

Supported Decision Making

Joint Commission on Health Care
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Study Information

- HJR 729 (Delegate Kaye Kory) requested the Secretary of Health and Human Resources study supported decision-making for individuals with intellectual and developmental disabilities
- Approved by JCHC members during work plan meeting
- Study topics: (See HJR 729 in appendix)
 - examine uses of supported decision making
 - compare policies and practices used in other states
 - determine if supported decision-making can be an appropriate alternative to guardianship
 - consult with stakeholders
 - recommend strategies and insure that individuals with intellectual and developmental disabilities are informed of supported decision making
 - determine whether legislation is necessary
 - propose legislative recommendations

2015 Supportive Decision-Making Study Report to Governor and General Assembly – House Document 6

- Findings on Supported Decision Making
 - no official position
 - no defined policies or practices
- Recommendations
 - add Supportive Decision Making (SDM) to guardianship and DBHDS authorized representatives code
 - require SDM and Person Centered Planning training for guardians and authorized representatives
 - standardize procedures for capacity evaluations
- Actions taken following report
 - no VA Code changes concerning SDM
 - DARS implemented Person Centered procedures for public guardians (22VAC30-70-30.F)
- Related VA Code – Guardianship and Decision Making
 - 2016 – final rules effective for public guardians
 - ✓ inclusive decision-making process
 - ✓ focus on expressed preferences, personal values, and needs of individual
 - ✓ empower and support individual as much as possible
 - 2012 – § 51.5-150 amended, person-centered practice procedures for public guardians
 - 1997 – § 64.2-2019 amended, requirements for private guardians
 - ✓ encourage participation in decisions
 - ✓ consider expressed desires and personal values of person

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Understanding adult guardianship helps in understanding Supported Decision Making (SDM)

- Adult Guardianship
 - a judicial determination that an adult person lacks the capacity to make decisions for him or herself, and
 - the appointment of another person to make decisions for the incapacitated (VA Code § 64.2-2000 et. seq. § 51.5-149 et. seq.)
- Guardianship, in general, means the incapacitated person
 - may lose decision making and other rights, such as:
 - ✓ voting (Article II, Section 1 of the Constitution of Virginia)
 - ✓ medical decisions
 - ✓ financial decisions, including signing a contract or lease
 - ✓ file lawsuits in own name
 - ✓ sign a power of attorney (VA Code § 64.2-1601 et. seq.)
 - ✓ sign an advanced directive (VA Code § 54.1-2981 et. seq.)
 - ✓ where to live, work
 - ✓ ability to drive, own a gun
 - ✓ choice of friends, companions
- Research indicates
 - overly restrictive guardianship
 - ✓ may be associated with decreased life competencies and overall health
 - guardianship may
 - ✓ “set up expectancies of failure . . . that diminish subsequent [life] performance”
 - young adults who receive instruction designed to increase self-determination
 - ✓ enhance employment opportunities
 - ✓ are independent
 - ✓ become part of their community

Source: Blanck, Peter and Martinis, Jonathan G. "The Right to Make Choices". The National Resource Center for Supported Decision-Making. 2015, Vol. 3, No. 1, 24-33

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Virginia guardianship can be private or public, limited or full

- Private guardianship, VA Code § 64.2-2000 et. seq.
 - petition to the Circuit Court
 - review by court appointed guardian ad litem
 - guardianship approved if person found to be incapacitated
 - guardian posts bond, qualified by Court Clerk
- Public guardianship, VA Code § 51.5-149 et. seq.
 - same process for appointment as private guardian
 - available to indigent
 - administered by Department for Aging and Rehabilitative Services (DARS) in collaboration with Department for Behavioral Health and Developmental Services (DBHDS)
 - regulated (22VAC30-70-10 et. seq.)
- Limited Guardians VA Code § 64.2-2009
 - only those responsibilities for personal affairs as specified by the written order of appointment
 - person may retain some rights based on a determination of capacity

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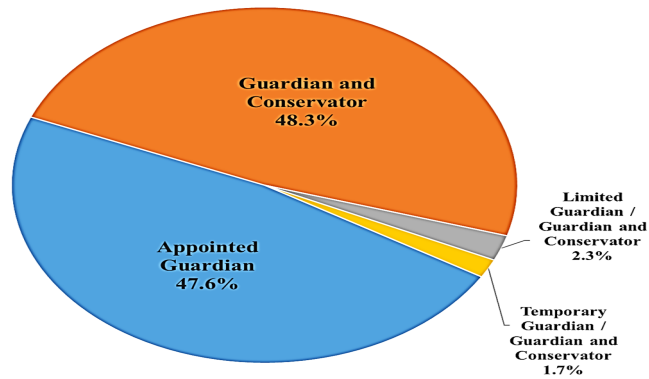
There are differences between private and public guardians

