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Medical Decision and Guardianship of Individuals with Intellectual and/or Developmental Disabilities (ID/DD)

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INTRODUCTION

At the age of 18, individuals with intellectual and/or developmental disabilities (ID/DD) legally transition to adulthood. Many will be placed under full or limited guardianship at this time because they need ongoing support in navigating complex healthcare and financial systems, and because they are unable to make independent medical and dental decisions. There are 95,639 adults age 18 to 64 in Nevada[1] with a cognitive or intellectual disability that may impact their ability to access healthcare. National data estimate that across the country, roughly 53% of adults with ID/DD are under limited or full guardianship. This makes it important that providers understand guardianship and its implications on medical decision-making and medical clearance. It is equally important for state public health leadership to ensure that guardians and potential guardians are educated, informed and aware of the importance of supporting individuals to make their own decisions and retain as much autonomy as possible.

An adult with ID/DD placed under guardianship can impact their access to healthcare in several ways, including the need for guardians to approve medical care and procedures, as well as make decisions that are in the best interest of the patient. Guardianship can also pose ethical dilemmas for healthcare providers if the patient with ID/DD and the guardian do not agree on the course of treatment or care. For this reason, it is important to educate healthcare providers, including physicians and dentists, on the legal and ethical considerations of guardianship and how to support positive healthcare decision-making and medical clearance for an individual with ID/DD.

[1]U.S. Census Bureau. 2022: ACS 1-Year Estimates. Table S1810 Disability Characteristics. Retrieved from https://data.census.gov/table?q=Disability&g=040XX00US32

The contemporary guardianship system in the United States places a priority on the individual with ID/DD being engaged in decision-making, and given all the information the individual would need to make informed decisions about care, including the risk and benefits of care, possible complications, and the costs the client might incur. If the patient is unable to make the healthcare decisions on their own, respect for the client and a focus on maximizing their independence and autonomy should be prioritized by providers and guardians.

Examples of healthcare-related activities a guardian may undertake on behalf of the individual with ID/DD include, but are not limited to, matters as simple as scheduling physician or dental appointments, helping them to complete medical history forms and healthcare information -- sharing authorizations, and authorizing nonemergency treatment for minor illnesses or injuries.[2]

Because a physician or dentist may not perform a medical procedure on a patient unless that patient has consented to it, informed consent becomes a critical issue in ensuring the patient accesses appropriate and timely care. Physicians and dentists can play an important role in advocating for patients with ID/DD to be active participants in their own care by speaking to the client and not just the guardian when discussing care, presenting decisions in a clear manner to the patient so they are able to understand as much as possible, and actively working to preserve the patient's autonomy as much as possible.

[2] Dayton, A. Kimberley, "Standards for Health Care Decision-Making: Legal and Practical Considerations" (2012). Faculty Scholarship. Paper 249. Retrieved from https://www.guardianship.org/wp-content/uploads/2017/08/Standards_Health_Care_Decision_Making.pdf

INTELLECTUAL DISABILITY

A life-long condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 18. Significant limitations in intellectual functioning refers to impairments in general mental capacity, such as learning, reasoning and problem solving. Significant adaptive behavior limitations are demonstrated in conceptual, social, and practical skills. It should be noted that some adults with an intellectual disability have acquired the disability after age 18 due to an accident, illness, or injury. These are called acquired intellectual disabilities.

DEVELOPMENTAL DISABILITY

Severe, chronic disabilities attributed to neurologically or genetically based disorders found to be closely related to an intellectual disability because the condition results in impairment of general intellectual functioning and or adaptive behavior similar to that of a person with an intellectual disability. Developmental disabilities are manifested before the age of 22 and are likely to continue indefinitely. Neurological or genetically based disorders include but are not limited to cerebral palsy, epilepsy, autism spectrum disorder, traumatic (acquired) brain injury, fetal alcohol spectrum disorders and other chromosome/genetic disorders such as Down Syndrome or Fragile X.

GUARDIANSHIP AND LEGAL DOCUMENTATION IN THE CONTEXT OF HEALTHCARE DECISION MAKING

An adult that does have a legal guardian (full or limited) may face significant hurdles in managing their medical and dental care if they do not have the appropriate paperwork on hand to share with a healthcare provider, which can lead to delays in essential healthcare services.

