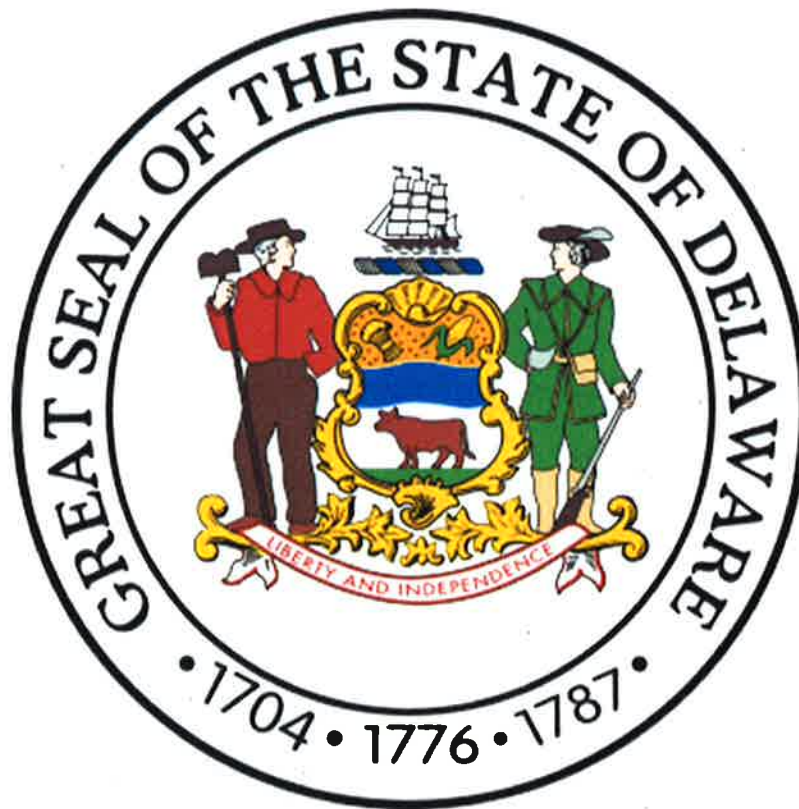
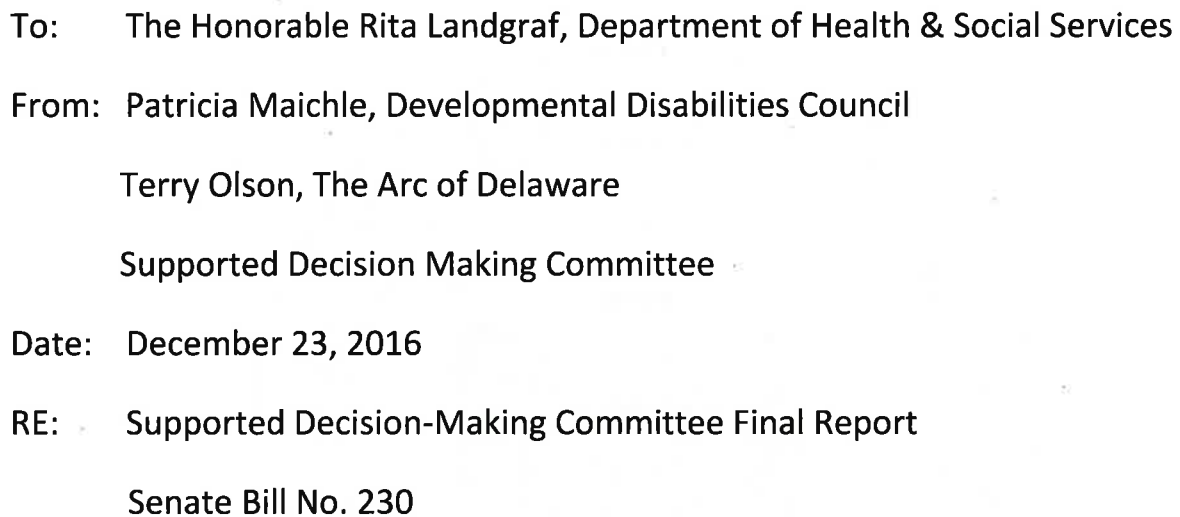