- Private guardians (est. ~12,000)
 - required to file annual reports to local department(s) of social services
 - otherwise not regulated
 - answerable to circuit court if guardian decisions are challenged
 - may be investigated by Adult Protective Services (APS) for abuse, neglect, exploitation
 - appointments can be
 - ✓ changed or reversed
 - ✓ temporary, limited or permanent
- Public guardians (1,049)
 - no other proper and suitable person willing and able to serve
 - publicly funded through DARS
 - required to file annual reports to local department(s) of social service
 - other state regulations include:
 - ✓ required face-to-face visit at least once a month
 - ✓ annual review to determine if guardianship remains appropriate
 - ✓ utilize person-centered planning
 - ✓ client-to-staff ratio of 20-to-1
 - ✓ maintain client files, subject to audit, required to attend trainings
 - 13 organizations serve as public guardian through contracts with the state
 - ✓ 454 slots reserved for the ID/DD referred by Community Service Boards
 - ✓ 98 slots reserved for individuals coming out of state mental health inpatient facilities
 - ✓ 497 slots unrestricted, generally individuals with dementia or a traumatic brain injury but no specific diagnosis required

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**All Guardian Cases: Appointment by Type
Circuit Case Management System (CCMS)
FY-2016 through FY-2019 (N = 6,252)**

- Half of all guardian cases (public and private) include the appointment of a conservator
 - conservator’s manage the estate and financial affairs of an incapacitated person
- 4.0% of all cases are either limited or temporary



Source: JCHC analysis of CCMS data provided by the Office of the Executive Secretary, Supreme Court of Virginia, July 19, 2019. Unduplicated case numbers; includes public and private guardian appointments; does not represent the number of persons under guardianship or the number of guardians. "Appointed guardian" includes "granted". Case information does **NOT** include case information for Fairfax County Circuit Court or Alexandria Circuit Court.

**DBHDS uses “authorized representative” in lieu of guardianship
(VA Code § 37.2-400 et. seq. and 12VAC35-115-146 et. seq.)**

- Authorized Representative
 - applies to individuals in treatment with DBHDS
 - evaluation determines if individual lacks capacity
 - if an attorney-in-fact, health care agent or legal guardian is not available
 - director of the DBHDS program designates a substitute decision maker
 - capacity determination is reviewed every 6 months and at discharge when requested by person, or annually by program
 - does not automatically transfer when a person moves to an area served by a different program
 - affords the individual with some decision-making rights
- DBHDS does not collect data to determine how many individuals served by the mental health system have a “program-director-appointed” authorized representative
- 8,800 of the 27,000 clients either enrolled (~14,000) or on the wait list (~13,000) for IDD Medicaid Waiver services have a guardian, conservator or powers of attorney

Recommendation: amend VA Code § 37.2-401 to improve the data on the number of people determined to be incapacitated in the state, require DBHDS to record information concerning whether a consumer of mental health system services has an authorized representative

There are other legally recognized decision-making options for individuals with IDD, such as...

Power of attorney
(VA Code § 64.2-1601 et. seq.)

Health care decision act / advanced directive
(VA Code § 54.1-2981 et. seq.)

Education power of attorney
(8VAC20-81-180)

Temporary Guardian
(VA Code § 64.2-2000)

Limited guardianship
(VA Code § 64.2-2009)

Supported Decision Making is not legally recognized in Virginia...

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Supported Decision Making...

- presumes that
 - all adults have the capacity to make their own decisions
 - making decisions is a process
 - individual decision making often includes
 - ✓ assistance and advice from others
- means helping a person identify where help may be needed and
 - finding a way to provide that help
 - ✓ recognizing that people have a right to consult with others
- solutions are different for each person
 - some may need more help than others

Source: Whitlatch, Morgan K. Esq. Project director, national resource center for supported decision-making. "Supported decision-making: practical tips for implementation." (http://www.supporteddecisionmaking.org/sites/default/files/event_files/NRC-SDM%20NGA%20Presentation.pdf)

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Supported Decision Making

- May be
 - a valid contract or informal agreement
 - recognized by law
 - voluntarily entered into
 - between 1 IDD adult and at least 1 supporter
- May be used in lieu of, or in combination with, guardianship
 - supporter is not the decision-maker
 - does not remove the current ability to petition for guardianship
- May preserve individual rights
 - least restrictive
 - affords IDD with the dignity to assume risk
 - right to succeed and make mistakes
- Adding SDM to the VA Code
 - makes clear to courts and others that SDM is a viable alternative to guardianship
- Provides a legal framework for
 - physicians
 - hospitals
 - banks
 - landlords and
 - others
 - ✓ that SDM is a legitimate tool for the IDD and disabled adults

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Federal law - accommodation and least restrictive environment for the disabled