Various decision-making supports are available to adults with ID/DD including but not limited to full guardianship, limited guardianship, health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, and representation agreements.

In recent years, in recognition of the ability of so many adults with ID/DD to independently make their own decisions, the trend has been toward encouraging individual decision making and prioritizing the least restrictive types of legal supports for a person with ID/DD. These include limited guardianship, supported decision making and other means of ensuring an individual retains maximum rights while still being safe and supported. Experts recommended that these options "… should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered." [3]

Without the paperwork in place that allows another individuals such as a parent or caregiver to make and/or support medical decisions and sign paperwork accepting financial responsibility (when applicable) for care, individuals with ID/DD may face significant hurdles in managing their medical and dental care due to potential limitations in decision-making capacity, which can lead to delays in essential healthcare services.

If the adult with ID/DD can make decisions for themselves, and understand the medical choices, potential risks, and financial responsibilities, then additional legal paperwork will not be required. When the adult with ID/DD is unable to make decisions about medical procedures or care or is

[3] The Arc. (2021) Autonomy, Decision-Making Supports, and Guardianship. Retrieved from https://thearc.org/wp-content/uploads/2023/02/Autonomy-Decision-Making-Supports-and-Guardianship.pdf

unable to understand and sign paperwork accepting responsibility for payment of services, having the proper guardianship and/or medical decision-making paperwork in place is critical to avoid delays in care and medical clearance.

BARRIERS TO ACCESSING HEALTHCARE FOR ADULTS UNDER A GUARDIANSHIP

In a recent study found in the National Core Indicators Data Highlight, 53% of adults with ID/DD were found to have a guardian [4] , demonstrating the need for outreach, education and awareness for parents/guardians about how to ensure the proper paperwork is in place and accessible to share with medical providers when care is required.

While having the proper documentation as a guardian is important, there are several barriers related to accessing care and obtaining timely medical clearance that adults with ID/DD and their guardians/caregivers may face, including:

1. Not Having the Proper Medical Decision-Making Paperwork- In order to provide care, healthcare providers will often ask for the client or caregiver to sign documents approving medication, procedures, or surgery. At this time, if the parent/caregiver is going to sign on behalf of the patient, they will need to provide proof of guardianship or a healthcare proxy for the provider to obtain the necessary medical clearances. Many families are not aware of the need to obtain limited or full healthcare guardianship when their child turns 18 (and is unable to make their own decisions around healthcare even with support). This can become a critical issue when the individual with ID/DD needs health care, and the provider is unable to obtain clearance without the legal paperwork. The caregiver would need to petition the court for guardianship to facilitate treatment or medical intervention. This will involve financial costs associated with the legal process, and also extends the wait time from diagnosis to treatment. If an adult with ID/DD will require guardianship to support healthcare decision making and health and safety, it is recommended that families pursue this option before a healthcare crisis occurs, as the guardianship process does take a considerable amount of time.

[4] National Core Indicators. (2021). Data Highlight. Retrieved from https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_Data_Highlight_Guardianship_2021_Final.pdf

2. Lack of awareness and understanding of autonomy and self-determination considerations: It can be a challenge to find trained healthcare professionals who are experienced in navigating the unique healthcare needs and decision-making capacity of individuals with ID/DD. This can contribute to delays in obtaining medical clearances or difficulties in finding professionals who can adequately assess and provide recommendations regarding person centered, client engaged treatment planning that promotes health and safety but also increases patient autonomy and self-determination.

3. Financial constraints: The time and cost associated with the legal processes to obtain guardianship when needed can be a barrier for individuals and families, particularly for those with limited financial resources. Additionally, for culturally and linguistically isolated and historically underserved populations, the process can be difficult to navigate and complete. The financial burden may prevent individuals from pursuing guardianship or a healthcare proxy if their loved one requires healthcare and cannot make the decisions themselves.

