

HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: CS/HB 1207 Supported Decisionmaking for Adults with Disabilities

SPONSOR(S): Children, Families & Seniors Subcommittee, Tant

TIED BILLS: IDEN./SIM. **BILLS:** SB 1772

| REFERENCE | ACTION | ANALYST | STAFF DIRECTOR or BUDGET/POLICY CHIEF |
|---|------------------|---------|--|
| 1) Children, Families & Seniors Subcommittee | 15 Y, 0 N, As CS | Poche | Brazzell |
| 2) Civil Justice & Property Rights Subcommittee | | | |
| 3) Health & Human Services Committee | | | |

SUMMARY ANALYSIS

Supported decisionmaking (SDM) is a person-driven decisionmaking model that empowers a person with a disability, the decisionmaker, to make life choices with help from a supporter, while the values, priorities, and wishes of the decisionmaker drive the process. SDM helps the disabled person understand and explore options, to know the risks and benefits associated with each option, to receive recommendations, and to choose. SDM also provides the assistance of a supporter, advisor, or agent to carry out each choice. SDM enables an individual to ask for support where and when needed.

CS/HB 1207 allows an adult with a disability to enter into an SDM agreement with at least one supporter if the adult does so voluntarily, without coercion or undue influence, and that adult understands the nature and effect of the agreement. The bill requires each supporter to be an adult but, unless the person is an immediate family member of the decisionmaker, excludes the following persons from serving as a supporter:

- An employer, employee, health care provider, creditor, or debtor of the decisionmaker;
- An employee or contractor of a state agency who provides services directly to the decisionmaker;
- A person who provides paid support services, excluding decisionmaking assistance, directly to the decisionmaker;
- A landlord or an employee of a landlord of the decisionmaker; or
- A person against whom a protective order or restraining order has been entered by a court at the request of or on behalf of the decisionmaker.

Excluding the forgoing individuals avoids conflicts of interest that may serve the needs of the supporter rather than the decisionmaker.

The bill permits an adult with a developmental disability to enter into an SDM agreement that authorizes a supporter to:

- Assist the decisionmaker in understanding the options, responsibilities, and consequences of life decisions;
- Assist the decisionmaker in accessing, collecting, and obtaining information and records relevant to a life decision including, but not limited to, medical, psychological, financial, educational, or treatment records, to which the decisionmaker is entitled, from any person or entity;
- Assist the decisionmaker in communicating his or her decisions; or
- Access the decisionmaker's personal information, to the extent authorized by the SDM agreement.

The does not appear to have a fiscal impact on state or local governments.

The bill provides an effective date of July 1, 2022.

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. EFFECT OF PROPOSED CHANGES:

Background

Agency for Persons with Disabilities

The Agency for Persons with Disabilities (APD) is responsible for providing Medicaid home and community-based services to persons with developmental disabilities. A developmental disability is defined as a disorder or syndrome that is attributable to intellectual disability, cerebral palsy, autism, spina bifida, Down syndrome, Phelan-McDermid syndrome, or Prader-Willi syndrome; that manifests before the age of 18; and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.¹ The overarching goal for APD is to prevent or reduce the severity of the developmental disability and implement community-based services that will help individuals with developmental disabilities achieve their greatest potential for independent and productive living in the least restrictive means.²

iBudget Florida Program

Individuals with specified developmental disabilities who meet Medicaid eligibility requirements may choose to receive services in the community through the state's Medicaid Home and Community-Based Services (HCBS) waiver, known as iBudget Florida. Alternatively, they may choose to live in an institutional setting known as an Intermediate Care Facility for the Developmentally Disabled (ICF/DD) through traditional Medicaid administered by the Agency for Health Care Administration (AHCA).³

APD administers iBudget Florida under s. 393.0662, F.S. iBudget Florida uses an algorithm, or formula, to set individuals' funding allocations for waiver services. The statute authorizes APD to give individuals additional funding under certain conditions (such as a temporary or permanent change in need, or an extraordinary need that the algorithm does not address).⁴ APD phased in the implementation of iBudget Florida, with the final areas transitioned from the previous tiered waiver system on July 1, 2013.⁵

APD serves just over 35,000 individuals through iBudget Florida⁶, contracting with service providers to offer 27 supports and services to assist individuals to live in their community.⁷ Examples of waiver services enabling children and adults to live, learn, and work in their communities include residential habilitation, behavioral services, personal supports, adult day training, employment services, and occupational and physical therapy.⁸

iBudget waiver services are only one source of supports available to clients. Clients, families, legal representatives, support coordinators, and providers are responsible for seeking non-waiver supports to augment and replace waiver services. The iBudget waiver is the payer of last resort.⁹

¹ S. 393.063(9), F.S.

² S. 393.062, F.S.

³ S. 393.0662, F.S.

⁴ S. 393.0662(1)(b), F.S.

⁵ Agency for Persons with Disabilities, *Quarterly Report on Agency Services to Floridians with Developmental Disabilities and Their Costs: First Quarter Fiscal Year 2017-18*, November 2017, available at <http://apd.myflorida.com/publications/reports/docs/Quarterly%20Report%201st%20Quarter%20FY%202017-18%20FINAL%20v3.pdf>

⁶ Agency for Persons with Disabilities, *Home and Community Based Services (HCBS) Waiver Monthly Surplus-Deficit Report for Waiver Program Expenditures – FY 2021-22*, December 30, 2021, available at <https://apd.myflorida.com/publications/reports/docs/FY%202021-22%20Surplus%20Deficit%20Worksheet%202021-12-30.pdf>

⁷ Supra, FN 5.

⁸ Id.

Eligibility for iBudget Services

The application process for individuals wishing to receive services through the iBudget program are detailed in section 393.065, F.S. APD must review applications for eligibility within 45 days for children under 6 years of age and within 60 days for all other applicants.¹⁰ Individuals who are determined to be eligible for the waiver program are either given a slot in the program or placed on a wait list. Currently, due to demand exceeding available funding, individuals with developmental disabilities who wish to receive HCBS services from APD are placed on a wait list for services in priority categories of need, unless they are in a crisis.¹¹

As of January 2022, 22,759 individuals are on the HCBS wait list.¹² A majority of people on the wait list have been on the list for more than five years, though some are children receiving services through the school system and others are individuals who have been offered waiver services previously but refused them and chose to remain on the wait list.¹³

The needs of APD clients are prioritized as prescribed by section 393.065(5), F.S. There are seven categories listed below in decreasing order of priority:

- Category 1 – Clients deemed to be in crisis.
- Category 2 – Children from the child welfare system at the time of:
 - Finalization of an adoption with placement in a family home;
 - Reunification with family members with placement in a family home; or
 - Permanent placement with a relative in a family home.
- Category 3 – Includes, but not limited to, clients:
 - Whose caregiver has a documented condition that is expected to render the caregiver unable to provide care within the next 12 months and for whom a caregiver is required but no alternate caregiver is available;
 - Who are at substantial risk of incarceration or court commitment without supports;
 - Whose documented behaviors or physical needs place them or their caregiver at risk of serious harm and other supports are not currently available to alleviate the situation; or
 - Who are identified as ready for discharge within the next year from a state mental health hospital or skilled nursing facility and who require a caregiver but for whom no caregiver is available.
- Category 4 – Includes, but not limited to, clients whose caregivers are 70 years of age or older and for whom a caregiver is required but no alternate caregiver is available;
- Category 5 – Includes, but not limited to, clients who are expected to graduate within the next 12 months from secondary school and need support to obtain or maintain competitive employment, or to pursue an accredited program of postsecondary education to which they have been accepted.
- Category 6 – Clients 21 years of age or older who do not meet the criteria for categories 1-5.
- Category 7 – Clients younger than 21 years of age who do not meet the criteria for categories 1-4.¹⁴

Guardianship

When a court deems an individual legally incompetent (incapable of making some or all decisions for himself or herself), a third party, often termed a guardian or substitute or surrogate decision maker, is

⁹ Id. at pg. 2-75.