- Federal laws protect the rights of people with disabilities:
 - Section 504 of the Rehabilitation Act; 29 U.S. Code § 701, et. seq.
 - ✓ prohibits discrimination against people with disabilities in programs that receive federal financial assistance
 - Americans with Disabilities Act (ADA); 42 U.S.C. § 12101, et. seq.
 - ✓ people with disabilities have the same rights and opportunities as everyone else; definition of disabilities includes IDD
 - Individuals with Disabilities Education Act (IDEA); 20 U.S. Code § 1400, et. seq.
 - ✓ requires students with a disability receive
 - › free appropriate public education
 - › tailored to individual needs
 - › in the least restrictive environment
- Olmstead V. L. C. (98-536) 527 U.S. 581 (1999)
 - requires states to eliminate unnecessary segregation of persons with disabilities, and to
 - ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs
(source: <https://www.ada.gov/olmstead/>)

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The Jenny Hatch Case

supported decision making in a limited and temporary guardianship

- Circuit Court of the City of Newport News
 - guardian petition hearing filed in 2012; followed by a six day trial in 2013
 - 29 year old; Down Syndrome
 - professional evaluations indicated that with appropriate support she could manage her property and finances
 - lay witness testimony indicated inability to take care of herself
 - Court recommended co-guardians
 - ✓ limited powers – medical and safety decisions with deference to {Ms. Hatch’s} wishes
 - ✓ assist Medicaid waiver service providers, guide {Ms. Hatch} to self-reliance and independence
 - ✓ limited duration – 1 year
 - ✓ goal to transition to supportive decision making
- As of today
 - guardianship order ended in 2014
 - Jenny Hatch is thriving on her own
 - writes, publishes, does speaking engagements
 - transitioning to independent living
 - working with supporters, no written agreements

(source: telephone conversation, Jonathan Martinis, Senior Director for Law and Policy. Burton Blatt Institute. Syracuse University, 9/23/2019)

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Other states have made SDM a legal option

Example - Delaware

- 80 Del. Laws, c. 427; Code § 9401A, et. seq.
 - Individuals with Disabilities -Supported Decision-making
 - ✓ help adults who do not need a guardian make decisions
 - ✓ give “supporters” legal status to participate in discussions and assist in making decisions
 - ✓ lists 11 specific services where SDM may be needed, allows for others
 - specifies that
 - ✓ the way an adult communicates is not grounds for incapacity
 - ✓ SDM cannot be used as evidence of incapacity
 - ✓ does not preclude adult from acting independently
 - SDM is a contract
 - ✓ agreement is in a writing on a form developed by the Department of Health and Social Services
 - ✓ entered into voluntarily
 - ✓ adult designates 1 supporter
 - ✓ list where support is needed and not needed, defines roles
 - ✓ complies with
 - Health Insurance Portability and Accountability Act (HIPAA)
 - Family Educational Rights and Privacy Act (FERPA)
 - ✓ protects participants from liability when acting in good faith
 - ✓ dated, signed and witnessed by 2 people

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Opportunities for SDM with the IDD population

- There are two issues related to whether to petition for guardianship for the IDD, pursue SDM, or reverse a previous guardianship
 - what is the age and level of capacity of the person at the time of the order, and
 - is there potential for the person to gain capacity as the person ages
- Under current VA Code
 - guardianship can be temporary and/or limited
 - as with Jenny Hatch case, the supported decision making model can be added to a guardianship order (see slide 13)
- ***If*** the annual reports include age and reason for determination they can be reviewed periodically to determine if there is a change in capacity that may influence a change of the guardianship order (annual reports are covered in next section)

Recommendation: add a new section to the VA Code, Title 37.2 (Behavioral Health and Developmental Services) and/or Title 59.1 (Trade and Commerce) creating SDM for Individuals with Developmental Disabilities and/or all disabled adults as an option for DBHDS and to formalize the contract in code that provides protections for private individuals that want to use a contract (see Delaware, slide 14)

Recommendation: add a reference to supported decision making to VA Code § 64.2-2003.C., requiring guardian ad litem to consider whether supported decision making is a viable option when reviewing and reporting on the extent of the duties and powers of the guardian or conservator

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The annual report is the only tool available to monitor and regulate private guardians

- VA Code § 64.2-2020
 - annual reports
 - ✓ submitted by guardian to local department(s) of social services
 - ✓ then submitted to the court clerk
 - report form prepared by the Office of the Executive Secretary of the Supreme Court
 - ✓ list of 7 items enumerated in the Code and covered on form: medical and mental health condition; living arrangements; services provided to meet needs; visits by guardian; guardian statement on agreement with treatment and habilitation plan; need for continued guardianship with possible proposed changes; whether the guardian incurred expenses, requests for reimbursement and from whom, and amount of compensation
 - annual report form does not include
 - ✓ age of incapacitated person *at time of initial guardianship appointment*
 - ✓ what type of guardianship: limited, temporary or full
 - ✓ reason for guardianship, e.g. IDD, dementia, mental illness
 - ✓ relationship to person or profession of guardian

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Lack of data is a national issue

