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Human Rights Authority Legal Advocacy Service Office of State Guardian

Supported Decision-Making Act Public Act 104-0614 Effective Date: 02-27-22 Frequently Asked Questions

- 1. **To whom does this Act apply?** This legislation is intended to provide a mechanism of support for adults with intellectual and developmental disabilities (ID/DD).
- 2. Why is it needed? Sometimes, persons with ID/DD have been subjected to unnecessary and restrictive court-appointed guardianships upon turning age 18 simply because they have a disability when a less formalized structured support may be more appropriate. Individuals with ID/DD should have options that promote self-sufficiency and support. Supported decision-making is a model of assistance for persons with disabilities who have a range of decisional capacity and could benefit from personal assistance and support provided by persons that they select and trust who will be referred to as supporters. This model aims to maximize the person's autonomy in personal choice and self-determination.
- 3. **Will Guardianship still be available?** Guardianship will still be an option for individuals who lack decision-making capacity as determined by the court.
- 4. How will a supporter know if the individual with ID/DD has this diagnosis before agreeing to act as a supporter? According to the Mental Health and Developmental Disabilities Code (405 ILCS 5) an individual with ID/DD would have a diagnosis pertaining to ID/DD such as "intellectual disability," "Down Syndrome," "Autism," or Cerebral Palsy." The diagnosis would have been in place prior to the age of 18. In addition, the individual would likely have a history of receiving services related to a diagnosis such as therapy services, early intervention, special education, or DD adult services. If in doubt, the supporter could request that the individual provide documented proof such as a physician or psychological statement or a school or other evaluation.

- 5. Does the supported decision-making form found in the legislation have to be used? The legislation does not specifically require the use of the exact form contained therein, only that any agreement substantially follow the legislated form; this is similar language used in sample forms for advanced directives such as a power of attorney. Most other states with supported decision-making statutes in place incorporate a sample form.
- 6. **Does the form have to be notarized?** No. However, two witnesses must observe the signing of the agreement and the supporter cannot serve as one of the witnesses.
- 7. Is a physician's statement required for an agreement? No.
- 8. What are examples of areas of support with which a supporter might assist? Examples of possible areas of support include: helping the person with ID/DD with acquiring food/clothing and shelter; assisting with decisions related to physical and emotional health; helping with financial affairs; applying for public benefits; seeking and applying for employment; assisting with residential services; helping with school issues; and advocacy. With regard to financial assistance, a supporter cannot open a bank account or make deposits or withdrawals without the individual present; however, the supporter could assist the individual in developing a budget and paying bills.
- 9. What might a supporter do in these areas of support? A supporter might help the person with ID/DD gather and understand information regarding a decision, help the person weigh options, assist with related appointments, help monitor services, advocate when needed and perhaps help communicate the person's decision. The areas of supported are based on the person's needs and choice. A person might need help with just one area of support or multiple areas. Again, the person with the disability still makes all decisions. The person with a disability should be present when decisions they have made are being communicated by the supporter to others.

- 10. **Are there specific things a supporter can't do?** A supporter *can't*: make decisions for the person with ID/DD; obtain information without the consent of the person; use information about the person for any other reason than for assisting the person; and the supporter can't receive pay for being a supporter. A supporter can only have access to information relevant to identified areas of support and a release of information allowing access to information must be signed by the person with ID/DD.
- 11. What safeguards are in place to ensure that the interests, choices and preferences of the individual with ID/DD are protected against potential abusive situations? The legislation emphasizes that the person with ID/DD still makes all decisions; there are built-in protections related to supporter disqualifications, supporter duties and abuse reporting should a supporter overstep identified areas of assistance. The person with a disability can also end the agreement at any time. The supporter helps the individual gather information regarding decisions, weigh options, determine risks/benefits and may help communicate the final decision but the person with the disability still makes the final decision.
- 12. **Who can serve as a supporter?** The legislation specifies who **CANNOT** serve as a supporter, including: 1) an employee or employer of the person with ID/DD unless an immediate family members; 2) a paid support services worker unless an immediate family member; 3) a person who works for an agency that is financially responsible for the person with ID/DD; 4) a person ineligible under the Health Care Worker Registry; 5) a person against whom there is a court order prohibiting contact with ID/DD; and 6) a person who has been convicted of a sex offense, aggravated assault, fraud, theft, forgery or extortion. Examples of possible supporters might be a parent, sibling, cousin, aunt, uncle or trusted family friend.
- 13. Can the person with a disability have more than one Supported Decision-Making Agreement? Yes, if that is the individual's desire. More than one supporter can help gather information to make informed decisions, weigh options, determine risks and benefits and help communicate final decisions made by the individual. To help avoid conflicts between supporters, any such arrangements should be documented in in the Agreement.