¹⁰ S. 393.065(1), F.S.

¹¹ S. 393.065, F.S.

¹² University of South Florida, Florida Center for Inclusive Communities, *Florida's DD Waitlist Campaign*, available at www.ddwaitlist.cbcs.usf.edu (last viewed on January 23, 2022)(based on information from APD).

¹³ Id.

¹⁴ S. 393.065(5), F.S.

appointed to make decisions on that individual's behalf.¹⁵ Most often, appointing a substitute decision maker occurs through a formal guardianship proceeding. In the U.S., guardianship proceedings are governed by individual state laws, with each state establishing its own statutes, policies, and procedures. In many states, a person may not be placed under guardianship if there is a less restrictive option available.¹⁶ When an individual is found to lack legal capacity to make her or his own decisions, the court appoints a third-party guardian or conservator who has the authority to make decisions for the individual, who thereby becomes a ward of the state.¹⁷

Guardianship is divided into two types. First, limited or partial guardianship occurs when an individual has been deemed incapable of making decisions in only specific areas of life, and a guardian has the authority to decide for the individual in those specific areas only. Second, full or plenary guardianship occurs when the court has found that an individual lacks capacity to make all legal decisions, and the guardian is authorized to make all decisions for the ward.¹⁸

Substitute decision makers are guided by two decisionmaking standards. A substituted judgment standard maintains that guardians should make decisions that the patient would have wanted, if capable. In contrast, a best-interest standard holds that guardians should make decisions based on what the guardian determines to be in the ward's best interest. Most state laws argue that a substituted judgment standard should guide guardian decision making, and a best interest standard is allowable when guardians lack sufficient evidence to determine what decision the ward would have made if she or he had the capacity.¹⁹

Adjudicating a person totally incapacitated and in need of a guardian deprives a person of his or her civil and legal rights.²⁰ The Legislature has recognized that the least restrictive form of guardianship should be used to ensure the most appropriate level of care and the protection of that person's rights.²¹

In Florida, the process to determine an individual's incapacity and the subsequent appointment of a guardian begins with a verified petition detailing the factual information supporting the reasons the petitioner believes the individual to be incapacitated, including the rights the alleged incapacitated person is incapable of exercising.²² Once a person has been adjudicated incapacitated, the court appoints a guardian, and the letters of guardianship are issued.²³ The order appointing a guardian must be consistent with the ward's welfare and safety, must be the least restrictive appropriate alternative, and must reserve to the ward the right to make decisions in all matters commensurate with his or her ability to do so.²⁴

Relationship Between Guardian and Ward

The relationship between a guardian and a ward is a fiduciary one.²⁵ A fiduciary relationship exists between two persons when one of them is under a duty to act for or to give advice for the benefit of another upon matters within the scope of that relationship.²⁶ The guardian, as fiduciary, must:

¹⁵ Martinis, J, *Supported decisionmaking: Protecting rights, ensuring choices*, BIFOCAL: A Journal of the ABA Commission on Law and Aging, 36(5), pgs. 107-110 (2015).

¹⁶ Quality Trust for Individuals with Disabilities, *Supported decisionmaking: An Agenda for Action* (2014), available at <http://jennyhatchjusticeproject.org/node/264>.

¹⁷ Jameson, J, et al., *Guardianship and the potential of supported decision making with individuals with disabilities*, Research and Practice for Persons with Severe Disabilities, 40(1), pgs. 36-51 (2014).

¹⁸ Blanck, P, and Martinis, J, "The right to make choices": *The National Resource Center for Supported Decisionmaking, Inclusion*, 3, pgs. 24-33 (2015).

¹⁹ Shalowitz, DI, et al., *The accuracy of surrogate decision makers: A systematic review*, Archives of Internal Medicine, 166(5), pgs. 493-497 (2006).

²⁰ S. 744.101(1), F.S.

²¹ S. 744.101(2), F.S.

²² S. 744.3201, F.S.

²³ SS. 744.3371-.345, F.S.

²⁴ S. 744.2005, F.S.

²⁵ *Lawrence v. Norris*, 563 So.2d 195, 197 (Fla. 1st DCA 1990); S. 744.361(1), F.S.

- Act within the scope of the authority granted by the court and as provided by law;
- Act in good faith;
- Not act in a manner contrary to the ward's best interests under the circumstances; and
- Use any special skills or expertise the guardian possesses when acting on behalf of the ward.²⁷

Additionally, the fiduciary relationship between the guardian and the ward may not be used for the guardian's private gain, other than the remuneration for fees and expenses provided by law.²⁸ As such, the guardian must act in the best interest of the ward and carry out his or her responsibilities in an informed and considered manner. Should a guardian breach his or her fiduciary duty to the ward, the court is authorized to intervene.²⁹

Powers and Duties of the Guardian

The guardian of an incapacitated person may exercise only those rights removed from the ward and delegated to the guardian.³⁰ The guardian has a great deal of power when it comes to managing the ward's estate. Some of these powers require court approval before they may be exercised. The following chart details some of the guardian's powers, either with or without court approval:

| Examples of Powers That May Be Exercised by a Guardian | |
|--|--|
| Upon Court Approval³¹ | Without Court Approval³² |
| <ul style="list-style-type: none"> • Enter into contracts that are appropriate for, and in the best interest of, the ward. • Perform, compromise, or refuse performance of a ward's existing contracts. • Alter the ward's property ownership interests, including selling, mortgaging, or leasing any real property (including the homestead), personal property, or any interest therein • Borrow money to be repaid from the property of the ward or the ward's estate. • Renegotiate, extend, renew, or modify the terms of any obligation owing to the ward. • Prosecute or defend claims or proceedings in any jurisdiction for the protection of the estate. • Exercise any option contained in any policy of insurance payable to the ward. • Make gifts of the ward's property to members of the ward's family in estate and income tax planning. • Pay reasonable funeral, interment, and grave marker expenses for the ward. | <ul style="list-style-type: none"> • Retain assets owned by the ward. • Receive assets from fiduciaries or other sources. • Insure the assets of the estate against damage, loss, and liability. • Pay taxes and assessments on the ward's property. • Pay reasonable living expenses for the ward, taking into consideration the ward's current finances. • Pay incidental expenses in the administration of the estate. • Prudently invest liquid assets belonging to the ward. • Sell or exercise stock subscription or conversion rights. • Consent to the reorganization, consolidation, merger, dissolution, or liquidation of a corporation or other business enterprise of the ward. • Employ, pay, or reimburse persons, including attorneys, auditors, investment advisers, care managers, or agents, even if they are associated with the guardian, to advise or assist the guardian in the performance of his or her duties. • Consent on behalf of the ward to a sterilization or abortion procedure on the ward.³³ |

²⁶ *Doe v. Evans*, 814 So.2d 370, 374 (Fla. 2002).

²⁷ S. 744.361(1), F.S.

²⁸ S.744.446, F.S.

²⁹ S. 744.446(4), F.S.

³⁰ S. 744.361(1), F.S.

³¹ S. 744.441, F.S.

³² S. 744.444, F.S.

³³ S. 744.3215, F.S.