- Poor and incomplete data on guardianship is a nationally recognized problem
 - US Senate Special Committee on Aging, November 2018
 - guardianship data is “largely unavailable”
 - few states track individuals subject to guardianship, such as
 - ✓ demographic information
 - ✓ types of guardianships used
 - ✓ extent of guardian authority
 - advocates and policy makers are left in the dark when trying to enact reform
- Sources of Guardianship data in Virginia
 - DARS collects annual report data entered by 120 local department(s) of social services
 - Circuit Case Management System (CCMS) maintained by the Office of the Executive Secretary of the Supreme Court (OES)
 - ✓ VA Code § 17.1-502 authorizes each circuit court to manage their own system
 - ✓ permits OES to aggregate data (VA Code § 17.1-208)
 - ✓ data used by courts for case management purposes, certain fields may be reported upon request
 - ✓ 118 of 120 circuit courts provide data to OES, Fairfax and Alexandria maintain their own systems
- Improvements to data collection
 - DARS implemented a new case management system for all local departments between 2018 and 2019
 - CCMS added fields to manage cases better in 2017, new fields include:
 - ✓ the type of guardian and/or conservator appointed,
 - ✓ hearing result options specific to guardians and conservators

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Age at time of guardianship appointment can help identify where other options may be considered and made available to those deemed incapacitated

Annual Reports by Age and Filing Type *

Initial Guardian Annual Report filed with local social services offices Code of VA § 64.2-2020 (Six Month Report for FY-2019)				
Summary Table	Private Guardian	Public Guardian	Total	Percent of Total
Age at time of Order (17.5 to 21)	177	11	188	14.2%
Age at time of Order (>21 to 30)	121	21	142	10.7%
Age at time of Order (>30 to 49)	137	36	173	13.1%
Age at time of Order (>49 to >100)	566	256	822	62.0%
Total	1001	324	1325	

Subsequent Guardian Annual Report Code of VA § 64.2-2020 (Six Month Report for FY-2019)				
Summary Table	Private	Public	Total	Percent of Total
Age at time of Order (17.5 to 21)	659	30	689	18.0%
Age at time of Order (>21 to 30)	410	49	459	12.0%
Age at time of Order (>30 to 49)	585	151	736	19.2%
Age at time of Order (>49 to >100)	1345	598	1943	50.8%
Total	2999	828	3827	

- Parents may petition for guardianship 6 months before their child turns 18
- DARS annual report data includes age of person when the annual report was sent to local department(s) of social services, and whether the report is the first (initial) or an annual report for subsequent years
- All annual reports should include both
 - age at time of initial guardianship appointment, and
 - age when report was submitted
- Two ages on the form provide information needed during desk top reviews to determine if
 - an alternative may have been more appropriate if the person was still in high school at the time of appointment, and
 - the person has potential to gain capacity over time

* Source: JCHC analysis of Virginia Department for Aging and Rehabilitative Services (DARS); Annual Reports by Age when report was filed and Filing Type (6 months, Jan-June 2019 for FY-2019)

Guardianship appointments by age (cont.)

Circuit Court of Fairfax County Appointments

Circuit Court of Fairfax County; FY-2016 to FY-2019 Guardian & Guardian/Conservator Cases By Filing Date Age		
Age	Cases	Percent
< 18	67	12.9%
18 to 21	130	25.0%
22 to 30	38	7.3%
31 to 55	45	8.7%
≥ 56	239	46.1%
Total	519	

* Unduplicated case numbers; final and final orders pending. Source: JCHC analysis of Circuit Court of Fairfax County, July 23, 2019.

- current Circuit Court of Fairfax County data is limited
 - does not indicate why the person was determined incapacitated
 - does not indicate if the guardianship was limited or temporary or full

- Circuit Court of Fairfax County
 - records the the age of a person at the time a guardianship order is filed
- As noted in the previous slide, in some cases
 - an alternative may have been more appropriate if the person was still in high school at the time of appointment, and
 - the person has potential to gain capacity over time

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Data collection improvements can help determine the appropriateness of guardianship

- Recommendation: amend VA Code § 64.2-2020 to increase the list of questions on the annual report form prepared by OES to include age of incapacitated person at time of appointment, what type of guardianship was appointed (temporary, limited, full), reason for appointment (e.g. IDD, dementia, mental illness), and guardian's relationship to the incapacitated person (or profession)
- Recommendation: amend VA Code to require each circuit court to add fields in their case management system to identify date of birth or age at time of initial guardianship appointment and reason for appointment (e.g. autism, dementia, mental illness) [Note: type of guardianship and guardian relationship/profession already are included in the CM system]

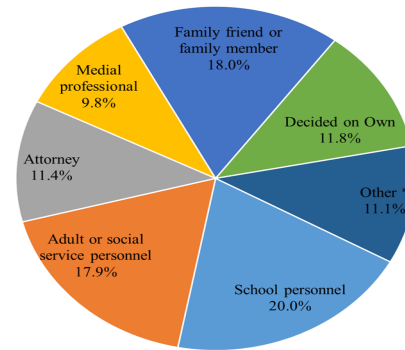
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How do people find out about guardianship or other options?

