SUPPORTED DECISION MAKING IN INDIANA

Guardianship, Civil Rights and the Case for a Less Restrictive Alternative

Supported Decision Making can alleviate court congestion, allow for families to tailor the program to their needs, and potentially restore rights to thousands of Hoosiers to determine their own lives.

The Arc of Indiana, through a grant from the National Resource Center for Supported Decision Making and the Administration for Community Living

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Introduction

Adults with intellectual and other developmental disabilities, those who have experienced traumatic brain injuries, and individuals whom due to aging have lost some level of functionality are all at risk of losing all legal, financial and medical authority over their lives due to the implementation of adult guardianship. While a wide spectrum exists for which people may experience the above listed diagnoses, the use of a guardianship as the single tool to address them is problematic. Guardianship is inflexible, burdensome, expensive, difficult to reverse, and in cases where it is implemented where it is not needed can tear families apart and have a severe negative impact on adults capable of making life decisions for themselves. For this reason states have begun to look to the more flexible and individualized supported decision-making (SDM) model as an alternative to adult guardianship for those who are not truly or fully incapacitated. As of this writing Texas, Virginia, Maryland, Massachusetts, North Carolina, New York, and Washington D.C. have officially begun implementing or examining SDM at varying levels while momentum toward legal recognition in many other states has been gaining traction.

It is important to note that guardianship, by its nature, is the most restrictive infringement upon a person's individual freedom outside of incarceration. The imposition upon individual freedom makes this a civil rights issue, and as such guardianship should not be issued lightly by the courts. Along the way a few very influential individuals shape the course of a request for the awarding of guardianship. In the case of minors approaching the age of majority the bulk of that influence lies with schools. For an adult living in a managed care facility that influence lies with the administration. The information from these influential parties weighs heavily upon the physicians reviewing that information in making their recommendation to a court. In turn the court then relies heavily upon that information and the clinical determination. Any restriction upon personal freedom should be done in the least restrictive means

necessary and often adult guardianship does not fit that mold. This is the very void for which SDM can be the missing piece of the puzzle.

Legal Landscape in Indiana

The single largest legal barrier to implementation of the Supported Decision Making (SDM) model in Indiana is the level to which guardianship is engrained in the system. Being the only model for assisting "incapacitated adults" utilized by the courts in Indiana through its history makes it difficult for the system to simply pivot and begin doing things differently. Further, the laws concerning guardianship in the Indiana Code are extensive and would require significant alteration to permit people currently under the care of a guardian to smoothly transition to the SDM model if it would be in their best interest. To facilitate the SDM model a new section could be added to the probate code mirroring those laws regarding guardianship, but that would only address those persons who have not yet been appointed a guardian. Given the widespread use of professional guardians in Indiana it is safe to assume many guardians would contest being removed vigorously. Those persons who would benefit from having an advisor as opposed to the guardian they currently have could face a costly and time consuming legal battle to win the right to remove their guardian.

Current Statutory Scheme in Indiana

The laws governing guardianship laws in Indiana are found in Indiana Code (IC) 29-3, and the statutes controlling how to terminate a court appointed guardianship are in IC 29-3-12. Because the focus of this program is how to implement a SDM system in Indiana which will both require a full slate of new statutes outlining the requirements, processes and regulation of those within it, the initial barriers are how to terminate a guardianship to allow people to transition to a new SDM system. Below is a brief

outline of the most pertinent portions of the code relating to guardianships and terminating guardianships:

- IC 29-3-1-7.5 defines an incapacitated Person as a person who (2) "is unable to (A) manage in whole or in part the individual's property" or (B) to provide self-care."
 - Of note here is the wording "whole or in part," suggesting the legislature recognized that not all "incapacitated persons" are completely unable to manage their affairs, but the system of guardianship does not provide for meaningful engagement in decisions for people with court ordered guardians. This obvious gap in the law will provide a good starting angle to provide for SDM implementation in Indiana.
- IC 29-3-12-1 provides that termination of a guardian must come from the court and only upon "the death of the protected person," or "adjudication by the court that the person is no longer an incapacitated person."
- IC 29-3-12-3 states that "the protected person or any other person may petition for an order that the
 protected person is no longer an incapacitated person and for termination of the guardianship or
 protective order."
- IC 29-3-12-4 covers the resignation or removal of a guardian. Most pertinent is in subsection (b) which states that "If the appointment of a successor guardian is required, the court shall appoint a qualified successor guardian to succeed to the title, powers, and duties of the predecessor guardian unless otherwise ordered by the court."
 - o The significance of this clause is to show that even if an SDM program is implemented or piloted in Indiana, the resignation of a guardian to allow the protected person to participate is insufficient because the court is required to appoint another guardian until, as stated above, the protected person dies or is deemed to be no longer incapacitated by a court.

- 29-5-5-3 does provide for limited guardianships if "the court finds that the welfare of an incapacitated person would be best served by limiting the scope of guardianship." A court could make this finding to "(1) encourage development of the incapacitated person's self-improvement, self-reliance, and independence; and (2) contribute to the incapacitated person's living as normal a life as that person's condition and circumstances permit without psychological or physical harm to the incapacitated person."
 - This section would seem natural to insert SDM language as the intent is there already to allow greater self-involvement for protected persons capable of so participating. Further, this section may be utilized in a SDM pilot program by authorizing a judge to specifically outline any limitations of guardianship in the best interest of a protected person.

Statutory Barriers

In order to utilize the SDM model for many protected persons would require first a dissolution of their current court appointed guardian. The Indiana Code provides for how to terminate a guardianship in IC 29-3-12, laying out how and for what reasons this may be achieved. This process would not only be costly for those seeking to transition from a guardian to an advisor, but could also put a large strain on the courts depending on how many of the over 7,000 incapacitated adults with a guardian in Indiana choose to do this. For this reason any proposed legislation would need to make significant alterations to the probate law to make this process faster, cheaper and seamless. Currently, in order to have a court appointed guardian removed, a protected person would have to prove to the court they were no longer incapacitated (IC 19-32-12-2). Further, having the guardian resign will not permit the appointment of an advisor in place of the guardian because once a person has been deemed incapacitated, the court order of a guardian stands and another guardian must be appointed until the end of such order from the court (IC 29-3-12-4).

Additional legislation would be required to accommodate minors who would otherwise have been appointed a guardian (or whose guardian would seek extension of the guardianship) an opportunity to seek to use the SDM model instead. Right now the system is a pipeline to guardianship making it extremely difficult for protected minors to ever get off the track. This, however is where utilizing the SDM model would be most beneficial so as to encourage social development and personal responsibility.

Finally, to properly facilitate a SDM system the code would need updates to the civil and criminal code to protect individuals from advisors who abuse their position. This could simply be fixed in language to apply laws governing guardians to advisors, but it is essential none-the-less. Optimally money would be made available to inform those under guardianships to inform them, their guardians, and/or their families of the change in law and where to learn more about transitioning if they so choose. Additionally, some system of dispute resolution between supporters and the person they support would need to be created. If a decision is considered to be substantially adverse to the person supported what recourse is available to protect them? Because one of the goals of transitioning away from adult guardianship is cost avoidance, optimally a panel comprised of trained supporters could determine if the conduct by a given supporter was within the bounds of the agreement. This could be a more cost effective manner to dispute resolution and at the same time provide guidance for supporters who are not acting maliciously against the interest of their client.

Statutory Steps

It would be easiest for any pilot program to begin with new cases so as to not circumvent the current statutory scheme. Anyone who would want to change from a guardian to the SDM model for the pilot program would have to obtain a court order to dissolve the guardianship first. While this may be the easiest path forward for a pilot program, to truly gauge the efficacy, benefits and drawbacks of a

SDM in practice would require persons who have been under the care of a guardian for some amount of time be transitioned such that the results can be compared and measured against the guardianship model.