Before allowing a guardian to consent to any of the above actions, the court must follow the procedure for extraordinary authority, as follows:

- Appoint an independent attorney to act on the incapacitated person's behalf and the attorney must have the opportunity to meet with the person and present evidence and cross examine witnesses at any hearing on the petition for authority to act;
- Receive as evidence independent medical, psychological, and social evaluations of the incapacitated person or appoint its own experts to assist in the evaluations;
- Personally meet with the incapacitated person to obtain an impression of the person's capacity and to allow the person the opportunity to express his or her personal views or desires regarding a Do Not Resuscitate Order (DNRO);
- Find by clear and convincing evidence that the person lacks the capacity to make a decision about a DNRO and that their capacity is not likely to change in the foreseeable future; and
- Be persuaded by clear and convincing evidence that the authority to consent to or sign on behalf of the ward an order not to resuscitate is in the best interest of the incapacitated person.³⁴

There are also a number of duties imposed on a guardian. The guardian must:

- File an initial report within 60 days after the letters of guardianship are signed;
- File an annual report with the court consisting of an annual accounting and/or an annual guardianship plan;
- Implement the guardianship plan;
- Consult with other guardians appointed, if any;
- Protect and preserve the property of the ward; invest it prudently, apply income first to the ward before the ward's dependents, and account for it faithfully;
- Observe the standards in dealing with the guardianship property that would be observed by a prudent person dealing with the property of another; and
- If authorized by the court, take possession of all of the ward's property and of the rents, income, issues, and profits from it, whether accruing before or after the guardian's appointment, and of the proceeds arising from the sale, lease, or mortgage of the property or of any part.³⁵

A guardian who is given authority over a ward's person shall, as appropriate under the circumstances:

- Consider the expressed desires of the ward when making decisions that affect the ward;
- Allow the ward to maintain contact with family and friends unless the guardian believes that such contact may cause harm to the ward;
- Not restrict the physical liberty of the ward more than reasonably necessary to protect the ward or another person from serious physical injury, illness, or disease;
- Assist the ward in developing or regaining capacity, if medically possible;
- Notify the court if the guardian believes that the ward has regained capacity and that one or more of the rights that have been removed should be restored to the ward;
- To the extent applicable, make provision for the medical, mental, rehabilitative, or personal care services for the welfare of the ward;
- To the extent applicable, acquire a clear understanding of the risks and benefits of a recommended course of health care treatment before making a health care decision;
- Evaluate the ward's medical and health care options, financial resources, and desires when making residential decisions that are best suited for the current needs of the ward;
- Advocate on behalf of the ward in institutional and other residential settings and regarding access to home and community-based services; and
- When not inconsistent with the person's goals, needs, and preferences, acquire an understanding of the available residential options and give priority to home and other community-based services and settings.³⁶

³⁴ S. 744.3725, F.S.

³⁵ S. 744.361, F.S.

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Additionally, a professional guardian must ensure that each of the guardian's wards is personally visited by the guardian or one of the guardian's professional staff at least once each calendar quarter.³⁷

Who Can Be Appointed Guardian

The following persons may be appointed guardian of a ward:

- Any resident of Florida who is 18 years of age or older and has full legal rights and capacity;
- A nonresident if he or she is related to the ward by blood, marriage, or adoption;
- A trust company, a state banking corporation, or state savings association authorized and qualified to exercise fiduciary powers in this state, or a national banking association or federal savings and loan association authorized and qualified to exercise fiduciary powers in Florida;
- A nonprofit corporation organized for religious or charitable purposes and existing under the laws of Florida;
- A judge who is related to the ward by blood, marriage, or adoption, or has a close relationship with the ward or the ward's family, and serves without compensation;
- A provider of health care services to the ward, whether direct or indirect, when the court specifically finds that there is no conflict of interest with the ward's best interests; or
- A for-profit corporation that meets certain qualifications, including being wholly owned by the person who is the circuit's public guardian in the circuit where the corporate guardian is appointed.³⁸

Appointment of Professional Guardians

A professional guardian is a guardian who has at any time rendered services to three or more wards as their guardian; however, a person serving as a guardian for two or more relatives is not considered a professional guardian.³⁹ A public guardian is considered a professional guardian for purposes of regulation, education, and registration.⁴⁰

In each case when a court appoints a professional guardian and does not use a rotation system for such appointment, the court must make specific findings of fact stating why the person was selected as guardian in the particular matter involved.⁴¹ The findings must reference the following factors:

- Whether the guardian is related by blood or marriage to the ward;
- Whether the guardian has educational, professional, or business experience relevant to the nature of the services sought to be provided;
- Whether the guardian has the capacity to manage the financial resources involved;
- Whether the guardian has the ability to meet the requirements of the law and the unique needs of the individual case;
- The wishes expressed by an incapacitated person as to who shall be appointed guardian;
- The preference of a minor who is age 14 or over as to who should be appointed guardian;
- Any person designated as guardian in any will in which the ward is a beneficiary; and
- The wishes of the ward's next of kin, when the ward cannot express a preference.⁴²

The court may not give preference to the appointment of a person based solely on the fact that he or she was appointed to serve as an emergency temporary guardian.⁴³ When a professional guardian is appointed as an emergency temporary guardian, that professional guardian may not be appointed as the permanent guardian of a ward unless one of the next of kin of the alleged incapacitated person or the ward requests that the professional guardian be appointed as permanent

³⁶ Id.

³⁷ Id.

³⁸ S. 744.309, F.S.

³⁹ S. 744.102(17), F.S.

⁴⁰ Id.

⁴¹ S. 744.312(4)(a), F.S.

⁴² S. 744.312(2)-(3), F.S.

⁴³ S. 744.312(5), F.S.

guardian.⁴⁴ However, the court may waive this limitation if the special requirements of the guardianship demand that the court appoint a guardian because he or she has special talent or specific prior experience.⁴⁵

The court may not appoint a professional guardian who is not registered by the Office of Public and Professional Guardians.⁴⁶ The following are disqualified from being appointed as a guardian:

- A person convicted of a felony;
- A person who is incapable of discharging the duties of a guardian due to incapacity or illness, or is otherwise unsuitable to perform the duties of a guardian;
- A person who has been judicially determined to have committed abuse, abandonment, or neglect against a child;
- A person who has been found guilty of, regardless of adjudication, or entered a plea of nolo contendere or guilty to, any offense prohibited under s. 435.04, F.S.;
- A person who provides substantial services to the proposed ward in a professional or business capacity, or a creditor of the proposed ward, may not be appointed guardian and retain that previous professional or business relationship, with exceptions; or
- A person who is in the employ of any person, agency, government, or corporation that provides service to the proposed ward in a professional or business capacity, unless that person is the spouse, adult child, parent, or sibling of the proposed ward or the court determines that the potential conflict of interest is insubstantial and that the appointment would clearly be in the proposed ward's best interest.⁴⁷

An estimated 1.3 million adults are currently living under guardianship or conservatorship, and courts control over \$50 billion in assets of those under guardianship or conservatorship. Researchers have estimated that approximately 1.5 million people in the United States are subject to guardianship at any one time.⁴⁸

Alternatives to Guardianship

Before a plenary guardian is appointed, the least restrictive form of guardianship should be made available to assist people who are only partially incapable of caring for their needs. Alternatives to guardianship and less restrictive means of assistance, including, but not limited to guardian advocates, should also be explored.⁴⁹

In October 2016, Chief Justice Jorge Labarga of the Florida Supreme Court established a Guardianship Workgroup to better protect vulnerable people who are subject to guardianship and guardian advocacy. The workgroup was charged with examining "judicial procedures and best practices pertaining to guardianship," focusing on topics including, but not limited to, the use of least restrictive alternatives that address specific functional limitations.⁵⁰

⁴⁴ S. 744.312(4)(b), F.S.