- VA Attorneys and advocacy groups report that parents are “told” to get guardians by school personnel
 - anonymous survey, VCU’s Partnership for People with Disabilities
 - not scientific, not all questions answered by all respondents
 - 70 families emailed; Facebook shares: 27 of 1,200 followers
 - 9 of 28 - “told to pursue” by school personnel
 - 9 of 28 - guardianship discussed during IEP meeting
 - 6 of 29 - not aware of other options
 - 4 of 14 - would reverse guardianship if given the chance

Online survey of parents and guardians of individuals with disabilities or individuals with disabilities (2015) *

Who first suggested guardianship or conservatorship to you?
(Responses - 979)



- Respondents (754) could choose more than one response
- Majority of respondents were parents (>80%)
- 37% of respondents indicated guardianship was recommended

Other - Judge or other court personnel, Special needs trust/financial advisor, Life insurance agent or salesperson.

* Source: JCHC analysis of Table 1. Q.5. Jameson, J. Matt., et. al. Guardianship and the Potential of Supported Decision Making With Individuals with Disabilities. Research and Practice for Persons with Severe Disabilities. June 29, 2015. 21

School may be the best first place

- A child with a developmental disability who is in school and found eligible for special education services will have
 - A “Development and implementation of an Individualized Education Program” (IEP; 20 U.S. Code § 1400, et. seq.)
 - ✓ annual update, includes individual goals and progress
 - ✓ includes age appropriate:
 - transition plan, may begin when child turns 14 or when entering post secondary school
 - services put into place when child turns 16
 - ✓ 1 year before child turns 18 students/parents informed of rights transferred when student turns 18
 - Virginia Department of Education (VDOE) state that
 - school personnel do not recommend
 - parents seek guardianship, or
 - give out legal advice
 - transition pamphlets are provided and include
 - information on power(s) of attorney for education
 - recommendation to seek legal advice for other uses of powers of attorney
 - definition of guardianship
 - last update 2015

Virginia Public School Students in Special Education by Disability (2015 through 2018)

Description of Disability	2015	2016	2017	2018
Specific Learning Disability	54,222	54,763	55,375	55,578
Other Health Impairment	32,354	33,336	34,631	35,602
Speech or Language Impairment	24,537	24,262	24,441	24,316
Autism (may include areas that fall under Autism Spectrum Disorder)	18,256	19,566	21,106	22,704
Developmental Delay	11,291	11,910	12,603	13,374
Emotional Disturbance (can include Emotional Disability)	9,425	9,500	9,779	9,811
Intellectual Disabilities	9,054	9,089	9,015	9,034
Multiple Disabilities	3,290	3,248	3,224	3,168
Hearing Impairment (can include Deaf and Hard of Hearing)	1,511	1,468	1,425	1,356
Visual Impairment (including blindness)	656	649	648	612
Orthopedic Impairment	747	693	676	594
Traumatic Brain Injury	409	438	448	418
Deaf-Blindness	25	21	24	17
Totals	165,777	168,943	173,395	176,584

Source: JCHC analysis of VDOE Department of Special Education and Student Services Division of School Quality, Equity, and Instruction. “December 1 Data”; Primary Disability Trends. Report as of July 9, 2019.

VA Code § 64.2-2003 requires the court to appoint a Guardian Ad Litem (GAL)

- GAL's represent the interests of the person
 - Duties of the GAL include:
 - ✓ visit and advise the person of the right to counsel and a hearing
 - ✓ recommend to the court if legal counsel should be appointed for the person
 - ✓ investigate the petition and evidence
 - ✓ request additional evaluations if necessary, and
 - ✓ appear at all court proceedings and conferences
- The GAL is required to file a report with the court
 - The report includes:
 - ✓ whether the court has jurisdiction and if a guardian is needed
 - ✓ the extent of the guardian's duties and powers
 - ✓ the propriety and suitability of the person selected guardian; and
 - ✓ proper residential placement of the person
- Health care providers are required to disclose or make available, upon request
 - any information, records, and reports concerning the person that the GAL determines necessary to perform their duties

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The GAL plays a pivotal role in guardianship proceedings

- The GAL
 - reviews petitions and submits a written report with recommendations to the judge
 - ✓ persons between ages 17.5 through 21 years of age should have IEPs if they were in special education
 - ✓ a review and report on the IEP for persons between the ages of 17.5 through 21 years of age should be required

Recommendation: VDOE should update special education transition materials for students and parents; school divisions should be directed to use the VDOE material to the fullest extent possible and include more information about transition for students and parents during the annual IEP meetings related to health care and other options available, including supported decision making