Pilot programs are by nature a short study, meaning any lengthy guardianship terminations would consume a significant portion of the study period. For this reason providing for expedited hearings in a pilot would be very impactful. Because there would still be lost time in transitioning protected persons from guardians to advisors, to create a large enough model for observation the majority of the pilot may be comprised of minors entering majority being appointed advisors in lieu of guardians. Lastly, a focus on professional and not family guardians would be best for a pilot as familial guardians most likely engage in some level of SDM already. Comparing progress and quality of life for protected individuals who have lived under guardianship of a professional may provide the most significant measurable results while also avoiding familial infighting that may taint the results.

Current Disposition

As it stands today students who are engaged in special education programs in Indiana schools each receive an Individual Education Program (IEP) which is tailored for their success. Parents, as the legal guardians of minor children have access to all their children's school records, including their IEP. A school is required to inform parents before their child turns 17 that they will lose access to this information when their child turns 18 unless they are appointed guardian or an educational representative for their child. This is the sole requirement for the schools, and while a particular school, teacher, or administrator may give a parent more information sometimes it is not required by law or any guideline my research has found. This preys on a parents feeling of duty and care for their child's wellbeing, leading many to seek legal remedy to remain involved in the process. Granted, if their child gives consent the parent may remain in the process but parents may never hear this, or simply out of

fear ignore it. Due to the limited range of information given parents, they may seek guardianship without realizing its implications.

Through conversations with a teen care doctor and nurse, a physician normally relies on the school to determine if a child dependent would benefit from guardianship beyond the age of 18. A physician is privy to any medical diagnosis a child may have and knowledge of where they place along a spectrum as defined by the medical community. This does not necessarily correlate to anyone's ability to function on their own or make decisions for themselves except in extreme cases. For this reason physicians rely on the IEP provided by the schools that spend far greater time with the student and are better suited to gauge their social ability and potential for self-reliance. A student's physician who is asked to make a recommendation to a court regarding guardianship will normally request the IEP and determine based on scholastic progress and goals whether they are a good candidate for guardianship. This, in essence, places the schools as providing the primary guidance for parents, physicians and courts to determine if guardianship is necessary.

There seems to be a middle ground to appoint an educational representative. This would allow a parent to remain in the loop regarding their 18 year-old child's IEP and records but not extend beyond graduation. To obtain an educational representative it must be requested of the school by the student in writing and a parent may be that representative. Further, a student may request in writing that an educational representative may be removed at any time. It is difficult to know how often these options are fully explained to parents and students but based on the figures on guardianship it would seem this is wholly underutilized.

Recommended Cultural Steps

Schools hold an enormous amount of authority regarding the guardianship decision and are only required to provide minimal information to parents and students. A review of these guidelines and

implementation of a more in depth education to parents and students on what this decision entails, good and bad, should accompany any statutory changes. Schools are the gatekeeper of this information and only telling parents they will no longer be able to be involved in the process has dire consequences. It is only natural that parents want to protect their children and help them through the process and it would not be costly to provide more information than is currently being given. To transition to an SDM model schools will need to play a significant role in educating parents as to their options. Further, physicians need to be educated on the differences in guardians, educational representatives, and advisors in an SDM model such that they may make the best determination when their expertise is required for courts or parental advice. This information could flow naturally through the Indiana State Medical Association and the Indiana Board of Education in the form of bulletins and educational materials for members.

SDM in Other States

As mentioned above several states have taken affirmative steps to implement SDM and their progress is briefly covered below. Because many of these state movements have not made their way through the legislative process there is no record that I could find to document where these other states stand but a few other states we know are moving on this issue are: Wisconsin, Delaware and Maine. Other states also have groups and organizations working to give the courts and families a better alternative to the antiquated adult guardianship system. Rest assured this is a national movement and it is gaining momentum.

Texas

In 2015 Texas passed a series of SDM statutes to provide courts with SDM as an alternative to adult guardianship. The Supported Decision-Making Act set out its purpose is "to recognize a less

restrictive alternative to 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 under this title." The Act defines SDM as a "means a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult." Texas Code 3-1-1357(a) (3).