⁴⁵ *Id.*

⁴⁶ S. 744.2003(9), F.S.

⁴⁷ S. 744.309(3), F.S.

⁴⁸ Uekert, B, and Van Duizend, R, Nat'l Ctr. for State Courts, *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform* 107, 108-09 (2011).

http://www.guardianship.org/reports/Uekert_Van_Duizend_Adult_Guardianships.pdf (estimating that there are 1.5 million guardianships in the United States but suggesting that the actual number could range from 1 to 3 million); Millar, D & Renzaglia, A, *Factors Affecting Guardianship Practices for Young Adults with Disabilities*, 68 *Exceptional Children* 465 (2002) (estimating 1.25 million adults under guardianship in the United States); Teaster, P, *infra*, FN 76 (discussing different estimates and the overall lack of evidence on the frequency of guardianship); Wood, E., Am. Bar Ass'n Comm'n on Law & Aging for the Nat'l Ctr. on Elder Abuse, *State-Level Adult Guardianship Data: An Exploratory Study* 11 (2006) (discussing different estimates and the overall lack of good numbers on the frequency of guardianship).

⁴⁹ S. 744.1012(1), F.S.

⁵⁰ Judicial Management Council, Guardianship Workgroup Final Report, pg. 7 (June 2018) (on file with Health and Human Services Committee staff).

The workgroup recommended requiring the petitioner, in the petition for appointment of a guardian, to explain why alternatives to guardianship are insufficient and expanding the types of alternatives that must be addressed. The report specified alternatives to guardianship include SDM, durable powers of attorney, trusts, banking services, advance directives, medical proxies, and representative payees.⁵¹

Additionally, the workgroup recommended the petitioner specify whether he or she is aware of the existence of a designation of preneed guardian and to identify his or her efforts in determining whether a designation exists in the petition for appointment of a guardian.⁵² Florida law recognizes several types of guardianships, including preneed guardians, and:

- Natural guardians;
- Guardians of minors;
- Emergency temporary guardianship;
- Standby guardianship;
- Preneed guardian for a minor; and
- Foreign guardians.⁵³

For people with capacity (the mental ability to make and understand important legal and other decisions), the following are less restrictive options to guardianship:

Advanced Directives: Written ahead of need, the following are documents that express a person's desire or give decisionmaking authority to someone who is trusted. In each case, the person must have the mental capacity to understand what they are doing at the time the directive is signed. Each has legal requirements for both the contents and validity:

- *Durable Power of Attorney (POA):* If a person has the capacity to understand the transfer of decisionmaking rights to another, a durable POA may be appropriate. This is a legal document that allows the grantor to give decisionmaking rights to an agent, also known as an attorney-in-fact. The rights granted can be as broad or as limited as the law allows and can include health care decisions. A POA is "durable" when it is intended to continue even if the grantor becomes incapacitated.
- *Health Care Surrogate:* A written document that names one or more people to represent a person in health care decisions if he or she becomes unable to make them.
- *Living Will:* This document sets out the maker's wishes for the withholding or withdrawal of life prolonging procedures in the event of a terminal condition.

For people with limited capacity, the following are less restrictive options to guardianship:

Medical Proxy: A medical proxy can make health care decisions for an incapacitated or developmentally disabled patient if there is no advance directive or, if there is an advanced directive, no surrogate is available to make health care decisions.⁵⁴ The statute does not require any legal action or document for appointment as proxy. Instead, there is a statutory priority, starting with a guardian, then moving to spouse, adult child, parent, adult sibling, adult relative "who has exhibited special care and concern," close friend, and finally a social worker selected by a bioethics committee.

Client Advocate: If a parent is unavailable, a family member or friend may be appointed as the client advocate for a person with developmental disabilities receiving services through the Agency for Persons with Disabilities.⁵⁵ This does not result in any legal authority, but allows the client advocate to participate in decisions related to services.

Co-signer of Bank Accounts: If a bank account is set up to require more than one signature, this is a way to exercise some control over expenditures while a co-signer is learning financial skills.

⁵¹ Id. at Appendix B.

⁵² Id.

⁵³ Part III, Ch. 744, F.S.

⁵⁴ S. 765.401, F.S.

⁵⁵ S. 393.0651, F.S.

Representative Payee: The Social Security Administration may appoint a representative payee to receive and manage benefits for another. The “rep payee” must account for these benefits annually.

Parent Representative: Ordinarily, when a child in the public school system turns 18, parental rights are automatically transferred to the child. If the student does not have a guardian and also does not have the ability to provide informed consent on his or her educational program, the parent can be appointed to represent the educational interests of the student.

Guardian Advocate

Guardian advocacy is a process for family members, caregivers, or friends of individuals with a developmental disability to obtain the legal authority to act on their behalf if the person lacks the decisionmaking ability to do some, but not all, of the decisionmaking tasks necessary to care for his or her person or property.⁵⁶ This is accomplished without having to declare the person with a developmental disability incapacitated.

A petition to appoint a guardian advocate for a person with a developmental disability may be executed by an adult person who is a resident of this state.⁵⁷ The petition must be verified by the petitioner and must state:

- The name, age, and present address of the petitioner and the petitioner’s relationship to the person with a developmental disability;
- The name, age, county of residence, and present address of the person with a developmental disability;
- That the petitioner believes that the person needs a guardian advocate and the factual information on which such belief is based;
- The exact areas in which the person lacks the ability to make informed decisions about the person’s care and treatment services or to meet the essential requirements for the person’s physical health or safety;
- The legal disabilities to which the person is subject;
- If authority is sought over any property of the person, a description of that property and the reason why management or control of that property should be placed with a guardian advocate;
- The name of the proposed guardian advocate, the relationship of the proposed guardian advocate to the person with a developmental disability, the relationship of the proposed guardian advocate with the providers of health care services, residential services, or other services to the person with developmental disabilities, and the reason why the proposed guardian advocate should be appointed. If a willing and qualified guardian advocate cannot be located, the petition must so state; and
- Whether the petitioner has knowledge, information, or belief that the person with a developmental disability has executed an advance directive or a durable power of attorney.⁵⁸

Notice of the filing of the petition must be given to the person with a developmental disability, both verbally and in writing, in the language of the person and in English.⁵⁹ Notice must also be given to the person with a developmental disability’s next of kin, any designated health care surrogate, an attorney-in-fact designated in a durable power of attorney, and such other persons as the court may direct.⁶⁰ A copy of the petition to appoint a guardian advocate must be served with the notice. The notice must state that a hearing will be held to inquire into the capacity of the person with a developmental disability to exercise the rights enumerated in the petition.⁶¹ The notice must also state the date of the hearing on

⁵⁶ S. 393.12(2)(a), F.S.

⁵⁷ S. 393.12 (3), F.S.

⁵⁸ S. 393.12(3)(a)-(f), F.S.

⁵⁹ S. 393.12(4)(a), F.S.

⁶⁰ Id.