WHAT TO BRING TO AN APPOINTMENT AS A GUARDIAN

When visiting the dentist or other healthcare provider, the guardian must be prepared to bring the relevant information and documentation to ensure proper care and communication. Options are to bring the papers to the appointment in person, or scan them to save on your phone or other device so they can be emailed. Below is a list of papers and information to bring/scan.

1. Legal Guardianship Papers – Provide copies of legal documents establishing your guardianship status if applicable. This is crucial for the healthcare provider to recognize your authority in making healthcare decisions on behalf of your loved one with ID/DD if they are not able to make decisions on their own.

2. Healthcare Information – Bring a comprehensive medical history of the individual, including any existing medical conditions, allergies, and past surgeries or treatments. Also provide an up-to-date list of medications, dosages, frequency for any prescription and over-the-counter medications.

3. Communication Preferences – If the individual with ID/DD has specific communication preferences or needs, communicate this information to the healthcare provider. Include details about effective communication strategies and any assistive devices.

4. Behavioral Information – Share information about any behavioral challenges or triggers that may impact the healthcare visit. This allows the healthcare provider and staff to approach your loved one with sensitivity.

5. Emergency Contacts – Provide current emergency contact details, including names, phone numbers, and relationships. This ensures that the dentist can reach someone familiar with the individual in case of any unforeseen circumstances.

6. Insurance and Billing Information – Bring the individual's insurance card and any necessary billing information to facilitate the billing process and ensure that the necessary procedures are covered.

7. Dental History – To help the dentist understand dental history, bring past dental records, including information about previous dental procedures, treatments, and X-rays if available, or ask the dentist if you can sign the paperwork needed for them to access the client's records ahead of time from previous dentists to ensure they understand the client's dental care history.

8. Comfort Items – Bring specific comfort items or tools that help your loved one cope with anxiety or sensory issues if needed.

9. Advance Directives – Share any advance directives or specific healthcare preferences with the healthcare provider.

In addition to having these files on hand, there are digital storage options and medical lockboxes in Nevada to store guardianship papers and other key documents. The Nevada Secretary of State offers a service called the Nevada Lockbox, an electronic registry securely maintained on the Nevada Secretary of State website that contains an electronic reproduction of each document filed by the registrant. The Nevada Lockbox has two filing components:

1. The Advance Directive Registry is a simple and secure approach to ensure that your medical wishes are followed. A copy of your advance directive will be kept confidentially and readily available to you and your health care provider, when needed, 24-7.

2. The Guardianship Nomination Registry is a secure filing of your "Request to Nominate Guardian Form", which is available in the event that an authorized entity needs to determine whether a person has nominated a guardian.

GUARDIANSHIP INFORMATION FOR CAREGIVERS

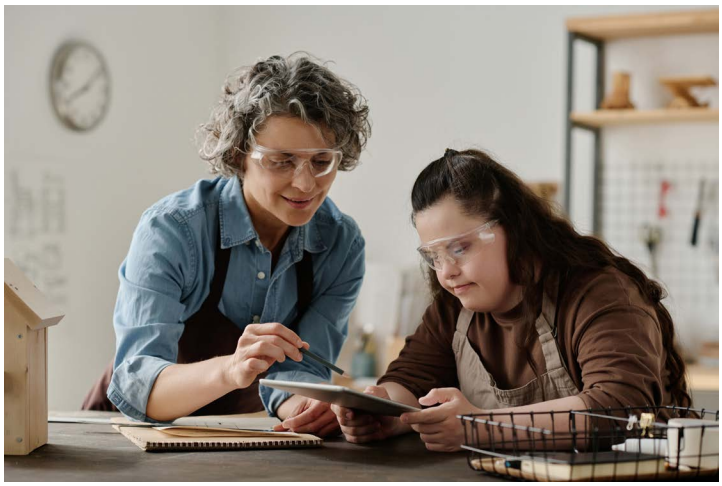
What is a Guardian?

A guardian is a person lawfully invested with the power, and charged with the duty, of taking care of the person and managing the property and rights of another person, who, for some peculiarity of status, or defect of age, understanding, or self-control, is considered incapable of administering his own affairs.[5]

To assist with determining if guardianship is the right choice, the National Center for State Courts offers a free online training course, The Right Fit: Decision-Making Supports and Guardianship training, which provides a broad overview of decision-making supports and guardianship that is not specific to state laws or rules.