Recommendation: VA Code § 64.2-2003 should include a requirement that a person's IEP be part of the GAL's review and report for those between 17.5 through 21 years of age

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Virginia's Guardianship Code can be difficult to follow

- Parents, family members and others
 - may seek information about guardianship directly from the VA Code
 - VA Code on guardianship should be “user” friendly
- The first section of the guardianship Code, § 64.2-2000, definitions should be more complete so prospective guardians, family members and others are aware of what is included in the Code
 - definitions should be added for
 - ✓ annual reports required by § 64.2-2020 (to indicate oversight)
 - ✓ guardian ad litem required by § 64.2-2003 (to clearly identify who will review and report to the judge at the hearing)
 - ✓ temporary guardian and conservator (clearly defined options to pursue, ask questions about)
 - ✓ power of attorney(s) to inform (clearly defined options options to pursue, ask questions about)
 - ✓ Individual Education Plan (20 U.S. Code § 1414) that should be reviewed by guardian ad litem for persons between the ages of 17.5 through 21
- Clarify
 - the advanced directive reference in the definition section; currently refers to the short title of the health care decisions act and not to the definition of advanced directive, the reference should be directed to the actual definition in § 54.1-2982
 - “Guardian” definition should include a reference to the duties and powers section § 64.2-2019 of a guardian
 - § 64.2-2007.C. related on the petition hearing should include a reference to § 64.2-2019.E. to make it clear that, to the extent feasible, the respondent {incapitated person} will be encouraged to participate in decisions, act on his or her own behalf, and to develop or maintain the capacity to manage personal affairs

Recommendation: clarify the Virginia Guardianship Code sections to make the Code user friendly

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Judicial orders for guardians

- are written by petitioning attorneys
 - one person described some of the orders they receive as “a hot mess”
 - another indicated that some orders lack basic information
 - ✓ for example, whether it is a full or limited guardianship
 - some orders list rights retained and lost, others provide partial lists
 - not all orders refer to annual reports and responsibilities of guardians
 - not all orders indicate that orders can be changed or reversed

Recommendation: the following standard language should be included in all guardianship orders:

- Clearly state whether the order is a full order removing all rights, a limited order and what rights are removed from the respondent {incapacitated person}, or a temporary order indicating the time-frame that the order is in effect for.
- Subsection E. from § 64.2-2019: a guardian, to the extent possible, should encourage the incapacitated person to participate in decisions, consider the expressed desires and personal values of the incapacitated person to the extent known, shall not unreasonably restrict an incapacitated person's ability to communicate with, visit, or interact with other persons with whom the incapacitated person has an established relationship.
- Annual reports should be filed by the guardian with the local department of social services for the jurisdiction where the incapacitated person then resides pursuant to § 64.2-2020
- Guardianship orders are subject to petition for restoration, modification, or termination pursuant to the provisions of § 64.2-2012

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Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS)

- Part of national movement to update and reform guardianship laws
 - court-community partnership to improve practices in adult guardianship
 - Virginia WINGS
 - began in 2016/2017, meets twice a year
 - 2016 survey of circuit court clerks was presented during the June 25, 2019 meeting
 - ✓ Are filed, pending concluded cases available – 89% responded, no
 - ✓ Does the circuit court provide standard form for petitions – 92%, no
 - ✓ Is training or orientation provided for guardian – 93%, no
 - ✓ Is there an active monitoring program – 84%, no
 - ✓ Does court review annual reports – 78.6%, no
 - ✓ Is there court action if annual reports not filed – 70.5%, no
 - ✓ Is there a formal process for complaints or concerns – 85%, no
- Circuit Court Judge: “I’ve been on the bench for 6 years and had no idea guardians filed an annual report until just now”, June 25, 2019 meeting
 - Second time during a WINGS meeting that a judge stated they did not know about annual reports
 - First judge checked with predecessors, none knew about annual report
 - ✓ annual reports – required by law since 1997 (VA Code § 64.2-2020)

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As a result of the Circuit Court Clerk Survey and the WINGS meetings

- OES reports that there have been increased training and system improvements
 - several trainings during annual mandatory judicial conference for circuit court judges
 - ✓ 2015 - session on guardianship and conservatorship
 - ✓ 2016 - session on elder abuse and the role of judges in improving prevention and response (included training points on guardianship)
 - 2018, day-long judicial training on elder abuse (including a three and a half hour session on ageism, capacity and guardianship issues), offered on three different dates in three different locations
 - in addition to judicial training, OES has conducted multiple training sessions for court clerks on
 - ✓ improving court clerk processing of cases, and
 - ✓ meeting the statutory reporting requirements
 - A guardian training module was developed to address concerns from survey
 - Changes were made to the statewide case management system to improve data collection, e.g. type of appointment, results of hearing
 - SB1144 (2019) amended Va. Code § 64.2-2020
 - ✓ authorizes court to issue a summons or rule to show cause why the guardian failed to file the annual report
- OES is not seeking a budget amendment for increased judicial training on guardianship

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Conversations....