⁶¹ S. 393.12(4)(b), F.S.

the petition.⁶² The notice must state that the person with a developmental disability has the right to be represented by counsel of the person's own choice and the court must initially appoint counsel.⁶³

Within 3 days after a petition has been filed, the court must appoint an attorney to represent a person with a developmental disability who is the subject of a petition to appoint a guardian advocate.⁶⁴ The person with a developmental disability may substitute his or her own attorney for the attorney appointed by the court.⁶⁵

If the court finds the person with a developmental disability requires the appointment of a guardian advocate, the order appointing the guardian advocate must contain findings of facts and conclusions of law:

- The nature and scope of the person's inability to make decisions;
- The exact areas in which the person lacks ability to make informed decisions about care and treatment services or to meet the essential requirements for the individual's physical health and safety;
- If any property of the person is to be placed under the management or control of the guardian advocate, a description of that property, any limitations as to the extent of such management or control, and the reason why management or control by the guardian advocate of that property is in the best interest of the person;
- If the person has executed an advanced directive or durable power of attorney, a determination as to whether the documents sufficiently address the needs of the person and a finding that the advanced directive or durable power of attorney does not provide an alternative to the appointment of a guardian advocate that sufficiently addresses the needs of the person with a developmental disability;
- If a durable power of attorney exists, the powers of the attorney-in-fact, if any, that are suspended and granted to the guardian advocate;
- If an advanced directive exists and the court determines that the appointment of a guardian advocate is necessary, the authority, if any, the guardian advocate shall exercise over the health care surrogate;
- The specific legal disabilities to which the person with a developmental disability is subject;
- The name of the person selected as guardian advocate; and
- The powers, duties, and responsibilities of the guardian advocate, including bonding of the guardian advocate as provided by law.⁶⁶

Upon compliance with all of the statutory requirements, letters of guardian advocacy must be issued to the guardian advocate.

Generally, the difference between guardian advocacy and guardianship in Florida is the process to gain the authority. For guardian advocacy, the process does not include an adjudication of incapacity, while guardianship requires a finding of incapacity, at least in part. However, the duties and responsibilities are identical for guardian advocates and guardians.

Supported Decisionmaking

Supported decisionmaking (SDM) is a person-driven decisionmaking model that empowers persons with disabilities to make life choices with help from a supporter or advisor. The values, priorities, and wishes of the individual drive the decisionmaking process. SDM helps the disabled person understand and explore options, to know the risks and benefits associated with each option, to receive recommendations, and to choose. SDM also provides the assistance of a supporter, advisor, or agent to carry out each choice. SDM enables an individual to ask for support where and when they need it.

⁶² Id.

⁶³ S. 393.12(4)(c), F.S.

⁶⁴ S. 393.12(5), F.S.

⁶⁵ Id.

⁶⁶ S. 393.12(8), F.S.

The SDM model assumes all persons seek advice and guidance with making decisions; that all persons, as long as they have the ability to communicate, have the ability and right to make choices; and that the choices of the individual should be honored.⁶⁷

Initial promotion of SDM occurred in the early 1990s in British Columbia as a part of the disabilities rights movement. This initial advocacy resulted in the first legislative recognition of SDM in the 1996 Representation Agreement Act in British Columbia. This act established a set of decisions regarding how individuals with cognitive disabilities may seek support, criteria for appointment of a supporter, and a mechanism by which decisions reached through SDM would be legally recognized.⁶⁸

SDM achieved a significant breakthrough with the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In a landmark statement, the UNCRPD declared that member states must assist individuals with disabilities so that they can exercise their right to legal capacity. Furthermore, UNCRPD identified SDM as a crucial legal mechanism toward achieving this basic human right. Spurred by this development, several countries—including Canada, Ireland, Israel, the United Kingdom, Germany, Australia, and the United States—have begun to promote integration of SDM into their respective legal systems.⁶⁹

The past decade has seen an expansion in recognition of and respect for SDM by U.S. courts, legislators, policymakers, and national organizations. In 2009, the Texas legislature created a pilot program to “promote the provision of SDM services to persons with intellectual and developmental disabilities and persons with other cognitive disabilities who live in the community”.⁷⁰ After that program ended, Texas passed new laws recognizing the availability and effectiveness of SDM and required courts to find that a person cannot make decisions using SDM before appointing a guardian.⁷¹

In 2016, a similar law was passed and signed in Delaware. The Delaware law allows people with disabilities to designate a person as a supporter. The supporter is given legal status and authorization to assist the person in making life choices, including health, safety, and educational decisions, but is not allowed to make decisions on the individual’s behalf.

In 2014, the Virginia General Assembly directed the state secretary of health and human services to “recommend strategies to improve the use of supported decision making in the Commonwealth and ensure that individuals ... are consistently informed about and receive the opportunity to participate in their important life decisions”. The resulting report made several recommendations, including amending state law to recognize SDM as a “legitimate alternative to guardianship”; requiring anyone appointed as a substitute decision maker to be trained in and commit to using SDM; and developing a required training on SDM for providers and professionals.⁷²

Two private organizations have also endorsed SDM. In 2012, the American Bar Association (ABA) convened stakeholders “to explore concrete ways to move from a model of substituted decisionmaking, like guardianship, to one of supported decision making, consistent with the human right of legal capacity”.⁷³ In 2015, the ABA published an article calling for the use of SDM as an alternative to

⁶⁷ Blanck, P., and Martinis, J., *The Right to Make Choices: The National Resource Center for Supported Decisionmaking*, 3 Inclusion 24 (2015), available at www.bbi.syr.edu/publications/2015/SDM_Overview.pdf.

⁶⁸ Browning, M, et al., *Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice*, Research and Practice in Intellectual and Developmental Disabilities, 1(1), pgs. 34-45 (2014).

⁶⁹ Supra, FN 33.

⁷⁰ Tex. Government Code Ann. § 531.02446 (2009), expired on Sept. 1, 2013.

⁷¹ Tex. Est. Code s. 1101.101(a)(D) and (E).

⁷² Virginia Department of Health and Human Resources, Report of the Secretary of Health and Human Resources, *Supportive Decision Making Study (HJR 190, 2014) To The Governor and The General Assembly of Virginia*, House Document No. 6 (2015) available at <https://rga.lis.virginia.gov/Published/2015/HD6/PDF>.

⁷³ American Bar Association, *Beyond Guardianship: Supported Decisionmaking by Individuals with Intellectual Disabilities: A Short Summary from the 2012 National Roundtable*, available at http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRRoundtable_Summary.auth_checkdam.pdf.

guardianship, stating, “In contrast to overbroad or undue guardianship, SDM can increase self-determination by ensuring that the person retains life control to the maximum extent possible”.⁷⁴

In 2015, the National Guardianship Association (NGA), which represents over 1,000 guardians, conservators and fiduciaries from across the United States, also published a position paper on SDM. It states that “modern day respect for individual rights dictates that we must allow each individual to make or participate to the extent possible in personal decisions.” The NGA concluded “supported decisionmaking should be considered for the person before guardianship, and the SDM process should be incorporated as a part of the guardianship if guardianship is necessary”.⁷⁵ The NGA’s position is consistent with most state laws, which require that less restrictive alternatives be considered or attempted prior to placing a person under guardianship.

SDM can increase self-determination and improve life outcomes.⁷⁶ Research has found that people with disabilities who exercise greater self-determination have a better quality of life. Two recent studies found that people who increased their self-determination became better employed, more independent and had more community integration.⁷⁷ Another found links between people with disabilities’ self-determination and their perceived quality of life.⁷⁸

These findings build upon decades of research identifying a direct relationship between self-determination and life outcomes. One study found that people with greater self-determination were more likely to want to live independently, manage their money and be employed.⁷⁹ Another found that individuals who exercised more self-determination were more likely to live independently, have greater financial independence, be employed at higher paying jobs, and make greater advances in employment.⁸⁰ Still another found that women with intellectual disabilities provided with education in self-determination were more likely to identify abusive situations and less likely to suffer abuse.⁸¹

While there is no one-size-fits all model, SDM generally occurs when people use one or more trusted friends, family members, professionals, or advocates to help them understand the situations and choices they face so they may make their own informed decisions. SDM mirrors how most adults make decisions – whether to get car repairs, sign legal documents, consent to medical procedures, review financial documents, and similar decision points. In each instance, individuals seek advice, input, and information from knowledgeable friends, family, and professionals so they may make their own informed choices. Offering people with disabilities more involvement in their own lives through preference and choice making is vitally important to their quality of life.⁸²

In contrast to guardianship, which is a drastic intervention that give one person complete authority over another’s life, SDM empowers people to make their own decisions with the assistance of a formal or informal network of supporters. SDM has primarily been available for people with intellectual and/or developmental disabilities; however, advocates and other stakeholders have begun exploring SDM’s

⁷⁴ Supra, FN 1.

