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***NDSC Position Statement on Guardianship for Individuals with Down syndrome***

The National Down Syndrome Congress (NDSC) recognizes that the guardianship system needs major reform. Further examination of the guardianship system is needed to ensure that people with Down syndrome retain, to the greatest extent possible, all of their civil rights and constitutional due process protections and to ensure that a less restrictive alternative is available should it meet a person's needs. **Given this, NDSC believes less restrictive means of decision-making support should be considered before the use of guardianship is considered as an option.** Less restrictive alternatives<sup>1</sup> to guardianship may include health-care proxies, advance directives, supported decision-making<sup>2</sup>, powers of attorney, notarized statements, and representation agreements<sup>2</sup>. We recognize that family members of individuals with Down syndrome and other developmental disabilities who may consider guardianship want the best for their loved one. It is important to provide accessible, understandable, and comprehensive information about the array of less restrictive alternatives to guardianship that will increase the chances of a person with Down syndrome finding decision support(s) that work for them without necessitating the level of intrusion in one's life that comes with guardianship. Optimal engagement of the individual with Down syndrome is critical to this process.

In short, guardianship<sup>3</sup> is a state legal process where a court removes some or many of the legal and decision-making rights from an individual and transfers all or some of them to another person<sup>4</sup>. Although the specifics of guardianship depend on state law, an adult usually becomes

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<sup>1</sup> See: [https://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/](https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/)

<sup>2</sup> See: [https://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice/supported-decision-making/](https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/supported-decision-making/)

<sup>3</sup> Guardianship includes adult guardianship, conservatorship and any other corresponding terms used by a state or tribe. The term includes both guardianship of the person and guardianship of the property unless otherwise specified. Source: <https://law.syracuse.edu/academics/conferences-symposia/the-fourth-national-guardianship-summit-maximizing-autonomy-and-ensuring-accountability?redirect>

<sup>4</sup> See: [https://www.americanbar.org/groups/senior\\_lawyers/publications/voice\\_of\\_experience/2022/voice-of-experience-february-2022/understanding-](https://www.americanbar.org/groups/senior_lawyers/publications/voice_of_experience/2022/voice-of-experience-february-2022/understanding-)

subject to guardianship when a court, through a judge, finds that the individual is incapable of making all or some of their own financial, legal, or personal decisions and deems it necessary to appoint a guardian to make those choices on their behalf<sup>5</sup>. When a person is subject to guardianship, their ability to make healthcare decisions, vote, control their finances, and make other decisions may be limited. Additionally, the individual may also lose many civil and legal rights guaranteed by civil rights law and the U.S. Constitution such as the right to vote, sign contracts, get married, and more.

People with Down syndrome, like many with intellectual and/or developmental disabilities (ID/DD), have unfortunately experienced a long history of low expectations coupled with the belief that people with ID/DD are incapable of maintaining autonomy over their own lives. The history of institutionalization captures the essence of this perspective when people with ID/DD were forced to live away from the community and were supervised by people who, at a minimum, did not have their best interests in mind, and at worst abused and neglected them in institutions. In many ways, unnecessary guardianship is a vestige of this idea that people with ID/DD could not care for themselves and thus needed excessively restricted supervision which came at the expense of people living the lives they chose. This is compounded in present situations when many schools across the country are still informing parents that they should, and in some cases tell parents they must, become their child's guardian as a matter of course, cautioning parents that they may not participate in their child's decision-making over education, healthcare, finances, and all other major life decisions once the student reaches the age of majority, without offering other alternatives such as powers of attorney that would still allow the parent to participate.

Systemic reforms to the legal system regarding guardianship are needed at the state and local level. This should include, among other reforms, assuring that supported decision-making is legally recognized in all states and that there is education and training for judges, lawyers, guardians and others involved in the court system on how to better determine the capabilities and need for support of an adult with a disability rather than solely relying on diagnosis.

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[guardianship/#:~:text=That%20can%20mean%20to%20protect,%2C%20physical%2C%20and%20adaptive%20limitations.](#)

<sup>5</sup> See: [https://ncd.gov/sites/default/files/NCD\\_Turning-Rights-into-Reality\\_508\\_0.pdf](https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf)

While more progress is needed, it is clear that people with Down syndrome can and do live, work, love, and engage in their communities and make their own decisions with varying levels of supports, many without enhanced supervision under a system such as guardianship.