guardianship petition.

In addition to the many positive outcomes for individuals with disabilities and their families we achieved through direct representation, Montgomery County Orphans' Court data shows that there were 20 less guardianship petitions filed in calendar year 2020 than in 2019. Out of the 199 guardianship petitions that were filed in 2020, 36 petitions were for a plenary guardian of the person and/or estate for people under the age of 39 – 9 less than in 2019. That is a 20% reduction in one year. Moreover, out of those 36 petitions only 5 resulted in plenary guardianship, 24 ended with no guardianship, and 7 ended with a less restrictive result than plenary guardianship.



SPREADING REFORM ACROSS THE COMMONWEALTH

It is critically important that all alleged incapacitated persons receive the assistance of counsel to defend against the petition and ensure that the request for guardianship is denied or limited as much as possible. Expansion and replication of this Project can help fill the void when there is a lack of legal representation and benefit individuals with disabilities and their families through diversion from legal guardianships when they are not necessary. Expansion and replication of this Project will also improve judicial economy by reducing the number of guardianships that courts have to adjudicate and then monitor through continuing oversight and review of yearly guardian reports.

The strategies and practices we adopted in Montgomery County can and should be replicated in other counties where there is a need for direct legal representation at guardianship hearings and education and outreach to individuals with disabilities, their families, providers, and allies to prevent and reduce the number of unnecessary guardianships granted in lieu of effective and less restrictive alternatives. We want to identify best practices to recruit and incentivize pro bono attorneys to represent alleged incapacitated persons and provide those attorneys with the training they need to offer competent and zealous representation that results in positive outcomes for their clients as well as their loved ones who are concerned for their welfare.

Put simply, we want to use this Project as a way to advance justice and promote equity for adult individuals with disabilities so they can exercise independence with appropriate support and thrive in their communities without the need for legal guardianship. We want to continue to provide legal representation to individuals with disabilities and utilize less restrictive alternatives to guardianship when possible through this Project, in Montgomery County and beyond. We are looking for Courts and other potential partners who share this vision and want to work with us to accomplish this mission. And, we again want to thank Judge Murphy, the Orphans' Court Division of the Montgomery County Court of Common Pleas, and the IOLTA Board for getting this Project off to a very successful start.