⁷⁵ National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making,” (2015), available at http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf.

⁷⁶ Infra, FN 53, at 1154.

⁷⁷ Karrie A. Shogren et al., *Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities*, 4 J. Special Educ. 256 (forthcoming Feb. 2015), available at <http://www.academia.edu/4518360/>; Laurie Powers et al., *My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education*, 34 Child. & Youth Services Rev. 2179 (2012).

⁷⁸ Janette McDougall et al., *The Importance of Self-Determination to Perceived Quality of Life for Youth and Young Adults with Chronic Conditions and Disabilities*, 31 Remedial & Special Educ. 252 (2010).

⁷⁹ Michael Wehmeyer & Michelle Schwartz, *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*, 63 Exceptional Child. 245 (1997).

⁸⁰ Michael Wehmeyer & Susan Palmer, *Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination*, 38 Educ. & Training Developmental Disabilities 131 (2003).

⁸¹ Ishita Khemka et al., *Evaluation of a Decisionmaking Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse*, 110 Am. J. Mental Retardation 193 (2005).

⁸² Jenkinson, J.C., *Who shall decide? The relevance of theory and research to decisionmaking by people with an intellectual disability*, Disability, Handicap, & Society, 8(4), pgs. 361-375 (1993).

application to persons with psychiatric disabilities, traumatic brain injuries, and age-related cognitive decline.

While SDM relationships can be of more or less formality and intensity ranging from informal support by people who speak with, rather than for, the individual with a disability⁸³ to more formalized microboards and circles of support,⁸⁴ they share three common elements:

- Based on a set of guiding principles that emphasize the person with disability's autonomy, presumption of capacity, and right to make decisions on an equal basis with others;
- Recognize that a person's intent can form the basis of a decisionmaking process that does not entail removal of the individual's decisionmaking rights; and
- Acknowledge that individuals with disabilities will often need assistance in decisionmaking through such means as interpreter assistance, facilitated communication, assistive technologies and plain language.

Through these relationships, an individual with limitations in decisionmaking abilities can receive support to understand relevant information, issues, and available choices, to focus attention in making decisions, to help weigh options, to ensure that decisions are based on her own preferences, and, if necessary, to interpret and/or communicate her decisions to other parties.⁸⁵

SDM typically involves a single decisionmaking supporter; however, private SDM relationships may also occur as a circle of support or a microboard. A circle of support is a group of people, typically family members and friends, who meet regularly with a person with a disability to help that person formulate and realize his or her hopes or desires. Circles of support are seen as a way of creating or reinvigorating a support network for a person with a disability,⁸⁶ which may be especially important for persons with intellectual disabilities experiencing generational transitions in their support network.

A microboard is similar to a circle of support – it is also comprised of a group of people who aim to help an individual meet his or her needs in a manner consistent with his or her hopes and desires. However, microboard typically refers to organizations that are more formal: non-profit organizations formed to support and, in some cases, to act as the service provider for an individual with a disability.⁸⁷ Both approaches can be mechanisms for implementing SDM.

SDM is increasingly being adopted by courts, legislatures, and policymakers as a less-restrictive alternative to guardianship. In 1999, the Supreme Court of Pennsylvania reversed an order placing Patricia Peery under guardianship because she “has in place a circle of support to assist her in making rational decisions concerning her personal finances and to meet essential requirements of health and safety.”⁸⁸ In 2012, a New York court terminated the guardianship of a woman because she is “able to engage in supported decision making.”⁸⁹ The court held “proof that a person with an intellectual disability needs a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends, and mental health professionals.”⁹⁰ It then found she made her own decisions, using the support of people who “understood [their] role, not as deciding for her, but in assisting her in making her own decisions.”⁹¹ The court hailed her SDM network as “a perfect example

⁸³ Dinerstein, R, *Implementing legal capacity under article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision making*, Human Rights Brief, 30, pgs. 8-12, 10 (2012).

⁸⁴ *Id.* at pgs. 10-11.

⁸⁵ *Infra*, FN 58, at pg. 306.

⁸⁶ Allison Rowlands, *Ability or Disability?: Strengths-based Practice in the Area of Traumatic Brain Injury*, 82 Families in Soc. 273, 274 (2001) (describing circles of support as “a contrived, purpose-built friendship network, established and facilitated by a worker or trained volunteer, to replace or re-invigorate the natural network of a person whose disability may have led to former friends dropping away . . .”).

⁸⁷ Paul H. Malette, *Lifestyle Quality and Person-Centered Support: Jeff, Janet, Stephanie, and the Microboard Project*, Person-Centered Planning 151 (2002).

⁸⁸ *In re Peery*, 727 A.2d 539, 540 (Pa. 1999).

⁸⁹ *In re Dameris L.*, 956 N.Y.S.2d 848, 856 (N.Y. Sur. Ct. 2012).

⁹⁰ *Id.* at 854 (emphasis in original).

⁹¹ *Id.* at 853.

of the kind of family and community support that enables a person with an intellectual disability to make, act on, and have her decisions legally recognized....”⁹²

In 2013, Margaret “Jenny” Hatch, a woman with Down syndrome, defeated a petition to place her under a permanent, plenary guardianship in favor of the successful SDM network she established.⁹³ At trial, Ms. Hatch presented evidence that she made her own decisions with the support of friends and professionals. The court denied the petition, naming the friends Ms. Hatch chose to support her as temporary limited guardians for one year, “with the . . . goal of transitioning to the supportive [sic] decision making model.”⁹⁴ The court charged the temporary guardians to “assist [Ms. Hatch] in making and implementing decisions we have heard termed ‘supported decision making.’”⁹⁵

Additionally, several other courts across the U.S. have ended guardianships or refused to order people into guardianship because the person was able to use SDM to make his or her own decisions without a guardian.⁹⁶

Legislatures and policymakers have also recognized and implemented SDM systems for people who might otherwise be placed under guardianship. In 2009, the Texas legislature created a pilot program to “promote the provision of supported decisionmaking services to persons with intellectual and developmental disabilities and persons with other cognitive disabilities who live in the community.”⁹⁷ The program trained volunteers to support people in making “life decisions such as where the person wants to live, who the person wants to live with, and where the person wants to work, without impeding the self-determination of the person.”⁹⁸

In 2014, the Virginia General Assembly directed the state Secretary of Health and Human Services to study SDM and “recommend strategies to improve the use of supported decision making in the Commonwealth and ensure that individuals . . . are consistently informed about and receive the opportunity to participate in their important life decisions.”⁹⁹ Also in 2014, the Administration for Community Living in the U.S. Department for Health and Human Services made funding available to create “a national training and technical assistance center on . . . supported decision making.”¹⁰⁰ The federal agency described SDM as “an alternative to and an evolution from guardianship” and stressed the importance of people “retaining their own decisionmaking authorities . . . with the assistance of appropriate services and supports.”¹⁰¹

In 2015, Texas became the first state to statutorily recognize SDM agreements as an alternative to guardianship for persons who need assistance but are not incapacitated. The law is generally intended to work in conjunction with the state guardianship law to enhance opportunities for persons with disabilities and decrease the burden on the courts.¹⁰² According to the Texas state court system, “the

⁹² Id. at 855.

