

Enhancing self-determination in less-restrictive alternatives to guardianship

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An Oregon adult guardianship can be a huge encroachment on a protected person's individual liberties. Guardianships often take away individuals' rights to decide the location of their home, the nature of their healthcare, the option of whether to work, the use of finances, and the ability to make decisions in many other arenas.² Moreover, unless a judge rules otherwise, guardianships last for the protected person's lifetime.

Any method employed to support an individual should be the least restrictive and allow maximum self-determination. The following sections discuss the importance of enhancing self-determination for protected persons who are under guardianships, and the importance of considering all relevant less-restrictive alternatives prior to imposition of a guardianship.

Maximum self-determination for protected persons in existing guardianships

Because Oregon law delineates stringent guidelines for determining the scope of a guardianship, limited guardianships are often the most appropriate option. A guardian may be appointed only "as is necessary to promote and protect the well-being of the protected person ... [and] may be ordered *only to the extent necessitated by the person's actual mental and physical limitations* [emphasis added]."³ Limited guardianships should be tailored to the circumstances—e.g., a respondent may need decision-making assistance with health care only, and the guardian's authority can be restricted accordingly. Despite this, in the experience of Disability Rights Oregon (DRO)⁴—the protection and advocacy law agency for people with disabilities—a broad-scoped guardianship (called "full" or "plenary") is generally used regardless of whether the protected person actually meets the definition of "incapacitated"⁵ in each of the decision-making areas taken away.

Whatever the scope of the guardianship, guardians should assist the protected person in a manner that maximizes independence and self-reliance,⁶ and honors the concept that the protected person retains all civil rights (aside from those specifically given to the guardian by the court).⁷ Certainly, protected persons should be given the opportunity to voice their expressed desires and wishes prior to any decisions that affect their lives. The National Guardianship Association (NGA) endorses "substituted decision making"—i.e., substituting the decision the protected person would have made when the person had capacity if they no longer

have capacity.⁸ At DRO we hear from many protected persons who feel that they essentially do not exist—they have been fully removed from any decision-making regarding their own lives.⁹ This causes a feeling of loss of control, loss of individuality, loss of dignity.

Then there are protected persons who are no longer incapacitated and/or it is in the protected persons' best interests to terminate the guardianship.¹⁰ For example, DRO reviewed an annual guardianship report that gave no answer as to why the guardianship should continue. Upon follow-up, both the guardian and protected person agreed that the guardianship was no longer necessary because it was put in place when the protected person was clinically depressed and thereby incapacitated. By the time of this report many years later, she no longer had this mental health concern.

Alternatives to guardianship

Below are some examples from DRO's experience working with respondents and protected persons that illustrate instances where a less-restrictive alternative to guardianship was optimal. This list is, of course, is non-exhaustive and we recognize that you may be using alternatives that are not addressed. Because guardianship is extremely intrusive, all possible less-restrictive alternatives, from the many options, should be ruled out before a guardianship is pursued and authorized. These alternatives provide greater opportunity for an individual to exercise his or her basic right to make choices. Many studies support the idea that people with disabilities who have greater self-determination are more likely to be employed, independent, healthier, and safer.¹¹

Supported decision making

Supported decision making (SDM) is an increasingly popular alternative to guardianship. Today, SDM is not specifically set forth as an option in Oregon guardianship law.¹² However, Oregon has been using SDM for many years in provision of services to individuals with developmental disabilities. Often, a person in developmental disabilities services has at least one team that comes together for the individual's individual support plan (ISP). This team is selected by the individual, and is tasked with helping him or her with making informed life decisions.

Unlike guardianship, SDM allows individuals with a disability to have the final say in their major life decisions. Supporters are

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responsible for gathering information, communicating with others on the individual's behalf, and consulting with the individual about major decisions. Importantly, supporters do not gain any special authority under SDM. If a supporter wishes to have access to medical records, for instance, the supported individual would be responsible for providing the supporter access. SDM allows persons with disabilities self-determination, which can empower them towards greater independence, health, and better defenses against abuse.¹³ Notably, there are many individuals in Oregon who do not have guardians because their ISP team is functioning as an alternative, essentially as SDM.