Final Report of the Supported Decision-Making Committee



Submitted December 23, 2016



2

The law contained the following provision (§ 9410A, subpart b, Section 2) related to the promulgation of regulations deemed necessary by the Secretary of Health and Social Services:

There is established under the Developmental Disabilities Council a committee to investigate the best practices for the selection, training, and oversight of those designated as supporters under this Act and to develop the mechanisms by which such selection, training, and oversight would occur. The committee is to be co-chaired by the Chair of the Developmental Disabilities Council, or a designee appointed by the Chair, and the Executive Director of The Arc of Delaware, or a designee appointed by the Executive Director. Each co-chair shall appoint 8 individuals to serve on the committee. The committee shall report its findings and recommendations to the Secretary of the Department of Health and Social Services for the Secretary's consideration in the development of the initial regulations promulgated under this Act.

The intentions of this committee, per S.B. #230, were to provide recommendations to the new administration of the Department of Health & Social Services (DHSS) by the end of December 2016 on how to best implement Senate Bill 230 regarding Supported Decision Making.

The committee met for four months once a month. The meetings were held at the Smyrna Rest Stop Conference Room in Smyrna, DE on the following dates: September 20, 2016 from 10:00 a.m. – 12:00 p.m., October 12th from 2:00 p.m. – 4:00 p.m., November 16th from 10 a.m. - 12:00 p.m., and December 12th from 10 a.m. - 12:00 p.m.

At the request of the Committee, Patricia Justice from the Department of Health & Social Services was invited to attend the meetings and she began to attend in October.

A copy of the legislation was provided to everyone who attended the first meeting and questions asked were answered satisfactorily by Members of the Committee.

Members of the Committee

Pat Maichle (Developmental Disabilities Council), Co-Chair

Terry Olson (The Arc of Delaware), Co-Chair

Cynthia Campbell (Families Speaking Up, Parent)

Thomas Cook (Ability Network of Delaware)

Terri Hancharick (EPIC)

Brian Hartman (Disabilities Law Program)

Vicki Haschak (Elwyn)

Verna Hensley (Easter Seals)

Emmanuel Jenkins (Self-advocate)

Lexie McFassel (Office of Public Guardian)

Daniese McMullin-Powell (ADAPT)

Debra Miller (Chimes)

Barbara Monaghan (Delaware People First)

Michael Pasquale (Self-advocate)

Laurie Romanowich (Parent/Families Speaking Up)

Wendy Strauss (Governor's Advisory Council for Exceptional Citizens)

Vivian Turner (CERTS)

Jamie Wolfe (State Council for Persons with Disabilities)

Staff: Stefanie Lancaster (Developmental Disabilities Council)

Guests Present: Patricia Justice (DHSS), Cory Nouri (Nemours), Micki Edelson, Lanny Edelson, Bill Monaghan, Lisa Elias, Elizabeth Gonzalez, Elizabeth Sauner (attendant).

“Supported Decision-Making: How We All Make Choices

Supported Decision-Making is just a fancy way of describing how we all make choices. We **all** need help making decisions, every single day. Think about it: when the doctor says you have a “somatic injury” or a “brachial obstruction,” or something else that sounds like a foreign language, what do you do? When you don’t know the difference between “itemized” and “standard” deductions, how can you file your tax return? When the mechanic says your car has a “blown head gasket,” how do you know whether to pay for repairs?

You probably ask a friend or family member what to do or if they know someone who can help you cut through the jargon so you can understand what’s going on and what you need to do. It’s just common sense, right? When you don’t know enough to make a good decision, you find people who can help you. It could be going to your brother the accountant with tax questions or talking to your friend the nurse when you need medical information.

When you do that, you’re using Supported Decision-Making. You’re getting the help you need and want so you can make the decisions you have to make (National Resource Center for Supported Decision Making 2016).”

