Supported Decision-Making

S.B. #230

Committee Meeting Minutes

September 20, 2016

Smyrna Rest Area, Smyrna, DE

10:00 a.m. – 12:00 p.m.

Members Present: Pat Maichle (Developmental Disabilities Council), Stefanie Lancaster (Developmental Disabilities Council), Daniese McMullin-Powell (ADAPT), Barbara Monaghan (Delaware People First), Brian Hartman (Disabilities Law Program), Lexie McFassel (Office of Public Guardian), Terri Hancharick (EPIC), Wendy Strauss (Governor’s Advisory Council for Exceptional Citizens), Jamie Wolfe (State Council for Persons with Disabilities), Terry Olsen (The Arc of Delaware), Debra Miller (Chimes), Michael Pasquale (self-advocate), Thomas Cook (Abilities Network of Delaware), Laurie Nicoli (parent), Vickie Haschak (Elwyn), Vivian Turner (CERTS), Emmanuel Jenkins (self-advocate).

Guests Present: Micki Edelsohn, Bill Monaghan, Lisa Elias, Elizabeth Gonzalez

1. Welcome & Introductions – Members of the committee and public introduced themselves at this time. One Member that had volunteered has since declined being on the committee. The Arc will find a replacement to serve. Pat Maichle stated that she and Terry Olsen (co-chair of this committee) would like to review the documents that brought us together today including a copy of the legislation that was signed in by the Governor.

The intentions of this committee are to provide recommendations to the new administration by December on how to best implement Senate Bill 230 regarding Supported Decision Making bill by sharing a copy of those recommendations with the Department of Health and Social Services (DHSS) per the legislation.

There will be a workshop on this topic at the LIFE Conference in January. We will share the recommendations during this workshop in January as well as template documents. The committee will meet for the next three months once a month. Brian Hartman asked if a representative from DHSS is on the committee. Pat said no unfortunately not. Patricia Justice will be invited to attend future meetings. Brian suggested that it would be good to have someone included during the deliberations from that agency and possibly invite a liaison to future meetings.

1. Review of S.B. #230 w/Amendment – A copy of the legislation was provided to everyone who attended. No changes are able to be made to this document however answers to questions were provided. Terry Olsen stated that his agency’s Public Policy Committee had a few comments and questions that prompted discussion.
	1. 1) Item 9402A (a)(1) “All adults should be able to live in the manner they wish and to accept or refuse support, assistance or protection as long as they do not harm others and are capable of making decisions about those matters”. Terry stated the committee felt that there should be an added reference about not causing serious harm to themselves as well. Brian stated part of the wording for this was pulled from federal code. Jamie said she feels Terry’s suggestions is very subjective. Thomas Cook commented that the Arc was very clear in the 60’s and 70’s about dignity with risk. This harm you are speaking of could be physical or financial exploitation. **One recommendation is to offer training necessary for the supporter to help define for that person that fine line, that may exist, to allow the person to make the decision on their own without inserting the opinions of the supporter.** Pat stated the issue of training for supporters has come up in other states. Some curriculum has been developed and may be useful to use here in Delaware. **One recommendation from this committee could be to add training to the list of recommendations for Delaware.**
	2. Terry also stated page 3 of 6 – 9404(a) “All adults are presumed to be capable of managing their affairs and to have capacity unless otherwise determined by the Court of Chancery.” Terry asked about what parameters does the court follow in determining the amount of capacity and decide if a guardian is needed or not. Lexie McFassel (Office of Public Guardian) stated they look for an impairment or disability such as dementia or cognitive disability which impairs process and ability to make decisions. Then evaluate what the person is capable of and determine if a guardian is needed. Court of Chancery will not evaluate a person’s decisions. They will evaluate if something is interfering with their capability of making decisions.

Brian Hartman stated there is statute in place, Title 16, Chapter 11 that covers residential sites. This covers anyone taking medications and that the decisions would go to next of kin if the person is unable to make decisions regarding this. Terry’s concern is that many people do not have capacity to make informed decisions but have never been to Court of Chancery. Thomas Cook stated there is a black and white part of this…if they lack capacity, they need a guardian. If the individual has some capacity, then Supported Decision Making is the better option. Lexie said a doctor has to fill out the form to state you lack capacity to make decisions. This takes formal Court process to get this all in place. People who provide services (DDDS, Division of Aging, APS, etc) should be able to help with the decision of whether a person is capable or not of making decisions. Terry asked what happens in a situation where an individual is capable of decision making but a family member states that they are not. That issue can be resolved through the legal process if need be.

* 1. Laurie wanted to suggest when we talk about decision making, not just discussing ability to make decision, but also understanding the consequences to making that decision. Abstract thinking is needed here as well. **When we talk about the range of options available, we should include training for Direct Support Professionals.** Some candidates for guardianship have fallen through the cracks such as those that lack family members.