- Eight attorneys, guardian ad litem (GAL), court clerks, and 2 circuit court judges
 - laws are pretty good in Virginia, lots of protections
 - safeguards in code work pretty well, most issues worked out before court hearing
 - GAL review and report - thorough if GAL is trained
 - ✓ GALs do a pretty good job, some issues with training
 - ability to challenge petition by person and/or family exists in Code
 - cases are often complex
 - ✓ orders are tailored to individual circumstances
 - ✓ orders can be crafted to fit model of supported decision making, as described
 - ✓ some not aware of supported decision making or Jenny Hatch decision
 - parents are informed at time of visit with lawyer about different options
 - judges ask questions, change language in orders, at times before ruling
 - ✓ judges send attorneys back for more information if necessary
 - special judges, separate docket for guardianship – good ideas
 - ✓ may work well in busier courts, hard to be squeezed between different cases the judges hear
 - people who can't afford attorney may file "pro se", referred to legal aid
 - some not aware of WINGS meetings
 - the Circuit Court of Fairfax County hosts continuing education classes with the local bar association for GALs, guardians and stakeholders; reserves one day a week for all guardianship cases

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Conclusions

- Most stakeholders indicate that guardianship should be the last option
- Adding supported decision making to the Virginia Code moves "what we don't know" to "what we need to know" and gives families and others more options and choices
- Clarifying and making the Code more user friendly may help parents, family members and others decide what options to pursue



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Policy options based on recommendations and findings

Policy Option	Description	Slide
1	Take no action	—
2	Introduce legislation to amend VA Code § 37.2-401 by adding a subsection B. to improve data collection and reporting on all persons in Virginia who are determined to be incapacitated, require DBHDS to record information concerning whether a consumer of mental health system services has an authorized representative	8
3	Introduce legislation to add a new section to the VA Code, Title 37.2 (Behavioral Health and Developmental Services) and/or Title 59.1 (Trade and Commerce) creating SDM for Individuals with Developmental Disabilities and/or all disabled adults as an option for DBHDS and to formalize a supported decision making contract in code that provides protections for private individuals that want to use a contract (see Delaware, slide 14)	15
4	Introduce legislation to amend VA Code § 64.2-2003.C. by adding a requirement that guardian ad litem consider whether supported decision making is a viable option when reviewing and reporting on the extent of the duties and powers of the guardian or conservator	15
5	Introduce legislation to amend VA Code § 64.2-2020 to increase the list of questions on the annual report form prepared by OES to include age of incapacitated person at time of appointment, what type of guardianship was appointed (full, limited, temporary), reason for appointment (e.g. IDD, dementia, mental illness), and guardian's relationship to the incapacitated person	20

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Policy options based on recommendations and findings (cont.)

Policy Option	Description	Slide
6	Introduce legislation to amend VA Code by adding a new subsection to require each circuit court to add fields in their case management system to identify date of birth or age at time of a guardianship appointment and reason for appointment (e.g. IDD, dementia, mental illness)	20
7	Introduce a Section 1 bill directing VDOE to update special education transition materials for students and parents; directing school divisions to use the VDOE material to the fullest extent possible and include more information about transition for students and parents during the annual IEP meetings related to health care and other options available, including supported decision making	24
8	Introduce legislation to amend VA Code § 64.2-2003 to include a requirement that a person's IEP be part of the GAL's review and report for those between 17.5 through 21 years of age	24
9	Introduce legislation to amend VA Code § 64.2-2000, et. seq. to clarify the code sections as detailed on slide 25 of this presentation. If approved, language from slide 25 will be included in the "approved" policy option.	25

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Policy options based on recommendations and findings (cont.)

Policy Option	Description	Slide
10	<p>Introduce legislation to amend VA Code § 64.2-2007 by adding a requirement that the following language be included in all guardianship orders:</p> <p>Clearly state whether the order is a full order removing all rights, a limited order and what rights are removed from the respondent {incapacitated person}, and/or a temporary order indicating the time-frame that the order is in effect for.</p> <p>A guardian, to the extent possible, should encourage the incapacitated person to participate in decisions, consider the expressed desires and personal values of the incapacitated person to the extent known, shall not unreasonably restrict an incapacitated person's ability to communicate with, visit, or interact with other persons with whom the incapacitated person has an established relationship pursuant to VA Code § 64.2-2019.E.</p> <p>Annual reports should be filed by the guardian with the local department of social services for the jurisdiction where the incapacitated person then resides pursuant to VA Code § 64.2-2020</p> <p>Guardianship orders are subject to petition for restoration, modification, or termination pursuant to the provisions VA Code § 64.2-2012</p>	26

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Public Comments

Written public comments on the proposed options should be submitted to JCHC by close of business on October 25, 2019.