“Supported Decision-Making: How We All Make Choices

Supported Decision-Making is just a fancy way of describing how we all make choices. We **all** need help making decisions, every single day. Think about it: when the doctor says you have a “somatic injury” or a “brachial obstruction,” or something else that sounds like a foreign language, what do you do? When you don’t know the difference between “itemized” and “standard” deductions, how can you file your tax return? When the mechanic says your car has a “blown head gasket,” how do you know whether to pay for repairs?

You probably ask a friend or family member what to do or if they know someone who can help you cut through the jargon so you can understand what’s going on and what you need to do. It’s just common sense, right? When you don’t know enough to make a good decision, you find people who can help you. It could be going to your brother the accountant with tax questions or talking to your friend the nurse when you need medical information.

When you do that, you're using Supported Decision-Making. You're getting the help you need and want so you can make the decisions you have to make (National Resource Center for Supported Decision Making 2016)."

"How Does Supported Decision-Making Work?"

So, how can you use Supported Decision-Making? The most important thing to do is understand that we all have the Right to Make Choices. And, even if a person has a lot of trouble making decisions, it doesn't always mean he or she needs a guardian. Once you make that commitment:

- Think about the type of decisions you or the person you support need help making, and the type of help needed.
- Talk to people who can help and discuss what type of help is needed and when.
- Then, when the person needs to make a decision and needs help to understand it, the person and supporter get together so the person can get the help and make the decision.
- You may want to, but don't have to, create a written plan saying the people who will provide support, when they will provide it, and how. And you may want to share that plan with others.
- So, if you want your sister to support you in making medical decisions, you'd write up a plan between you and your sister saying she'll help you do that and how. Then you could share that plan with your doctor, so the doctor knows that your sister is a part of your health care 'team.' (National Resource Center for Supported Decision Making 2016)"

SDM Committee Review Process

Review of Best Practices in the Selection of Supporters

The committee's discussion on this topic identified some differences of opinion regarding how vulnerable individuals could be protected from individuals who might prey upon them. Some Members felt there should be very few requirements for the selection of a supporter considering that any citizen in Delaware can choose to use Supported Decision Making as an option in their lives. Some Members were very concerned about the potential for abuse, neglect, or exploitation if DHSS did not adopt any standards in this area. It is not known

whether other jurisdictions, i.e., in Texas or other countries, restrict the selection of supporters in any way.

Review of Best Practice SDM Training Materials

Also, the committee reviewed and discussed training materials and curriculum that had been developed by other states and organizations, including the Texas training materials and the “My Health, My Decision” curriculum, which was found online. Materials used in other countries that have implemented SDM were not reviewed. There was no consensus reached regarding how training of supporters would be assured, although there are a variety of opportunities that can be utilized to bring awareness and education to the citizens of Delaware on this topic.

Review of a Best Practice SDM Resource Tool for Attorneys

The Public Guardian, Lexie McFassel, provided and discussed a new training document for lawyers that was 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. This document describes how people needing support in decision-making can seek advisement on different options, such as power of attorney, guardianship, etc. This tool assists attorneys in understanding each of the options available to individuals so that they can properly guide someone in the right direction. “Practical Tools for Lawyers: Steps in Supported Decision-Making” was highly recommended as a tool to be shared with attorneys and included in training for attorneys that is offered in Delaware during conferences and other events.

Review of Documents Drafted under the Quality Trust Grant for Implementation Recommendations and Review of Best Practices for the SDM Agreement Template

The committee members reviewed the draft documents that had been developed previously under the grant and provided edits/comments/suggested revisions (please see Appendix A for Meeting Minutes). At each meeting, recommendations related to these materials were put forward and considered by those Members present for submission to the DHSS. These documents include a SDM Agreement template (Appendix B), Endless Opportunities, a Chart of Options

(Appendix C), Spectrum of Capacity (Appendix D), an Education Plan (Appendix E), LIFE Conference Power Point (Appendix F).