Brian shared that with the current burden of guardianship, many are deterred from being guardians. He has clients calling the Disabilities Law Program about this new option so an individual with some capacity can appoint a parent to help by being their supported decision maker. The person accepting the role doesn’t have to be as afraid of being a decision maker as they may be as a guardian.

Pat stated the intention of the Supported Decision Making law is to help people use the SDM agreement and not get caught up in the system. DDDS already has protective laws and regulations in place for those that reside in the state system. **We need to offer public awareness and training to help them understand what all of the options available are and what each means so that they can choose the best option for themselves. These options are open to everyone in Delaware – not just those with disabilities. None of these options are exclusive or outweighs any other. Training for supporters is a must in Delaware. What do we need now to help people make informed choices and to help people make the least restrictive choice possible.**

* 1. Terry also asked if we are looking at paid supported decision makers but in the end it was decided that they should not be paid**. It was also clarified that DDDS case managers or staff cannot be supporters. This would be something we also recommend to the DHSS.**

1. Review of Chart of Options in DE – Endless Opportunities and the Spectrum of Capacity in Decision-Making. Those documents for training are what the workgroup put together for us. An individual can have more than one option at any given time and can move into a higher level at any given time, if needed. This is for anyone not just those with disabilities. It can be for aging individuals as well as others.

Laurie had a question under “termination of power” under guardianship. She suggested that it may be useful to add that annual reviews are available for this option only. We don’t want to give the idea this is available for all options. Lexie will update the document to help clarify.

The Spectrum of Capacity form is in draft format. This document was asked for by the sponsors of the bill, Senator Bethany Hall-Long, to use for training purposes to help understand each option. Laurie also stated said she was confused when she read this document. She stated it may be helpful to know some facts and examples of each situation in training. Examples are great. Terry asked who our training will be geared towards. **The training that will be recommended will be for individuals themselves as well as those that help them, in addition to other groups.**

1. Practical Tool for Lawyers – The Practical Tool for Lawyers: Steps in Supported Decision-Making is a tool developed by four American Bar Association entities – the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice and Section on Real Property, Trust and Estate law with the assistance from the National Resource Center for Supported Decision Making to allow people to seek advisement on different areas such as power of attorney, guardianship, etc. This allows for attorneys to have an understanding of each of the options available to individuals so that they can properly guide someone in the right direction. **Lexie stated we can recommend this be included in Elder Law Program training as well as advising the Bar Association.**
2. Review & Discussion – DRAFT Agreement – Pat suggested that everyone review the Indiana report that was provided. This is a supplement to work that we have done and that Texas has done. Texas is the only other state that has signed SDM into law.

To draft our template, there were a few revisions suggested:

* 1. In the first paragraph, second sentence, it states “the form of communication shall be appropriate to the needs of the individual with the disability, then individual’s language (an interpreter must be present) and sensory processing wants or needs.” It was recommended to change this to read “the form of communication shall be appropriate to the needs of the individual, the individual’s language……”.
	2. It was also suggested that under the Roles of my Supportive Decision-maker #1, that the last part of that sentence be removed as a separate form is required regarding HIPPA and HERPA laws. Lexie will revise the document to reflect each of the recommendations. **It was also recommended that when this form is provided in our recommendations, that this be available in various languages and possibly add pictures for other accommodations that might be needed. Also, there needs to be revocation language that includes** **notification in writing to all of the parties. There will need to be instructions for this along with other documents on the DHSS website.**

Terry questioned at the bottom of page 3 where it states that the witness to this agreement but may not be the following: “A supporter for the principal.” Can a direct support professional help with this process? They can certainly be there when signing is taking place so they can help person understand what is in place.

1. Suggested Recommendations – The following are the recommendations by the committee at this time:
	1. Develop and provide training for supporters, medical clinicians, bar association, education and higher education, senior world, the psychiatric and psychological clinicians, people with disabilities, families, direct support professionals, supporters, and state employees.
	2. PR for all of the options – for all citizens in Delaware
	3. Recommend that the Bar Association use the Practical tool.
	4. Develop and add a pamphlet reflecting each option to the DHSS website with all other pertaining documents in a variety of languages with available formats.
	5. DHSS Case Managers should not be supporters.
	6. The DDDS “360 Electronic Records” should be a mechanism to provide information concerning SDM to providers with direct support professionals as well as for DDDS staff.
2. Schedule Next Meetings – The remainder of the meetings will be held at the Smyrna Rest Stop Conference Room on the following dates: October 12th from 2-4 p.m., November 16th from 10-noon and December 12th from 10-noon. Please mark your calendars.
3. Adjourn – The meeting adjourned at 12:00 p.m.