SDM as an alternative to guardianship may apply to individuals with any disability or at any age. For example, SDM is a common method for parents to continue to support their children once they reach majority. DRO has had protected persons as clients who express their dismay with restrictions imposed by their parent guardians. In many cases, these individuals live independently and maintain steady employment, but need assistance with more complex life decisions. Tensions may arise when the guardian attempts to exert authority over minor and personal aspects of the protected person's life, such as friends, relationships, or choice of clothing. Consequently, protected persons may become frustrated with their lack of autonomy, and the relationship with their guardians can sour. SDM can be a very non-coercive method of providing support that, for many individuals, affords dignity. More information on SDM can be found at www.supporteddecisionmaking.org.¹⁴

Representative payees and VA fiduciaries

When an individual has difficulty managing public benefits, a third party can be appointed to provide assistance. A representative payee is typically an agent appointed by the Social Security Administration (SSA) to receive and manage a person with a disability's Supplemental Security Income (SSI). SSI benefit recipients are generally presumed to be competent to manage their income. However, an individual or organization that believes an SSI beneficiary cannot effectively manage his or her benefits can apply to become that individual's representative payee. The SSA will consider evidence to determine whether or not a representative payee is necessary to effectively manage an individual's SSI benefits. Similarly, VA fiduciaries can be appointed to manage an individual's veteran benefits. As with people receiving SSI benefits, recipients of veteran benefits are presumed competent, but a third party can apply with the field examiners of the Veteran Affairs Fiduciary Unit to receive and manage a finan-

cially incapable individual's benefits. Both programs provide beneficiaries the opportunity to contest the decision to appoint a representative payee or fiduciary, or to have someone other than the applicant appointed.

DRO has worked with a number of individuals who use either system as an alternative to guardianship. In one instance, DRO advocated for a respondent to a plenary guardianship petition that heavily relied on allegations that the respondent was financially incapable and vulnerable to being financially victimized by strangers. Upon further communication with the respondent, DRO learned that she operated a small home business for extra income, while her representative payee covered the bulk of her expenses with her SSI benefits. She explained that because her bills and groceries were covered by SSI, she chose to be generous with the small amount of money she made from her business. Fortunately, the petitioner in this case withdrew her petition once the respondent objected. Nonetheless, this illustrates how a representative payee can be effective in lieu of guardianship. Because her representative payee covered the respondent's major expenses, she was not at risk for mismanagement of her finances. She was additionally able to enjoy a small degree of financial autonomy without placing herself at risk financially. This autonomy allowed her the freedom to engage with her community in a way that felt meaningful.

Special needs trusts

A special needs trust (SNT) is a tool that allows disabled individuals to receive financial assistance without affecting their eligibility for public assistance. Most public assistance programs have specific limits on income and assets, and individuals that exceed these limits are ineligible for assistance. Much like a representative payee or VA fiduciary, a SNT trustee can ensure many of an individual's financial needs are met, while allowing him or her a degree of financial autonomy. In one case, DRO intervened on behalf of a respondent to a conservatorship petition filed in response to the respondent's unexpected large inheritance. While the respondent had a severe and persistent mental illness, she was functioning well due to her engagement in on-going treatment. In response to the respondent's objection, the petitioner withdrew the petition and the respondent established a SNT. This allowed this individual to continue living autonomously.