The Act follows contract law and permits an adult with a disability (defined at TC 3-1-1357(a) (2) as an individual "a physical or mental impairment that substantially limits one or more major life activities.") to contract with a "supporter" who can assist an adult with a disability with decisions when necessary and only to the degree contained in the contract (see attached sample contract provided by the Act as an addendum to this writing). The benefit of the Act as opposed to adult guardianship is the scope of a supporter's authority is strictly defined by the agreement. Further, because the adult entering into a SDM agreement has not been deemed incapacitated by the court the contract should be more easily terminable if an issue should arise or it is felt to be no longer necessary.

Virginia

The Commonwealth of Virginia passed a House Resolution in 2014 urging the study of SDM.

The study made a formal report titled House Document No. 6 to the House recommended a program to train supports for implementation of an SDM model be developed however the measure has yet to make it into the Virginia Code. While it is not specifically stated the document spoke of the need to develop a capacity measurement test which the absence of may be delaying legislative action on the matter.

Maryland and Massachusetts

Both have passed measures to implement SDM in health decisions only at this time.

North Carolina

In 2015 the North Carolina House of Representatives passed a resolution ordering the study of SDM in the state as an alternative to adult guardianship. The resolution seeks to find ways to allow persons to "exercise greater self-determination." The details and results of this study have yet to be published for public record.

Washington D.C.

The Council of the District of Columbia received a proposal for consideration entitled "Citizens with Developmental Disabilities Civil Rights Restoration Act of 2015." The proposal was received by the counsel in September of 2015 but no action has yet to be taken on it. As of this writing testimony was being heard on the Act but no action has yet been taken.

New York

The Courts in New York took the issue upon themselves to create space for SDM in their states common law. Holding that Due Process required the least restrictive measure be taken to assist a person with developmental disability, guardianship must be strictly proven necessary to be implemented because of its restrictive nature. (*In re Guardianship of Dameris L* 956 N.Y.S.2d 853-855, (2012 N.Y). The courts in New York highlight the fact that this is in fact a civil rights issue. If the rights of a person is to be infringed upon in the United States there has to be solid legal footing, sound reasoning and the restriction must be done in the least restrictive manner as necessary to carry out the interest of the states and interested parties.

Next Steps for Indiana

States have begun to recognize the problems with placing adults under the ward of a guardian where it is too restrictive. Further, while the focus of this study is mainly centered on assisting individuals with intellectual or other developmental disabilities, this will also positively impact the elder community. With an aging population, and none of us able to beat father time, this is an issue that in some way, shape or form will impact nearly all Hoosiers. Thus far only Texas has taken full measures to implement SDM into their state law but the studies being conducted in other states would suggest similar steps will be taken in other places. Typically, when momentum has begun nationally through states or courts the majority of jurisdictions begin to slowly incorporate similar provisions into their code. With there being a clear movement to study and recognize rights of those adults who have had them taken away through guardianship, many states will likely want to be seen as early adopters on this important civil rights issue.

Indiana has an opportunity to review what has been done already around the country and modify it to the needs of Hoosiers to implement a better alternative to adult guardianship. By taking affirmative steps following the adoption of a summer study in 2016, and putting SDM in the Indiana Code in 2017, Indiana can become one of the leaders in this movement. In that Act should be included an expedited review process for those wishing to transition from court ordered guardianship to a SDM model. Agreements for SDM should be rooted in contract law but any claims for and against should remain in probate court where judicial expertise and experience is best suited to hear and rule on cases arising from SDM. The necessary investment should be made available to ensure parents of school age children approaching the age of majority are fully aware of their options well in advance of time to make a decision. Similar strides should be taken to make sure families of persons who have recently endured a significant brain injury and families of elderly persons entering managed care. A

decision to seek guardianship should not be made in haste and all available alternatives should be presented before guardianship of an adult is sought.

