

## **Alternatives to Guardianship for Adult Texans with Intellectual and Developmental Disabilities**

by Megan Morgan, LMSW  
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### **Introduction**

Many Texans with intellectual and developmental disabilities (IDD) are placed under full guardianship in spite of having the ability to make their own choices. People with IDD may need extra support to make decisions, but this does not necessarily mean that their rights to make decisions should be removed. This paper explores biases in guardianship cases, recent developments in Texas law, alternatives to guardianship, and the next steps needed to protect the rights of Texans with IDD.

### **What is Guardianship?**

The Texas Guardianship Association defines guardianship as “a legal process designed to protect vulnerable persons from abuse, neglect (including self-neglect), and exploitation.”<sup>1</sup> Guardianship is a legal process in which a court determines if an individual is “incapacitated.” A judge will decide if, due to a physical or mental condition, a person is substantially unable to care for her/his own health, manage her/his own financial affairs, and manage her/his personal affairs (providing food, clothing, or shelter for herself/himself).<sup>1</sup> Under a guardianship, someone (the guardian) is appointed to make decisions on behalf of the incapacitated person, referred to as the “ward.” Guardianship is designed to protect members of vulnerable populations, while maintaining their rights whenever possible. There are two main types of guardianships: guardian of the person and guardian of the estate. In addition, each type of guardianship can either be plenary/full or limited/partial.

A guardian of the person is responsible for the physical well-being of the ward, and makes decisions about the ward’s residence, medical care, and more. A guardian of the estate manages the ward’s assets, including finances and property.<sup>2</sup> Under a limited guardianship, the guardian is only assigned the responsibilities that the ward cannot assume. In these cases, a judge protects certain rights for the ward, such as the right to choose where to live, choose roommates, maintain personal relationships, etc.<sup>3</sup> Under a full guardianship, all major decision-making rights are given to the guardian; however, guardians are supposed to take wards’ preferences into consideration whenever possible. If a ward is under a full guardianship of the person, she/he loses many rights, including the right to drive, choose where to live and work, vote, consent to get married, consent to medical treatment, and more.

A judge can appoint an individual, entity, or guardianship program to be guardian for a ward. In Texas, some entities and guardianship programs that can be appointed include the Department of Aging and Disability Services (DADS) or nonprofit organizations such as Family Eldercare. Judges should take the ward’s preferences for guardian choice into account whenever possible. Family members or other persons known to the ward will be considered first before judges appoint guardianship programs.<sup>4</sup> Additionally, a court may disqualify any person or program from being named guardian. Some reasons a proposed guardian may be disqualified include having certain criminal convictions or being indebted to the proposed ward.<sup>4</sup>

There are many things to consider when deciding whether to pursue guardianship for a person with IDD. DADS created the chart below to help Texans decide if guardianship is the right choice.<sup>4</sup>

Pros	Cons
Guardianship may protect vulnerable people from those who would abuse, neglect or exploit them.	Guardianship is the most restrictive action taken to protect a vulnerable person.
Guardians support their wards by helping them handle their personal and/or business affairs.	Wards can lose many or most of their basic rights, depending on the type of guardianship.
Guardianship is a legal process, requiring the services of an attorney, which is designed to provide maximum protection to a person.	Establishing a guardianship requires the services of an attorney and can be time consuming and expensive.
When a guardianship is established, the protected person becomes a ward of the court. Reports and/or accountings to the court are required annually or sometimes more frequently. New letters of guardianship are required annually.	Annual accounts require the assistance of an attorney. If the ward has sufficient funds, the legal fees may be reimbursed and court costs may be paid from the ward's estate. However, if the ward does not have adequate funds, the guardian may have to pay the fees, seek low-cost or free assistance, or seek payment from the court. The guardian may also pay or seek a waiver of the court costs under certain conditions. Annual reports of the person do not require the services of an attorney.
A proposed ward must be examined by a physician who furnishes the court a written letter or certificate of medical examination (CME) addressing the person's alleged incapacity. A document indicating a diagnosis of intellectual disability (subject to the requirements in statute) may be submitted to the court in appropriate cases.	The proposed ward might not cooperate with obtaining a capacity assessment. In those cases, a court order may be required to obtain one.
The letters of guardianship expire if they are not renewed annually (they expire one year and four months after issuance).	If the letters of guardianship are not renewed as required, the guardian loses authority to act and the court may remove the guardian.
Terminating or modifying a guardianship is a legal process requiring the services of an attorney involving a court hearing and requiring a preponderance of evidence of what changes are best for the welfare of the ward.	Once a guardian is appointed, terminating or modifying a guardianship (other than by death of the ward) requires the services of an attorney and a court hearing.