Declaration for mental health treatment

A declaration for mental health treatment (DMHT) allows Oregonians to establish a type of advance directive for mental health treatment.¹⁵ A DMHT is a legal document that allows individuals to indicate their consent to specific sorts of treatment and their lack of consent to other treatments; and to communicate additional information about their mental health needs should they become mentally incapacitated.¹⁶ DMHTs also allow individuals to appoint a health care representative (HCR) to make medical decisions on their behalf should they become incapacitated. DMHTs go into effect only when an individual is incapable of making informed choices about his or her treatment.¹⁷ Individuals with DMHTs should always keep a copy on their person, and provide copies to their named HCR and treatment providers. Individuals in state mental health services are required to be offered a DMHT to complete if the individual so chooses,¹⁸ and treatment providers and HCRs are obligated to follow its terms to the extent it is reasonable to do so.¹⁹ DMHTs allow individuals with a mental illness the freedom to make decisions about their health care while they have capacity, and allow third parties engaged with the individual to advocate for their preferred treatment during a mental health crisis.

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DRO recently worked with a protected person subject to a limited guardianship that authorized the guardian to make healthcare decisions on the protected person's behalf. The protected person generally maintained the capacity to make informed decisions in all aspects of her life, but had a history of occasional but serious mental health emergencies that required hospitalization. The protected person stated that she was misdiagnosed for years, and had only recently found treatment that was effective. She was consequently concerned that her treatment might be mishandled with a guardian making health care decisions. Further, she was concerned about the scope of the guardian's decision-making authority, and was uncomfortable with her inability to make routine healthcare decisions while she maintained capacity. Here, a DMHT would allow this individual to ensure her treatment preferences are followed, and ensure that a HCR could only intervene if and when she was incapable. During the majority of the time she maintained capacity, a DMHT would allow her maximum personal freedom.

Assistive technology

There are many forms of assistive technology (AT) that allow people with disabilities to be more integrated in their community. For example, speech-generating devices can afford nonverbal individuals the ability to communicate. It is always worth considering whether there is some form of AT that will allow the individual to communicate and process his or her decisions. DRO has had contact with clients who are trying to access assistive technology that will allow communication, such as the EyeGaze. This device has the potential to move the client from essentially nonverbal to having communicative abilities. If an individual can have access to the decision-making process through assistive technology, this should be explored as an alternative to guardianship and a self-empowerment tool.

Other means

The above list of less restrictive alternatives to guardianship is only a beginning. Options such as power of attorney, advanced directives for health care, a developmental disability service health care representative,²⁰ daily money management, and support from an individual's family, friends, or caregivers can replace guardianship. Ensuring individuals with disabilities have maximum self-determination requires creativity, but can ensure increased happiness, productivity, and sense of dignity.

Conclusion

There are many ongoing efforts to improve Oregon guardianship law. DRO has proposed legislation during the current legislative

session that would require guardianship petitions to detail which less restrictive alternatives have been considered and why they were ruled out. This is good practice whether or not the legislation passes. While guardianships are undoubtedly necessary for certain individuals, many individuals could be supported with less restrictive alternatives. In all cases, support should ensure that individuals retain the maximum amount of control regarding decisions. This positively affects an individual's sense of dignity and well-being. Given guardianship's effect on an individual's civil liberties, almost any alternative will be less restrictive.

Finally, while this article primarily focuses on the more negative aspects of guardianship, we recognize that there are instances where it is the appropriate option, and that many guardians are doing extraordinary work. DRO does not field many phone calls from protected persons who want to commend their guardian—although we recognize that some protected people are very grateful. Instead, we primarily hear from protected people who feel that their civil rights and ability to function as adults have been wrongfully taken away. Given that benefitting protected people is at the heart of guardianship proceedings, the maximum degree of self-determination and dignity should always be promoted. ■