If establishing guardianship has been decided, the process usually starts with someone, such as a family member, a governmental agency, or a service provider, filing a petition in the court with jurisdiction. Guardianship is a legal process where someone—like a family member, friend, or paid person—is approved and appointed by the court to be a guardian or conservator and act in their loved one's best interest, ensuring that someone familiar with their needs can advocate on their behalf.

In Nevada, "Guardian" means any person appointed under Nevada Revised Statutes (NRS) Chapter 159 (NRS 159.017 and NRS 159A 017) as a guardian of the person, of the estate, or the person and estate for any other person. The term includes, without limitation, a special guardian or, if the context so requires, a person appointed in another state who serves in the same capacity as a guardian in Nevada. A guardian of an adult functions as a "best interest" representative. [6]



As a guardian, you must always keep the protected person's best interest in mind when making decisions.

Different Types of Guardianship in Nevada

Types of guardianship vary from state to state. In Nevada, there are three types of guardianship with varying responsibilities:[7, 8]

1. Guardianship of the Person: A guardian of the person makes health care and other personal decisions for the protected person (or ward). Responsibilities: A guardian of the person has a duty to both to the protected person and to the court. A guardian of the person will be

[5]Black's Law Dictionary. Retrieved from https://thelawdictionary.org/guardian/#:~:text=A%20guardian%20is%20a%20person,of%20administering%20his%20own%20affairs

responsible for deciding where the protected person will live, food, clothing, shelter, medical care, transportation, and education. Ultimately, a guardian of the person will be responsible for the protected person's safety, well-being, and care. A guardian of the person is required to fill out an annual report of guardian, which can be obtained by the court.

2. Guardianship of the Estate: A guardian of the estate is someone the court names to manage money, property or assets and make financial decisions for a protected person. Responsibilities: A guardian of the estate also has a duty to both to the protected person and to the court. Annual accounts are required unless the court grants summary administration, which may allow a guardian to file accounting every two years, three years, or more. The court may require a budget to be submitted, which will serve as the financial plan for the protected person throughout the year. These responsibilities as the person's guardian of property last until the court relieves the guardian of the duties. The court may do this because someone else has been appointed, the person has died, or the person no longer needs a guardian.

3. Guardianship of the Person and the Estate: This type of guardianship carries the restrictions and rights of both above types of guardianship and allows the guardian to make all financial and personal decisions for the protected person.

"The personal autonomy, liberty, freedom, and dignity of each individual with IDD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with IDD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime." [9]

[6]Eighth Judicial District Court. Clark County, Nevada. Guardianship in Nevada. Retrieved from http://www.clarkcountycourts.us/departments/guardianship/guardianship-in-nevada/
[7]Nevada Legal Services. Guardianship. Retrieved form https://nevadalegalservices.org/guardianship/#:~:text=There%20are%20three%20types%20of,to%20make%20financial%20decisions%20only
[8]Eighth Judicial District Court. Clark County, Nevada. Guardianship in Nevada. Retrieved from http://www.clarkcountycourts.us/departments/guardianship/guardianship-in-nevada
[9]The Arc. (2021) Autonomy, Decision-Making Supports, and Guardianship. Retrieved from https://thearc.org/wp-content/uploads/2023/02/Autonomy-Decision-Making-Supports-and-Guardianship.pdf

Nevada Revised Statutes (NRS) Regarding Guardianship of Adults

NRS 159 – Guardianship of Adults NV Rev. Stat. § 159.044 (2)(i) & (3) (2021)
159.044. Petition for appointment of guardian: Who may submit; content; needs assessment required for proposed protected person.

1. A proposed protected person, a governmental agency, a nonprofit corporation or any interested person may petition the court for the appointment of a guardian.

2. To the extent the petitioner knows or reasonably may ascertain or obtain, the petition must include, without limitation:

...