## **Bias Toward Full Guardianship for People with IDD**

As the Baby Boomer generation continues to age, the demand for guardianships in the United States and Texas also increases. In 2013, Texas had over 46,000 active guardianship appointments.<sup>5</sup> According to the Texas Office of Court Administration, 58% of these appointments were made due to the ward's intellectual incapacity.<sup>6</sup> This means that each year, tens of thousands of Texans with IDD are denied their rights to make their own decisions through a guardianship. Though a guardianship may in some cases be a necessary protection for people with IDD, far too often guardianship appointments are made solely because of an individual's disability diagnosis. These individuals can lose even their most basic civil rights not because they are incapable of exercising them, but because of society's biases and prejudices. All people need and use support to make decisions. Adults with and without disabilities both rely on significant others, family members, friends, and others to provide advice and guidance when making choices such as where to live, who to date, what job to take, etc. Even if a person with a disability needs extra help to make decisions, she/he may still be capable of doing so.

Individuals with disabilities and advocates often use the term "dignity of risk" when explaining why all people should have the right to make their own decisions. The concept behind this term is that all life experiences come with some degree of risk, and that all people should have the ability to both succeed and make mistakes throughout their lifetimes.<sup>7</sup> People with disabilities, like their non-disabled peers, want to be able to make their own choices, even if these involve risk. After all, it is often from mistakes and failures that people learn and grow.

In 2013, 29-year-old Jenny Hatch made national news when she won a court battle to restore her rights and remove her guardians. Jenny, a woman with Down syndrome, was placed under a full guardianship in 2012, with her parents as guardians. Her parents chose to move Jenny into a group home where she was deeply unhappy. As Jenny explained:

My caseworker... was mean to me. She yelled at me and even hit me. I was not allowed to go to my job at the thrift store. I worked there for almost five years. I wasn't allowed to have my friends or co-workers visit or call me. I wasn't allowed to have my cell phone or computer. I felt like a prisoner but I didn't do anything wrong.

After a year of litigation and six days of trial, Jenny won back the right to make her own decisions. Her guardianship was terminated, and she was allowed to use a supported decision-making model (described in more detail below) to make future choices. Now Jenny travels the country to speak at various conferences about her experiences. She has also been involved in the creation of the Jenny Hatch Justice Project, which advocates for the rights of all people with disabilities to live self-directed lives.<sup>8</sup>

Jenny Hatch is not alone in her experiences. Ryan Keith Tonner is a Texan with a disability who has lived in a large institution, known as a state supported living center (SSLC), for many years. While residing in the SSLC, Ryan's guardian passed away. For several years, he made his own decisions with support. In spite of his history of successfully making his own decisions, the court denied his application to restore his capacity. Legal advocacy group Disability Rights Texas appealed this decision, and the case has moved to the Texas Supreme Court. Only time will tell if Ryan's rights will be restored.<sup>9</sup> These are just two examples of individuals with disabilities being forced under guardianship despite having the ability to make their own decisions with support. Jessaca Bond, a woman with Down syndrome from San Antonio, explains the importance of self-determination in her life. While testifying in support of HB

39 (discussed below) for the Texas Senate State Affairs Committee, she explained, “People with disabilities have the right to make their own decisions just as much as the next person...I have the ability and the right to make my own decisions, with support from people I trust.”<sup>10</sup>

In 2008, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD). Article 12 of the CRPD asserts that all people have full legal capacity, and that governments should provide the supports necessary for people with disabilities to make their own decisions. The CRPD has been adopted by over 150 parties. President Obama signed the CRPD shortly after taking office, though it has not yet been ratified by the Senate.<sup>11</sup> Clearly the global movement is toward more rights and supports for people with disabilities so they can live self-directed lives. Unfortunately, in spite of this shift in philosophy, many courts still automatically default to terminating the rights of Texans with IDD by placing them under full guardianship.

## **Recent Texas Legislation**

In light of the bias toward putting Texans with IDD under guardianship solely because of their disability status, advocates worked during the 84<sup>th</sup> Texas Legislative Session in 2015 to pass legislation that protects this population from having their rights needlessly taken away through guardianship. Advocates also worked to ensure that legal protections were put into place to protect the rights of Texans who already have a guardian. Three important bills from this session were SB 1882, HB 39, and SB 1881, which were all signed into law by Governor Abbott. SB 1882 by Senator Zaffirini, also known as the Bill of Rights for Wards, establishes a list of rights that all people under guardianship enjoy, unless they are specifically taken away by a judge. These include the right to live, work and play in the most integrated setting, visit with people of their choice, appear before the court to express preferences and concerns, have access to a monthly personal allowance, have the guardian visit at least once every three months, and more.<sup>12</sup>