As part of the committee's discussion on the draft template that had been developed under the Quality Trust grant, the committee reviewed a document developed by The Arc of Indiana about Supported Decision-Making that contained a SDM Agreement template and the SDM Agreement template being used in Texas.

Review of Guardianship Considerations

Brian Hartman shared his observation that with the current burden of guardianship, many are deterred from being guardians. He has had clients call the Disabilities Law Program about this new option, which would allow an individual with some capacity to appoint a parent to help by being their supporter. The person accepting the supporter role might be less concerned about this role, than the alternative responsibilities involved in becoming a legal guardian. An individual can use more than one option at any given time and can pursue moving to a different level of support at any given time, if needed. SDM is intended for use by anyone, not just for people with disabilities, i.e., for aging individuals, as well as others who might need some assistance in decision-making.

Review of Best Practices in Oversight of Supporters

There were also differences of opinion with respect to any obligations that should be met by DHSS with respect to oversight of supporters. As this option can be used by anyone, some Members of the committee felt that it would be difficult for DHSS to monitor and oversee this option for everyone. The cost of attempting to oversee this option for everyone would be prohibitive, some felt. DHSS might consider oversight for those citizens who receive services from them directly. Although, this issue was discussed, consensus for a path forward was not reached.

Review of Other SDM Uses

Some committee members asked if a principal wished to assign support roles to multiple individuals if these assignments would need to be on separate agreement forms that would be completed for each supporter. It was agreed the principal can be able to specify that more than one supporter is granted permission to provide support in separate designated decision areas in a single agreement.

Areas Deferred or Not Addressed

The language in the bill regarding whether a Direct Support Professional (DSP) can become a supporter under a temporary SDM Agreement was discussed. Most members of the committee felt that the law was clear about the exclusion of DSPs from becoming supporters, due to potential conflicts of interest and liability issues. However, reference was made to surrogate decision-making, under which this could occur in an emergency. It was suggested that more research and training take place on under what circumstances this could happen, especially when dentists or physicians do not consider an individual competent to provide consent for a healthcare procedure.

At several points in the discussion, there was recognition by members of the group that the existing mechanisms for guardianship could be improved. However, recommendations for that purpose were outside the scope of the committee's charge under the law, so they were not specifically addressed in the recommendations that are being made to DHSS.

Recommendations

Recommendations could be offered by any committee member and each of the proposed recommendations were discussed and considered by the full committee. The following are the recommendations that were endorsed by the full committee.

A. Selection of supporters

1. The principal should be free to select a supporter from among family and friends. Consensus could not be reached about whether DHSS should require restrictions on supporters that are chosen by vulnerable citizens (principals) who might be served by DHSS. Some Members felt that it would not be useful to attach restrictions on a "lesser" option than the options currently existing in Delaware; i.e. Powers of Attorney, Health Care Directives, etc. Some Members felt that it would be useful to attach restrictions on this option to protect those principals.

B. Training of supporters and others in the legal and service systems

1. Develop and provide training to the primary targeted audience categories of persons considering an SDM agreement and their families; direct service

providers; legal, medical, and educational personnel; and the public. A schedule of informational sessions should be posted on the DHSS website. Please see Appendix C for a list of groups and individuals who would benefit from SDM training, as identified by the committee.

2. Develop and implement a PR campaign to include the decision-making options available to all citizens in Delaware.
3. DHSS should encourage the Delaware State Bar Association to disseminate and use the “Practical Tool for Lawyers: Steps for Supported Decision-Making” 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.
4. Develop an informational pamphlet to be printed and distributed to target groups, which identifies decision-making options in Delaware. The pamphlet and all other pertinent documents should be produced in a variety of languages with a variety of formats including the use of pictures, and should be posted on the DHSS website. At a minimum, the pertinent documents should include the SDM Agreement template, the Endless Possibilities continuum of options document, and the Spectrum of Capacity document.
5. A core training tool should be developed similar to the Power Point presentation being developed for the LIFE Conference in 2017. More slides or other training materials should be added, as needed, to provide information tailored to each targeted audience.
6. The core training tool described in # 5 should be made available in a webinar format, either as a PowerPoint or as a video on DHSS’s website and should be fully operational by February 2017. Styles of learning and

language preferences should be considered carefully with respect to the need for different versions of the training to be made available.