Comments may be submitted via:

- ❖ E-mail: jchcpubliccomments@jhc.virginia.gov
- ❖ Fax: 804-786-5538
- ❖ Mail: Joint Commission on Health Care
P.O. Box 1322
Richmond, Virginia 23218

Comments will be provided to Commission members and summarized before they vote on the policy options during the JCHC's November 14th decision matrix meeting.

(All public comments are subject to FOIA release of records)

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APPENDIX
HOUSE JOINT RESOLUTION NO. 729

WHEREAS, supported decision-making is a process through which individuals with intellectual and developmental disabilities receive assistance in making and communicating important life decisions; and

WHEREAS, many individuals with intellectual and developmental disabilities in the Commonwealth have not been provided opportunities for supported decision-making with regard to important life decisions, including health care decisions and options; and

WHEREAS, it is important that individuals with intellectual and developmental disabilities in the Commonwealth have the opportunity to make supported, informed choices about important life decisions; and

WHEREAS, a comprehensive study of supported decision-making in the Commonwealth may improve the personal autonomy and quality of life of individuals with intellectual and developmental disabilities and help ensure that they receive assistance in making and communicating important life decisions;

NOW, therefore, be it RESOLVED by the House of Delegates, the Senate concurring, that the Secretary of Health and Human Resources be requested to study supported decision-making for individuals with intellectual and developmental disabilities. In conducting this study, the Secretary of Health and Human Resources shall (i) examine the use of supported decision-making for individuals with intellectual and developmental disabilities in the Commonwealth; (ii) compare the Commonwealth's policies and practices related to supported decision-making and informed choice to the policies and practices used in other states; (iii) examine situations in which the use of supported decision-making is an appropriate alternative to the appointment of a guardian; (iv) after consultation with the Arc of Virginia, Voices of Virginia, the Autism Society, the disAbility Law Center of Virginia, the Down Syndrome Association, the Jenny Hatch Justice Project, the Virginia Bar Association, the Virginia Department of Behavioral Health and Developmental Services, and the Office of the Executive Secretary of the Supreme Court of Virginia, (a) recommend strategies to improve the use of supported decision-making in the Commonwealth and ensure that individuals with intellectual and developmental disabilities are consistently informed and receive the opportunity to participate in their important life decisions and (b) determine whether legislation related to supported decision-making is necessary and, if so, propose specific legislative recommendations.

All agencies of the Commonwealth shall provide assistance to the Secretary of Health and Human Resources for this study, upon request. The Secretary of Health and Human Resources shall complete his meetings by November 30, 2019, and shall submit to the Governor and the General Assembly an executive summary and a report of his findings and recommendations for publication as a House or Senate document. The executive summary and report shall be submitted as provided in the procedures of the Division of Legislative Automated Systems for the 35
Processing of legislative documents and reports no later than the first day of the 2020 Regular Session of the General Assembly and shall be

Appendix
Links of Interest

- VCU Center on Transition Innovations
Virginia Parents' Tips on Transition Planning
<https://worksupport.com/documents/VirginiaParentsTipsonTransitionPlanning.pdf>
- American Association on Intellectual and Developmental Disabilities (AAIDD)
Definition of Intellectual Disability
<https://aaid.org/intellectual-disability/definition>

Autonomy, Decision-Making Supports, and Guardianship: Joint Position Statement of AAIDD and The Arc
<http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship>

Appendix

Supported Decision Making: Indiana and Texas

- Indiana Code § 29-3 et. seq. (P.L. 68-2019; 7/1/2019)
 - SDM helps make life decisions without impeding the self-determination of the adult
 - applies to all adults
 - agreement is in writing, entered voluntarily
 - agreement must include
 - ✓ at least 1 supporter
 - ✓ relationship to adult
 - ✓ description of decision making assistance and how supporter(s) may work together
 - ✓ dated, signed in presence of a notary
 - ✓ include supporter consent document with agreement
 - cannot be used as evidence of incapacity
 - cannot supplant authority of guardian unless guardian consents
 - supporter
 - ✓ resign with written notice
 - ✓ prohibited from exerting undue influence
 - ✓ cannot receive a fee for service
 - supporter(s) and those acting in good faith in use of agreement are immune from liability
- Texas Code Sec. § 1357.001 et. seq. 84th Leg., R.S., Ch. 214 (H.B. 39), Sec. 23; Ch. 1224 (S.B. 1881), Sec. 1; June 19, 2015)
 - Purpose: “recognize less restrictive substitute for guardianship for adults with disabilities who need assistance with decisions regarding daily living but who are not considered incapacitated persons for purposes of establishing a guardianship”
 - ✓ voluntary agreement
 - ✓ SDM form in Texas Estates Code
 - ✓ or simplified form on web (<https://tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/>)
 - ✓ agreement does not require attorneys or court filing
 - ✓ supporter does not act in the place of or make decisions for the person
 - ✓ created and ended at any time

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