⁹³ *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 7 (Va. Cir. Ct. Aug. 2, 2013), available at http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf

⁹⁴ Id at pg. 5; the temporary guardianship expired on August 2, 2014.

⁹⁵ Id.

⁹⁶ Cases include: *In Re: Ryan Herbert King*, D.C.Sup.Ct. (Probate) Case No.: 2003 INT249; *In Re: Tecora Mickel*, DC Probate Case No.: 2015 INT 000291; *In re: Tanya Powell*, DC Probate Case No.: 2015 INT 529; *In Re: Beck*, Circuit, Court, Wayne County, Indiana, Case No.: 89CO1-1011-GU-025; *In re: KH*, Case No.: PR03-00264 (2nd Judicial District Court, County of Washoe, NV, 2017); *In re C.B.* (Superior Court of Vermont, Orleans Unit, 4/11/2017); *Matter of Eli T.*, 89 N.Y.S.3d 844, 849 (N.Y. Sur. Ct., Kings Cty. 2018).

⁹⁷ *Volunteer-Supported Decisionmaking Advocate Pilot Program*, Tex. Govt Code Ann. s. 531.02446 (2009) (expired on Sept. 1, 2013).

⁹⁸ Id.

⁹⁹ *H.J.Res. 190*, Reg. Sess. (Va. 2014).

¹⁰⁰ Admin. for Cmty Living, U.S. Dep’t of Health & Human Servs., *Funding Opportunity HHS2014-ACL-AIDD-DM-0084, Supported Decision Making*, available at <http://www.grants.gov/web/grants/view-opportunity.html?oppId=256168>.

¹⁰¹ Id. at 2, 6.

¹⁰² The State of Texas Office of Courts Administrator, *Texas Guardianship Reform: Protecting the Elderly and Incapacitated*, 1, 3 (January 2019), available at https://www.txcourts.gov/media/1443314/texas-guardianship-reform_jan-2019.pdf.

exploration of alternatives to guardianship has reduced the number of guardianship applications filed in Texas, a trend that was not occurring prior to the reforms.”¹⁰³

In 2016, Delaware became the second state to statutorily recognize SDM agreements. In 2018, Alaska, the District of Columbia, and Wisconsin formally recognized SDM regimes. Indiana, North Dakota, Nevada, and Rhode Island passed SDM agreement laws in 2019.

Supported Decisionmaking Agreement

An SDM agreement is a written document evidencing an agreement between a disabled person and at least one supporter that describes, in detail, the type of help the person needs. The agreement outlines the terms and conditions of both parties and asks that third parties, including courts, recognize and respect the agreement. In an SDM agreement, those who can help in making decisions are called supporters; supporters agree to help explain information; answer questions; weigh options; and let others know about the decisions that are made. The supporter does not make the decisions.¹⁰⁴

As a general guideline, people may develop individualized SDM plans by:

- *Identifying Life Areas Where Support is Needed.* First, people with disabilities should be encouraged and empowered to identify the life areas (such as health care, money, work, and/or personal relationships) where they want support making decisions.
- *Identifying how the Person Wants to Be Supported.* Next, people should explore ways they have been supported before or would like to be supported. If a particular method has been effective in the past, it should be attempted again. They may also be encouraged to think about other support methods they would like to try.
- *Identifying and Working with Supporters.* In this step, people should consider the friends, family members, professionals, and others who are or could be their life and the way they may be able to provide support. They should then approach those potential supporters and discuss and develop plans for how they can work together.
- *Creating an SDM Plan.* Although a written agreement or plan is not required to use SDM, it is often helpful to create a document that outlines the life areas where the person wants support, the support the person wants, and the people who will provide that support. There are sample SDM agreement forms available or people can create personalized plans or Powers of Attorney, Advanced Directives, Individualized Service Plans or other documents that outline how they will use SDM.

Supported Decisionmaking vs. Guardianship

Plenary guardianship, in which a court gives a guardian authority across all legal rights, is ordered in the vast majority of cases. One study found that less than 10% of the public guardianships it reviewed were limited¹⁰⁵ – meaning that in 9 out of 10 cases, the guardian had the authority to make all life decisions for the ward. Another study found that only 13% of the guardianships it reviewed across ten states were limited in scope. A third study found that plenary guardians were appointed in 54% of the cases reviewed and that there was little difference between the authority given to full and limited guardians. As one researcher commented, “it seems that as long as the law permits plenary guardianship, courts will prefer to use it.”

The trend in using plenary guardianship continues despite federal laws and U.S. Supreme Court decisions mandating community integration of people with disabilities. Also, emerging research involving individuals with cognitive disabilities suggests that plenary guardianship presently may be applied too broadly and may have potentially harmful effects, such as lowered self-esteem, lowered

¹⁰³ Id.

¹⁰⁴ Martinis, J, *Making it happen: Strategies for supported decisionmaking*, Impact, 32(1), 45 (2019).

¹⁰⁵ Teaster, P, *Wards of the state: A national study of public guardianship*, Stetson Law Review, 37, pg. 193 (2007).

perceived self-efficacy, behavioral passivity, and the potential for abuse of privilege by appointed guardians.¹⁰⁶

Guardianship can deprive people of their most basic and fundamental rights. It provides guardians with “substantial and often complete authority over the lives of vulnerable [people].”¹⁰⁷ This control extends to personal and financial decisions.¹⁰⁸ A guardian of an estate has control over a person’s financial assets, including discretion to dispose of property or sign contracts.¹⁰⁹ Likewise, a guardian of a person dictates that person’s living conditions, social freedoms, and medical care.¹¹⁰ The demand for heightened due process in guardianship proceedings reflects the fundamental nature of the rights at stake.¹¹¹ In addition, research shows that people in overbroad or undue guardianships can suffer negative life outcomes from losing the right to make decisions and the opportunity to develop independent living skills.¹¹²

Limited and full guardianships restrict or remove entirely the person’s right to make decisions and give the guardian responsibility for making decisions on the person’s behalf. Establishing and declaring in court that a person is “incompetent” is painful for all involved because it emphasizes the person’s limitations, rather than his or her strengths. Having decisions made by someone else reduces self-confidence and the ability to develop decisionmaking skills. Overly restrictive guardianships can limit the individual’s independence, cost families and the court system, are difficult to change, and can result in over reliance on paid supports. The ward is at greater risk of abuse and exploitation by others, especially when the ward is unaware of the rights he or she retains and is inexperienced in asserting that the retained rights and preferences should be honored¹¹³

SDM is not without criticism. Most of these concerns arise from a dearth of empirical research on SDM. Despite years of use, there is almost no evidence as to how decisions are actually made in SDM relationships; the effect of such relationships on persons in need of decisionmaking assistance; or the quality of the decisions that result. For example, no research to date has systematically compared outcomes from SDM to those from substitute decision making, although such studies are now beginning.¹¹⁴ It is impossible to know whether SDM actually empowers persons with cognitive disabilities.

As an empirical matter, it is not proven whether, and to what extent, SDM may be associated with better decisions, greater satisfaction with the decisionmaking process, and an increased sense of empowerment among individuals with cognitive disabilities. Some authors have expressed concerns that SDM, like substitute decision making, may expose individuals with disabilities to undue influence, manipulation, coercion, or other abuse by their alleged supporters, thereby effectively disempowering

¹⁰⁶ Jameson, JM, et al., *Guardianship and the Potential of Supported Decision Making With Individuals With Disabilities*, Research and Practice for Persons with Severe Disabilities, 40(1), pgs. 36-51 (2015).