7. All materials developed about supported decision-making should be objective, respectful, and constructive. More specifically, while these materials should illustrate the differences between each decision-making option.
8. Supporters should be informed in the instructions for the SDM Agreement that they should view the webinar described in #6.
9. All educational materials including the webinar should include appropriate information regarding state policies relating to abuse, neglect and exploitation of vulnerable persons. In addition, these training materials regarding Supported Decision Making should include a section dedicated to a discussion of due diligence and appropriate caution in selecting an individual to assist in accessing and discussing the principal's information and records.

C. SDM Implementation

1. The SDM Agreement template should be posted on the DHSS web site in a fillable format so those who need to use the computer/technology to complete the document have easy access to it.
2. A link to the engrossed (final, amended) version of the law should be added to the DHSS website.
3. DHSS should include a Question and Answer document and instructions on the web site as a guide for people who are considering a SDM agreement to help them understand the relevant concepts in supported decision-making.

4. Current DHSS Case Managers and/or anyone acting in the capacity of Case Manager should be prohibited from becoming a supporter, to avoid a conflict of interest.
5. The status of the decision-making option selected by each individual should be included in the DDDS Electronic Record to provide information concerning whether a SDM Agreement exists, to providers, direct support professionals, and DDDS staff. This record should be accessible online so that the individual, their family, and staff can verify and share their "Supported Decision Making Agreement" with physicians, other medical professionals, and others as needed.

Senate Bill No. 230, now law, allows for the use of Supported Decision Making in Delaware as a decision making option on a continuum of options afforded to the citizens of Delaware. In accordance with this law, a committee was formed with a prescribed membership to discuss recommendations in line with this law to be submitted to the Department of Health & Social Services.

Members of this Committee developed over a four month period the above recommendations for consideration by the Department. The primary foci of these recommendations are awareness and education so that people will have the opportunity to make informed choices throughout their lives when making decisions. The Education Plan developed includes a broad base of individuals and organizations who should take advantage of these informational opportunities.

The tools developed with this Committee should be used as templates for everyone who wishes to learn about Supported Decision Making, those who choose to use this option of decision making, and those who are chosen as supporters.

These Committee Members and Chairs respectfully request that the Department of Health & Social Services sincerely consider our recommendations and act as quickly as possible to bring these to fruition.

APPENDIX

APPENDIX A – Meeting Minutes

APPENDIX B – Supported Decision Making Agreement Template

APPENDIX C – Endless Possibilities Chart of Options

APPENDIX D – Spectrum of Capacity

APPENDIX E – Education Plan

APPENDIX F – LIFE Conference PowerPoint presentation

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

- I. 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.

- II. 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.
 - a. 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.**

- b. 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.

- c. 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.**

- d. 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.**

III. 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.**

- IV. 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.**

- V. 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:

- a. 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.....”.
- b. 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.

VI. Suggested Recommendations – The following are the recommendations by the committee at this time:

- a. 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.
- b. PR for all of the options – for all citizens in Delaware
- c. Recommend that the Bar Association use the Practical tool.
- d. 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.
- e. DHSS Case Managers should not be supporters.
- f. 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.

VII. 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.

VIII. Adjourn – The meeting adjourned at 12:00 p.m.

Supported Decision-Making Committee

SB #230

Minutes

October 12, 2016

Smyrna Rest Area, Smyrna, DE

2:00 p.m. – 4:00 p.m.