HB 39 by Representative Smithee and SB 1881 by Senator Zaffirini both address alternatives to guardianship, among other issues. Alternatives to guardianship are ways to support people with IDD to make their own decisions without taking away their rights through a guardianship. Under HB 39, courts must first consider if any alternatives to guardianship exist that would meet the needs of the proposed ward and prevent a guardianship. The law lists 24 alternatives to guardianship, and the court must present clear and convincing evidence that these alternatives have been considered for the proposed ward. Additionally, the law adds formal and informal long-term services and supports to the list of alternatives that must be considered. Finally, the law requires the attorney for the proposed ward to receive one hour of training on alternatives to guardianship.<sup>13</sup> SB 1881, also known as the Supported Decision-Making Agreement Act, establishes supported decision-making (discussed in more detail below) as an informal alternative to guardianship.

## **Alternatives to Guardianship**

Texans with IDD can be supported in many ways to make their own decisions without taking away their rights through a guardianship. One of the most highly-used alternatives to guardianship is a power of attorney. Under a power of attorney, a person with IDD (the principal) authorizes someone they trust (the agent) to act on their behalf. The principal must have the mental capacity to authorize an

agent. A power of attorney may be revoked by the principal at any time, and is automatically revoked if the principal becomes incapacitated. A durable power of attorney is a special type of power of attorney that continues to exist even after the principal has been determined to be incapacitated. Powers of attorney can cover a wide array of decision-making areas including medical, financial, real estate, and more.<sup>14</sup>

Another guardianship alternative for Texans with IDD is to choose a representative payee to receive and manage social security benefits. Other options include joint bank accounts, advanced medical directives, money management programs, or special needs trusts. Informal and formal supports and services should also be considered as an alternative to guardianship. For example, an individual may receive Medicaid community-based services through a waiver like Home and Community-based Services (HCS) or Community Living Assistance and Support Services (CLASS). Services like personal attendant care or habilitation provided through these waivers may make a guardianship unnecessary. Finally, one new option for Texans with IDD is to use a supported decision-making agreement (more information below). Steven King, Texas judge for Tarrant County Probate Court Number One, has compiled a list of over 55 alternatives to guardianship.<sup>15</sup> All possible alternatives should be considered before taking away a person's rights through a guardianship.

### ***Supported Decision-Making***

In 2015, the 84<sup>th</sup> Texas Legislature passed SB 1881, the Supported Decision-Making Agreement Act, by Senator Zaffirini, making Texas the first state to have a law recognizing supported decision-making agreements as an informal alternative to guardianship. Supported decision making allows individuals to make their own decisions and stay in charge of their lives, while receiving any support they need to do so. Using a supported decision-making agreement, a person with a disability chooses someone they trust, like a parent, friend, former teacher, etc., to serve as their supporter. The supporter *can* help a person with a disability understand the options, responsibilities, and consequences of their decisions. Additionally, the supporter *can* help the person with a disability obtain and understand information relevant to their decisions, and communicate their decisions to the appropriate people. The supporter *cannot*, however, make a decision *for* a person with a disability.<sup>16</sup>

The law includes a sample supported decision-making agreement form, which can be filled out by the person with a disability and the supporter. Then the individual with a disability can present the agreement to people like doctors and bank managers, who are legally required to honor the agreement. The agreement is an excellent self-advocacy tool that people with disabilities can use to advocate for the right to make their own decisions, and to have the support they need to make those decisions. Supported decision-making empowers people with disabilities to make their own choices so they can live more independent and self-directed lives.

### **Conclusion and Next Steps**

People with IDD have repeatedly demonstrated that if they receive the proper supports, they can successfully make their own decisions. Guardianships take away the civil rights of people with disabilities, and should be avoided whenever possible. Although Texas has recently taken legislative action to help empower people with disabilities to make their own choices, much work still remains to be done. Education and training is needed to change the biases of those working

with people with disabilities.

Educators and school administrators must learn about the ways they can include the parents of people with IDD in educational decision-making without guardianship. They must be informed of guardianship alternatives like supported decision-making so that young Texans with IDD can begin their adult lives with their rights intact. Lawyers and judges similarly need further training on guardianship alternatives so they can shift their purpose from determining, “Is guardianship necessary?” to “What can be done to avoid a guardianship?” Families must learn about the importance of supporting their loved ones to be in charge of their own lives. And people with disabilities should be taught decision-making and self-advocacy skills from a young age, so that when they turn 18, they are ready to make their own decisions and to advocate for the support they need to make these decisions. If these groups and others are taught about guardianship alternatives, Texans with IDD will have their rights protected, and Texas will be one step closer to being a truly inclusive state where all of its residents are valued and respected.

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## Endnotes

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