- 14. **How are service providers to regard a supported decision-making agreement?** Service providers, such as schools, medical providers, residential providers and vocational providers, are to rely on the terms of the agreement. However, if a service provider or anyone suspects abuse or neglect, they are mandated to report the abuse/neglect to Adult Protective Services at 1-866-800-1409.
- 15. **How might a supported decision-making agreement be established?** A person with ID/DD asks for help from a family member or friend on a regular basis in certain life areas like helping with medical appointments and decisions. This arrangement can then be put into a written agreement and presented to involved service providers, medical providers, etc. The person with a disability and the supporter would discuss questions, needs and parameters of an agreement and then both the person and the supporter should take training to be offered at the Illinois Guardianship and Advocacy Commission website: GAC (illinois.gov)
- 16. How are supported decision-making agreements terminated? An agreement can be terminated if the Office of Inspector General or Adult Protective Services has a finding of abuse or neglect against the supporter or if there is a restraining order against the supporter by the person with the disability. In addition, either the Supporter or the Principal can terminate the agreement at any time. The principal can terminate the agreement by destroying it or directing someone to destroy it in the presence of the principal, making a written statement that the agreement is revoked that is signed and dated by the principal, or the principal can verbally indicate the agreement is revoked in front of two witnesses. A supporter can terminate the agreement by giving notice to the principal. It is recommended that the supporter provide a two week notice to the principal in the event that another supporter needs to be arranged.
- 17. Is there a mechanism within the agreement for the Principal to designate a back-up Supporter in case the Supporter is suddenly not able to function due to illness or death? There is nothing in the Act that would prohibit a Principal from adding an addendum to the Agreement that would identify a back-up.

- 18. How does a Supported Decision-Making Agreement differ from a Power of Attorney? A Power of Attorney document is an advance directive of a person who has decisional capacity to designate an agent for them to make decisions for them in the event they lose their capacity or, in some instances, to make financial transactions in their place even though they still retain capacity. The key distinction between the two is that under a Supported Decision-Making document the person with the intellectual disability makes their own decision whereas under a Power of Attorney the person with an intellectual disability has appointed a substitute decision-maker who makes decisions for them.
- 19. Do privileges like attorney-client or patient-doctor extend to discussions/information sharing between a Supporter and a Principal? Could a Supporter be subpoenaed? The Supported Decision-Making Act contains this provision on privilege and confidentiality: "If a supporter assists a principal in accessing, collecting, or obtaining personal information, including protected health information under the Health Insurance Portability and Accountability Act of 1996 or educational records under the Family Educational Rights and Privacy Act of 1974, the supporter shall ensure that the information is kept privileged and confidential, as applicable, and is not subject to unauthorized access, use, or disclosure." Nothing in the Act would prohibit a supporter from being issued a subpoena. If the subpoena was an effort to penetrate HIPAA or FERPA confidentiality this provision of the Act could be raised to not disclose that information.
- 20. If a person has a dual diagnosis of a developmental disability and a mental illness, does the Act apply? Yes, the Act applies as long as the person has an intellectual or developmental disability.
- 21. Can a Supporter act as a surrogate under the Health Care Surrogate Act? A medical provider could consider a Supporter as a close friend on the priority list of surrogates. GAC is considering legislation to specifically list a "Supporter in a Supported Decision-Making Agreement" in the priority list under the Health Care Surrogate Act.

- 22. When considering Supported Decision-Making by way of restoration of rights for someone under adult guardianship would a physician's report be recommended or would other supporting documentation be sufficient? Different courts could handle this differently. The Probate Act does not require a physician's statement as a pre-condition to filing a restoration petition but some judges won't consider such petitions if they are not supported by a physician's statement. It is a possibility, however, that should a supporter come forward and that a supported decision-making agreement be provided to the court that the court could consider a petition for restoration. Documentation supporting such a petition could vary and would be dependent upon the person's circumstances as well as the guardian's position on such a petition.
- 23. **Who can assist with additional questions?** Contact Teresa Parks at <u>Teresa.Parks@illinois.gov</u>. or by phone at 309-671-3061.