¹⁰⁷ Judge David Hardy, *Who Is Guarding the Guardians? A Localized Call for Improved Guardianship Systems and Monitoring*, 4 NAELA J. 1, 7 (2008).

¹⁰⁸ Naomi Karp et al., AARP, *Guardianship Monitoring: A National Survey of Court Practices*, 1-2 (2006).

¹⁰⁹ S. 744.3215, F.S. (2006); Sens. Gordon H. Smith & Herb Kohl, S., Spec. Comm. on Aging, *Guardianship for the Elderly: Protecting the Rights and Welfare of Seniors with Reduced Capacity* 7 (2007).

¹¹⁰ *Guardianships: Little Progress in Ensuring Protection for Incapacitated Elderly People: Hearing Before the S. Spec. Comm. on Aging*, 109th Cong. 3-4 (2006) (statement of Barbara D. Bovbjerg, Dir. Of Education, Workforce, and Income Security Issues).

¹¹¹ *Sullivan v. Ganim*, No. CV094030012, 2009 Conn. Super. LEXIS 3516, at *22 (Conn. Super. Ct. Dec. 10, 2009).

¹¹² Salzman, L, *Guardianship for persons with mental illness – a legal and appropriate alternative?*, St. Louis University Journal of Health Law and Policy, 4, pg. 279 (2011); Kohn, N, et al., *Supported decisionmaking: A viable alternative to guardianship?*, Penn State Law Review, 117, pgs. 1111-1157 (2014); Wright, J, *Guardianship for your own good: Improving the well-being of respondents and wards in the USA*, International Journal of Law and Psychology, 33, pg. 350 (2010).

¹¹³ Id., Kohn, et al. (2014).

¹¹⁴ Blanck, P and Martinis, JG, “*The right to make choices*”: *The National Resource Center for Supported Decisionmaking, Inclusion*, 3(1), pgs. 24-33 (2015).

them.¹¹⁵ In addition, it is possible that SDM may be applied too broadly and that people who could have made a choice independently will be required to seek supports during the decisionmaking process.

Effect of Proposed Changes

CS/HB 1207 acknowledges SDM by allowing an adult with a developmental disability to enter into an SDM agreement with at least one supporter if her or she does so voluntarily, without coercion or undue influence, and he or she understands the nature and effect of the agreement. The bill requires each supporter to be an adult but, unless the person is an immediate family member of the decisionmaker, excludes the following persons from serving as a supporter:

- An employer or employee of the decisionmaker;
- A health care provider, as defined in s. 768.381(f), F.S., of the decisionmaker;
- A creditor or debtor of the decisionmaker;
- An employee or contractor of a state agency who provides services directly to the decisionmaker;
- A person who provides paid support services, excluding decisionmaking assistance, directly to the decisionmaker;
- A landlord or an employee of a landlord of the decisionmaker; or
- A person against whom a protective order or restraining order has been entered by a court at the request of or on behalf of the decisionmaker.

Excluding the forgoing individuals avoids conflicts of interest that may serve the needs of the supporter rather than the decisionmaker.

The bill permits an adult with a disability to enter into an SDM agreement that authorizes a supporter to:

- Assist the decisionmaker in understanding the options, responsibilities, and consequences of life decisions;
- Assist the decisionmaker in accessing, collecting, and obtaining information and records relevant to a life decision including, but not limited to, medical, psychological, financial, educational, or treatment records, to which the decisionmaker is entitled, from any person or entity. Such information and records must include, but need not be limited to:
 - Protected health information under the Health Insurance Portability and Accountability Act of 1996, 42 U.S.C. s. 1320d;
 - Educational records under the Family Educational Rights and Privacy Act of 1974, 20 U.S.C. s. 1232g; Information available under the Individuals with Disabilities Education Act, 20 U.S.C. ss. 1400, et seq.; or
 - Records of the identity, diagnosis, prognosis, or treatment of a patient maintained in connection with the performance of any program or activity relating to substance abuse, education, prevention, training, treatment, rehabilitation, or research which are protected by 42 U.S.C. s. 240 290dd-2 and 42 C.F.R. part II;
- Assist the decisionmaker in communicating his or her decisions; or
- Access the decisionmaker's personal information, to the extent authorized by the SDM agreement.

A supporter is must act in good faith regarding all actions taken under an SDM agreement.

For individuals under a guardian advocate, they may enter into an SDM agreement with the written consent of the guardian advocate. Such consent is not required if the agreement concerns rights that were not removed by the court in appointing the guardian advocate.

The bill requires a petition to appoint a guardian advocate to include a statement on efforts to use decisionmaking options before seeking a guardian advocate. Such options include SDM, durable power of attorney, and an advance directive. The statement must include information on:

- Each guardianship alternative that was considered or implemented;

¹¹⁵ Supra, FN 84.
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- If a guardianship alternative was not considered, the reason why; and
- Any reason why a guardianship alternative is not sufficient to meet the needs of the person with a developmental disability.

The bill does not require the individual who is the subject of the petition to have attempted to use SDM prior to the appointment.

In appointing a guardian advocate, if an SDM agreement exists, the bill requires the court to specify in its order and letters of guardian advocacy any part of the agreement that is suspended.

The bill defines the following terms for purposes of SDM:

- A “decisionmaker” means an adult with a developmental disability who has entered into an SDM agreement with at least one supporter.
- “Supported decisionmaking” is a process of supporting an adult with a developmental disability to assist them with understanding options, responsibilities, and consequences of a life decision and enabling them to make a life decision without impeding self-determination.
- A “supported decisionmaking agreement” is a written agreement between a decisionmaker and at least one supporter for SDM.
- A “supporter” means a qualified adult who has entered into an SDM agreement.

Lastly, the bill makes several conforming statutory changes to reflect the new provisions in the bill.

The bill provides an effective date of July 1, 2022.

B. SECTION DIRECTORY:

Section 1: Amends s. 393.063, F.S., relating to definitions.

Section 2: Amends s. 393.065, F.S., relating to application and eligibility determination.

Section 3: Amends s. 393.12, F.S., relating to capacity; appointment of guardian advocate.

Section 4: Creates s. 393.121, F.S., relating to supported decisionmaking.

Section 5: Amends s. 383.141, F.S., relating to prenatally diagnosed conditions; patient to be provided information; definitions; information clearinghouse; advisory council.

Section 6: Amends s. 1002.394, F.S., relating to the Family Empowerment Scholarship Program.

Section 7: Provides an effective date of July 1, 2022.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

2. Expenditures:

None.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

None.

D. FISCAL COMMENTS:

None.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

Not applicable. The bill does not appear to affect municipal or county governments.

3. Other:

None.

B. RULE-MAKING AUTHORITY:

Not applicable.

C. DRAFTING ISSUES OR OTHER COMMENTS:

APD would need to ensure that its data management systems captured data related to SDM agreements. This may include updates to demographic fields and the ability to attach such documents within existing systems.

IV. AMENDMENTS/COMMITTEE SUBSTITUTE CHANGES

On January 25, 2022, the Children, Families, and Seniors Subcommittee adopted an amendment and reported the bill favorably as a committee substitute. The amendment:

- Removed references to nursing homes and ALFs, and employees of those entities, in the provision detailing who may not serve as a supporter.
- Included a broad definition of “health care provider” to capture as many providers and health care institutions, including nursing homes and ALFs, who may have a relationship with an adult with disabilities and exclude them from serving as a supporter in an SDM agreement.

This analysis is drafted to the committee substitute as passed by the Children, Families, and Seniors Subcommittee.