Footnotes

1. Or. Rev. Stat. Ann. § 125.005 (7) (2015) states: "Protected person" means a person for whom a protective order has been entered.
2. Or. Rev. Stat. Ann. § 125.315 (1) (2015)
3. Or. Rev. Stat. Ann. § 125.300 (1) (2015)
4. DRO reviews over 100 guardianship pleadings per month pursuant to ORS 125.060(7) and represents many additional respondents/protected persons in legal rights violation concerns under guardianship.
5. "Incapacitated: a condition in which a person is impaired to the extent of being unable to meet the essential requirements for the person's physical health or safety." These "essential requirements" include providing health care, food, shelter, clothing, personal hygiene, and other care without which serious physical injury or illness is likely to occur. Or. Rev. Stat. Ann. § 125.005(5) (2015).
6. Or. Rev. Stat. Ann. § 125.300 (1) (2015)
7. Or. Rev. Stat. Ann. § 125.300 (1) (2015)
8. NGA, Standards of Practice (Adopted 2000, Fourth Ed. 2013), Section 7: Standards of Decision-making
9. At DRO, we acknowledge that there are protected persons who are very grateful to be working with their guardians as well as guardians who function in a manner that allows the protected persons the greatest self-determination. Given that we address legal concerns with right violations under guardianship, we do not often hear these positive stories.
10. Or. Rev. Stat. Ann. §125.005(5) (2015); Or. Rev. Stat. Ann. § 125.090(1), (2)(b) (2015)
11. Francisco and Martinis, "Supported Decision-Making Teams: Setting the Wheels in Motion" (February 2017) citing Wehmeyer & Schwartz, 1997.
12. Texas has incorporated SDM in its guardianship statute as an alternative to guardianship.
13. Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998
14. The article "Supported Decision-Making Teams: Setting the Wheels in Motion" by Francisco and Martinis has nuts-and-bolts worksheets for using SDM.
15. Or. Rev. Stat. Ann. § 127.736 (2015)
16. *Id.*
17. The DMHT makes it clear that only a court or two physicians determine that the individual is incapable of making informed choices about his or her treatment. *Id.*
18. Or. Rev. Stat. Ann. § 127.703 (1) (2015)
19. Or. Rev. Stat. Ann. § 127.736 (2015)
20. Or. Admin. R. 411-365-0100



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Understanding Medicaid is an important part of elder law practice

By Monica D. Pacheco, Attorney at Law

In most cases, people want their money and assets spent and used during their lifetime as they choose; and after death, people want their money to go to whom they choose. People also want to be cared for when care needs arise. Depending on the level of assets, the care needed, and the income levels, Medicaid benefits can help with all of the above. Perhaps not all goals can be attained, but as practitioners we can assist families with identifying their options and the effects of their choices.

Medicaid is part of the state-federal partnership administered by the Centers for Medicare and Medicaid Services (CMS). CMS issues guidance and information bulletins to state Medicaid directors and state health officials. Medicaid assists with payment of medical care and custodial care, including the intermediate level of care provided in nursing homes, adult foster homes, residential care facilities, memory care and in-home healthcare services. There are several Medicaid programs, each with

different requirements. This article focuses on the Medicaid program that covers care needs at home or in various facility settings.

In Oregon, the rules, and exceptions, for eligibility are found in the Oregon Administrative Rules (OARs), Chapter 461, entitled Self-Sufficiency Programs. The basic definitions begin with OAR 461-001-0000, Definitions for Chapter 461 which defines such things as “assets,” “child,” “community based care,” “countable,” “eligibility,” “marriage,” “standard living arrangement,” and “variable income.” It is essential to become familiar with OARs because the rules and their exceptions are important to our clients. I remember when I started practice, my senior partner insisted that I read through the rules, and then maintain them when the rules changed. Of course, at that time, the OARs were kept in a binder, and updates were mailed when there were changes to the rules. There are days that I miss the binder, as I had become familiar with the OARs and could look them up by location in the binder. Now I spend more time reading through the table of contents or searching for the terms I know are used. The point here is that you need to read the OARs, so that you can understand what they say, how they work together, and what exceptions may be available to assist your clients.

Eligibility

Division 110 of OAR 461 defines eligibility groups. This is important as you start to read through the OARs, as many individual rules have different meanings and/or applications, depending on the different programs. For example, the filing group has six different rules (OAR 461-110-0310 through 461-110-0430), depending on the program you are looking for,

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