Members Present: Pat Maichle (Developmental Disabilities Council), Stefanie Lancaster (Developmental Disabilities Council), Daniese McMullin-Powell (ADAPT), Barbara Monaghan (Delaware People First), Patricia Justice (Division of Services for Aging Adults with Physical Disabilities), Terri Hancharick (EPIC), Michael Pasquale (self-advocate), Jamie Wolfe (State Council for Persons with Disabilities), Lexie McFassel (Office of the Public Guardian), Verna Hensley (Easter Seals), Brian Hartman (Disabilities Law Program), Cory Nourie (Nemours), Thomas Cook (Abilities Network of Delaware), Debra Miller (CHIMES), Terry Olson (The Arc of Delaware), Vicki Haschak (Elwyn), Vivian Turner (CERTS), Cynthia Campbell (parent)

Guests Present: Bill Monaghan, Elizabeth Sauner (attendant services), Lisa Elias

I. Welcome and Introductions- Members of the committee and public introduced themselves at this time. Pat stated that some slight changes were made to the draft version of the Endless Possibilities document as well as the Supported Decision-Making Agreement based on suggestions made at the last meeting. Pat expressed her gratitude to Patti Justice from DHSS for joining in our discussions as well as Cory Nourie from Nemours.

II. Review of the Agenda – There were no updates or additions requested at this time. The agenda was approved as written.

III. Review of Minutes – There were no updates or additions requested at the meeting. The minutes were approved. When the committee's recommendations are given to Division of Health and Social Services in December, the information from committee minutes will be included for their reference to track our discussions. **A list of recommendations will be documented separately.**

IV. Review of Chart of Options in DE Revised – A copy of the revised Chart of Options – Endless Possibilities – was given to everyone who attended. Lexie McFassel and Patricia Justice were involved in the revision of this document. Under the "Intended Population" section of the Supported Decision Making agreement – the language which previously stated "including those with physical disabilities, cognitive or intellectual disabilities, brain injuries and the elderly" has been removed. It was decided at the last meeting that this should be removed as this document is for the general population, not just those with disabilities. Also, under the "Termination of Power" within the Guardianship section, the language referring to "... petition of review by the Court of Chancery if the individual recovers capacity" – was changed to remove the words "petition to" and "if the individual recovers capacity". It was

decided that annual reviews on guardianship would be sufficient. **Lexie will provide the committee with the final document to submit along with the committee's recommendations in December, 2016.**

Jamie Wolfe asked if individuals signing SDM agreements must be able to physically sign the document themselves. Pat said whatever method individuals use for their signature – initials, a dot, lines, or a traditional signature will be accepted.

Terri Hancharick questioned if facial expressions are accepted as the individuals approval or signature for this document. Pat stated that consent/signature by facial expression is not an option. It was suggested that an individual may hold a pen in their mouth to sign or use other special software to assist them with their signature.

V. Review DRAFT Agreement Revised – Lexie McFassel and Patricia Justice added in the citation of the code where the law now sits. Patti stated that she and Lexie reviewed the Texas Supported Decision-Making Agreement (a copy was provided to everyone who attended). Check boxes were added to the Delaware forms along with a line for initials next to each area that the individual would like the Supportive Decision-Maker to help them with - Health Affairs, Supportive Services, and Financial Affairs. Also, a section was added to the last page as a declaration page for the individual, the Supportive Decision-Maker and witnesses to sign. Pat asked those present to share any further suggestions regarding the document, stating that the document can be edited later.

Pat stated that her daughter, Tara Bustard, recently was the first to sign her Supported Decision Making Agreement. Pat stated this document was something they both felt comfortable using to make her daughter's wishes known.

The wording under a) Health Affairs, "communicate or assist me in communicating my decision to other persons" will be added to sections b) and c).