(i) A summary of the reasons why a guardian is needed and recent documentation demonstrating the need for a guardianship. The documentation must include, without limitation:

(1) A certificate signed by a physician who is licensed to practice medicine in this State or who is employed by the Department of Veterans Affairs, a letter signed by any governmental agency in this State which conducts investigations or a certificate signed by any other person whom the court finds qualified to execute a certificate, stating:

(I) The need for a guardian;

(II) Whether the proposed protected person presents a danger to himself or herself or others;

(III) Whether the attendance of the proposed protected person at a hearing would be detrimental to the proposed protected person;

(IV) Whether the proposed protected person would comprehend the reason for a hearing or contribute to the proceeding; and

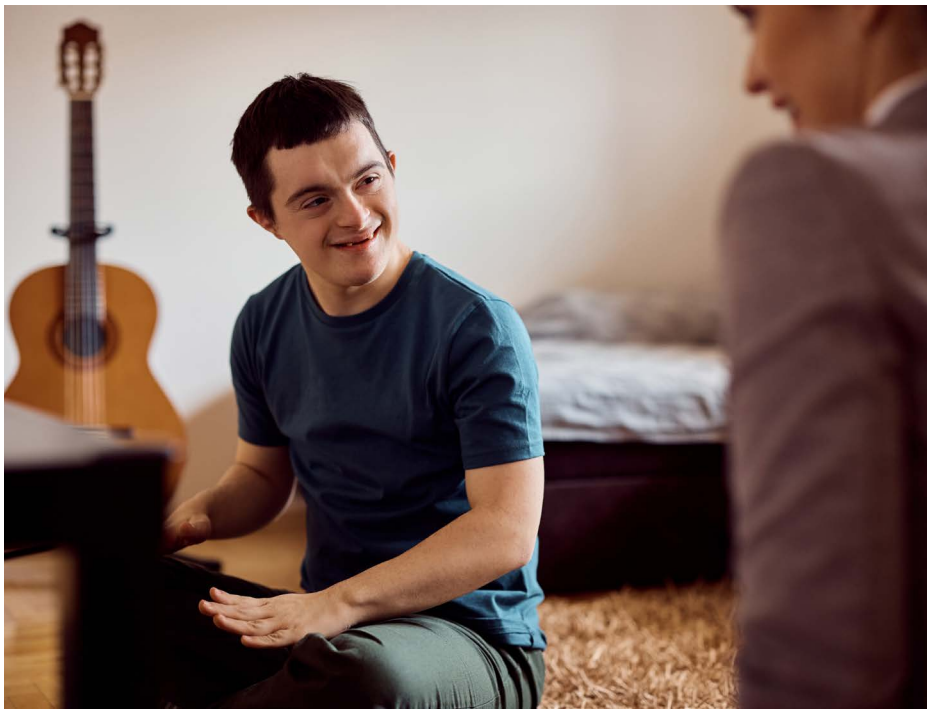
(V) Whether the proposed protected person is capable of living independently with or without assistance; and...

3. Before the court makes a finding pursuant to NRS 159.054, a petitioner seeking a guardian for a proposed protected person must provide the court with an assessment of the needs of the proposed protected person completed by a licensed physician which identifies the limitation of capacity of the proposed protected person and how such limitations affect the ability of the proposed protected person to maintain his/her safety and basic needs. The court may prescribe the form in which the assessment of the needs of the proposed protected person must be filed.

Barriers to Guardianship

There are several barriers to obtaining guardianship and medical clearance for individuals with intellectual and development disabilities (ID/DD) that caregivers may face, including:

- 1. Legal and procedural complexities: The process of establishing guardianship can be legally and procedurally complex, requiring court involvement and various documentation. This can be a barrier for individuals with ID/DD and their families, who may struggle to navigate the legal system or may not have access to the necessary resources for the process.



- 2. Lack of awareness and understanding: Healthcare providers and legal professionals may have limited knowledge or understanding of the unique needs and abilities of for individuals with ID/DD. This can lead to misconceptions, biases, or underestimation of their capacity to make decisions, resulting in unnecessary guardianship proceedings or restrictions.

- 3. Autonomy and self-determination considerations: Guardianship involves a transfer of decision-making authority from the individual to a guardian. However, there is a growing recognition of the importance of promoting autonomy and self-determination for individuals with ID/DD. Guardianship can be seen as a restriction on their rights and independence, and alternative models of decision-making support, such as supported decision-making or power of attorney, may be more appropriate in some cases.