As noted above, using SDM can alleviate court congestion, allow for families to tailor the program to their needs, and potentially restore rights to thousands of Hoosiers to determine their own lives. Here lies the best of all opportunities, low risk, low cost and significant legislation to improve people's lives. Opportunities such as this do not often present themselves to government, and it would be in the best interest of all three branches of the Indiana government, the schools, and most importantly the people of Indiana to take action in implementing SDM. For these reasons it is imperative to gain the support of judges, legislators, schools and families across the state to call for this common sense and very important set of legislation to make its way into the Indiana Code next year.

Texas Sample Supporter Contract Form

§ 1357.056. Form of Supported Decision-Making Agreement

(a) Subject to Subsection (b), a supported decision-making agreement is valid only if it is in substantially the following form:

SUPPORTED DECISION-MAKING AGREEMENT

Appointment of Supporter

I, (insert your na	ame), make this agreement of my own free will.
I agree and desi	gnate that:
Name:	
Address:	
Phone Number:	
E-mail Address:	
Is my supporter.	My supporter may help me with making everyday life decisions relating to the following:
Y/N	obtaining food, clothing, and shelter
Y/N	taking care of my physical health
Y/N	Managing my financial affairs.

My supporter is not allowed to make decisions for me. To help me with my decisions, my supporter may:

1. Help me access, collect, or obtain information that is relevant to a decision, including medical, psychological,

financi	ial, educatio	onal, or treatment rec	ords;		
2. Help	o me under	stand my options so I	can make an informed decis	sion; or	
3. Help	o me comm	unicate my decision to	o appropriate persons.		
	Y/N		y supporter to see protected Intability Act of 1996 (Pub. I	d health information under the Health Insurance No. 104-191) is attached.	
	Y/N A release allowing my supporter to see educational records under the Family Educational Rights a Privacy Act of 1974 (20 U.S.C. Section 1232g) is attached.				
		Effective [Date of Supported Decision-	Making Agreement	
This supported decision-making agreement is effective immediately and will continue until (insert date) or until the agreement is terminated by my supporter or me or by operation of law.					
Signed	l this	_ day of, 2	20		
			Consent of Sup	porter	
I, (name of supporter), consent to act as a supporter under this agreement.					
	_				
	(signature	of supporter)		(printed name of supporter)	
			Signature		
	In a second			(marini tali	
	(my signat	ure)		(my printed name)	

	_	
	(witness 1 signature)	(printed name of witness 1)
	_	
	(witness 2 signature)	(printed name of witness 2)
	State of	
	County of	
	This document was acknowledged before me on _	(date)
by_		and_
	(name of adult with a disability)	(name of supporter)
		-
		(signature of notarial officer)
(Seal,	if any, of notary) _	
	(p	rinted name)
		My commission expires: _

WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY

IF A PERSON WHO RECEIVES A COPY OF THIS AGREEMENT OR IS AWARE OF THE EXISTENCE OF THIS AGREEMENT HAS CAUSE TO BELIEVE THAT THE ADULT WITH A DISABILITY IS BEING ABUSED, NEGLECTED, OR EXPLOITED BY THE SUPPORTER, THE PERSON SHALL REPORT THE ALLEGED ABUSE, NEGLECT, OR EXPLOITATION TO THE DEPARTMENT OF FAMILY AND PROTECTIVE SERVICES BY CALLING THE ABUSE HOTLINE AT 1-800-252-5400 OR ONLINE AT WWW.TXABUSEHOTLINE.ORG.

(b) A supported decision-making agreement may be in any form not inconsistent with Subsection (a) and the other requirements of this chapter.

Credits

Added by Acts 2015, 84th Leg., Ch. 214 (H.B. 39), § 23, eff. Sept. 1, 2015; Acts 2015, 84th Leg., Ch. 1224 (S.B. 1881), § 1, eff. June 19, 2015.

V. T. C. A., Estates Code § 1357.056, TX EST § 1357.056 Current through the end of the 2015 Regular Session of the 84th Legislature