A question was raised about adding a protection clause to this agreement. A protection clause was required in the Texas statute, but it is not required here in Delaware. **After some discussion, it was decided to include a section on "Protection" at the end on the last page of our draft. The new section will state "A person who received the original or a copy of a supported decision-making agreement shall rely on the agreement. A person is not subject to criminal or civil liability and has not engaged in professional misconduct or an act or omission if the act or omission is done in good faith and in reliance on a supported decision making agreement". The Delaware draft document will be revised to reflect this change. Those present stated that perhaps a few sentences can be added to this section of the document with a link to refer to the statute for more details. Brian Hartman was also suggested to add a link to the engrossed version of the law as reference to the DHSS website. This will be added to the committee's list of recommendations.**

Some committee members asked if a SDM Agreement beneficiary wished to assign support roles to multiple individuals must be on a separate form completed for each supporter. It was suggested that this can be noted under section 5 of the Delaware draft agreement. SDM Agreement beneficiaries can specify which individual is granted their permission to provide support in each designated area.

Jamie Wolfe asked if this agreement form can be completed and printed for an individual to sign in a fillable PDF format. The committee stated that that option should be made available and will be included in the list of recommendations to DHSS.

VI. Review DRAFT Education Plan – There have been several recommendations regarding various agencies and groups of individuals that would need proper training on Supported Decision Making and other options available to all Delawareans. Pat included a draft of this document so the committee could begin discussion about this. After reviewing, Lexie recommended to limit the amount of different agencies/organizations to present this training and present it to “groups” rather than individual organizations separately— Direct Service Providers, Legal, Medical, Education and Public. **The presentation being developed for the LIFE Conference will be used as the core training tool and more slides will be added to provide information tailored to a targeted audience. Another recommendation that will be made to DHSS is to have this training available in a webinar, PowerPoint and video format on DHSS’s website and be fully operational by February 2017. Also, they should consider styles of learning and include a resource page and a point person at the department.**

Pat was at a conference in Texas recently where a presentation was done regarding the training that Texas offers regarding Supported Decision Making. The materials that were developed were presented. A copy of their presentation was provided to all those present at today’s meeting. One of the slides used is a pictorial layout that shows all different options available – not just Supported Decision-Making. Members from the Texas group have stated that they would be happy to come to Delaware to discuss what they have developed and allow Delaware to mimic what they have done.

VII. Suggested Recommendations – The following are the recommendations by the committee at this time. These will be added to a list of recommendations to provide to DHSS in December.

- a. Ask that DHSS add a link to the engrossed version of the SDM law for individuals and those helping to complete the form as reference on their website.
- b. Offer the SDM agreement in a fillable PDF format for individuals to complete online, print and then sign the document.
- c. Offer training to targeted audiences such as Direct Support Providers, Legal, Medical, Education and the Public.
- d. Have all the SDM information available on DHSS’s website including a resource page and a point person at the Department and be fully operational by February 2017.

VIII. Schedule next meetings – The next meeting is scheduled for November 16th from 10 a.m. until noon at the Smyrna Rest Stop. Please plan to attend. All documents for future meetings will be sent in advance. Some of the information for this meeting was not available to send in advance for this meeting.

IX. Adjourn - The meeting adjourned at 3:15 p.m.

Supported Decision-Making

S.B. #230

Minutes

November 16, 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 McMullen-Powell (ADAPT – present via phone), Barbara Monaghan (Delaware People First), Terri Hancharick (EPIC), Jamie Wolfe (State Council for Persons with Disabilities), Lexie McFassel (Office of the Public Guardian), Brian Hartman (Disabilities Law Program), Thomas Cook (Ability Network of Delaware), Debra Miller (CHIMES), Terry Olson (The Arc of Delaware), Vicki Haschak (Elwyn), Cynthia Campbell (parent), Wendy Strauss (Governor's Advisory Council for Exceptional Citizens), Emmanuel Jenkins (self-advocate)

Guests Present: Bill Monaghan, Elizabeth Sauner (attendant services), Lisa Elias, Tanner Polce, Kathy Dehacy, Micki Edelson, Lanny Edelson, Brigitte Hancharick, Cory Nourie (Nemours), Patricia Justice (Division of Services for Aging Adults with Physical Disabilities)

- I. Welcome & Introductions – Members of the committee and public introduced themselves at this time. Pat stated that during today's meeting the committee would review the revised DRAFT agreement, DRAFT Education Plan and DRAFT report to include final recommendations to DHSS.
- II. Review of Agenda – There were no updates or additions requested at this time. The agenda was approved as written.