- 4. Stigma and discrimination: Negative attitudes and societal stigma towards individuals with ID/DD can create barriers to accessing guardianship and medical clearance. These biases may result in assumptions about incompetence or an unwillingness to provide necessary support and accommodation..

- 5. Financial constraints: The cost associated with legal processes and medical evaluations can be a barrier for individuals and families, particularly for those with limited financial resources. The financial burden may prevent individuals from pursuing guardianship or obtaining the required medical clearances.

ALTERNATIVES TO FULL GUARDIANSHIP TO MAXIMIZE INDIVIDUAL AUTONOMY

A list of alternatives to full guardianship is provided in the table below: [10]

	Description	Potential Drawbacks
Advance directives	Documents such as a living will or Portable Medical Orders (POLST). Written by individuals to provide guidance on their future care preferences. Health care providers or surrogate decision makers may use these documents as a reflection of one's previously stated wishes.	• May require witness signatures and/or notarization in some states. • Variable content included; may be insufficient for specific medical decisions that arise. • Forms are variably recognized and honored geographically and across healthcare systems.
Supported decision making	Identifying and mobilizing trusted friends and family members who can help individuals with dementia or other disabilities make decisions. The individual retains decisional capacity.	• Potential for undue influence of support person(s). • Lack of formal legal recognition of the support person(s).
Durablea medical power of attorneyb	While a person maintains decision making abilities, they appoint a surrogate decision maker to make medical decisions at a point of future incapacity. (Also called "health care proxy" in some states).	• Requires witness signatures and/or notarization in some states. • Requires written physician activation in certain states. • Revokable by the individual at any time they have decisional capacity. • Can be overridden if the named POA is unavailable, unwilling to serve, or not acting in incapacitated individual's best interest.
Mediation	Private process in which an objective third party arbitrates disputes. In the context of potential guardianship, can be used to define roles, assign healthcare proxies, and/or identify less restrictive options.	• Not available or legally recognized in all 50 states. • May be impractical in the case of interfamilial conflict.
Limited (partial) guardianship	Guardianship is granted only over the domains for which the individual lacks capacity for rational decision making, (e.g., finances, properties, place of residence). The individual otherwise retains the right to make decisions and manage affairs on their own behalf.	• Requires nuanced evaluation by expert assessor to demonstrate domain-specific capacity assessments. • Loss of patient autonomy in relevant domains.
Temporary guardianship	Guardianship is granted for the identified domains for which the individual lacks capacity for rational decision making but is time-limited due to the possibility their condition could improve (e.g., prolonged delirium, post-stroke).	• Loss of patient autonomy. • Requires serial court appearances to reassess ongoing need for guardianship.

[10]Zietlow, K., Dubin, L., Battles, A., & Vitale, C. (2022). Guardianship: A medicolegal review for clinicians. Journal of the American Geriatrics Society, 70(11), 3070–3079. Retrieved from https://doi.org/10.1111/jgs.17797

IN SUMMARY

Addressing these barriers requires a multi-faceted approach involving education and training for healthcare providers, legal professionals, and the public. It also involves promoting alternative decision-making models and ensuring access to resources and support services for individuals with ID/DD and their families, as well as ensuring that information and supports are available throughout the process so that when medical care is needed, the process has already been completed and all paperwork is in place.

To decrease wait time, delays for treatment, and improve access to healthcare, including oral healthcare, it is best that guardians of adults with ID/DD have all the required paperwork and decision-making documentation completed ahead of time, and easily accessible to be shared with providers.

Checklist for Guardians

Below is a checklist of items to have prepared prior to visiting a healthcare provider:

CHECK	DOCUMENT	NOTES
☐	Legal Guardianship Papers	
☐	Healthcare Information	
☐	Communication Preferences	
☐	Behavioral Information	
☐	Emergency Contacts	
☐	Insurance/Billing Information	
☐	Dental/Medical History	
☐	Comfort Items	
☐	Advance Directives	

ABOUT THE AUTHORS

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