- III. Review of Minutes – There were no updates or additions requested at this time. The minutes were approved as written.
- IV. Review DRAFT Agreement Revised – The edits requested during the last meeting were reviewed. Some additional changes were requested:
 - a. “Supportive” should be changed to “Supported” throughout the DRAFT agreement document as well as the other documents created to reflect the same language that is in the law.
 - b. Within the first paragraph of agreement where it states “an interpreter must be present”, it was requested by Terry Olson to revise it to say “an interpreter must be present for foreign languages or alternative forms of communication”.
 - c. Within the second paragraph on page 1 in the last sentence “This agreement is not durable and would not survive a determination of incapacity”, it was requested to add “under Delaware Code” to the end of that sentence.
 - d. Terry Olson requested that page numbers be added to the document.
 - e. On the last page, last sentence of the document where it states “Under certain circumstances and further guidance please see Title 16, Chapter 94A”, it was suggested to change this to read “For further guidance”.

The above edits will be made to this document shared with the committee prior to the December meeting for final review and approval. This agreement will be used a template to recommend to DHSS. They will choose how to use this form.

- V. Review DRAFT Education Plan – The Education Plan chart was developed to reflect the broad range of categories to direct the educational training towards. For example, medical professionals, legal, education and public. Terry Olson suggested adding “persons considering SDM” to

the list. All agreed that this category is already listed in the Education Plan. A member of the public asked how the training will be able to be given to, for instance, all medical professionals. Pat stated it will be up to the Department on how to get this training to each of the targeted audiences.

Cynthia Campbell had a question relating to the training tools provided at the last meeting from Texas. With regards to guardianship, is there a list of what individuals under guardianship are still allowed to do as Texas has a list of 24 items. Lexie stated that Delaware does not have this tool. Cynthia felt that if we are educating the public on SDM that we should also educate more on guardianship as well.

- VI. Suggested Recommendations – The list of suggested recommendations was discussed during the review of the DRAFT report to DHSS.
- VII. Review DRAFT Report to DHSS – This is the first DRAFT of this document. Once a final document is developed we will add the State Seal to this document. Stefanie has received the necessary approvals to do so as this committee was included in the law.

The report begins with an explanation of Senate Bill 230 and of this committee which is to provide recommendations to the Department of Health and Social Services (DHSS) on how to best implement Senate Bill 230 regarding Supported Decision Making. The dates and location of the meetings are also included with the report. Copies of the minutes from each meeting will be shared with DHSS as an attachment to the report.

A background of what Supported Decision Making is has been included. It was noted that the information provided under the section labeled “Supported Decision Making: How We All Make Choices” has the

information listed twice. Pat will edit this section to remove the duplicate information.

The next section discusses background information on the grant award received from Quality Trust. There was a discussion regarding the statement that “disability advocates in Delaware have begun to embrace Supported Decision Making as an alternative to guardianship”. Several present felt that this statement is not accurate and should be revised. Pat will edit to quote the language from the purpose of the grant received. A copy of the final report provided for the grant will be provided to all before and at the next meeting for reference. And, Pat pointed out that the end sentence in the paragraph includes that the “overall message of the this is being that everyone has the right to make choices and that this option of decision making is one of a continuum of decision making options for citizens of Delaware”.

A list of members that were chosen by the chairs have been listed – their names and what agency they represent. Thomas Cook stated his agency should be listed in a singular format – Ability Network of Delaware. Also, Terry Olsen should have the correct spelling of Olson. Also, Laurie Nicoli should be listed as Laurie Romanowich.

The paragraph regarding the current burden of guardianship may be revisited.

There was a question regarding background checks for individuals that are SDM supporters. Considering that SDM is an option open to all citizens in Delaware, the possibility of requiring background checks is barely feasible. Terry Olson added he would help develop a recommendation for this for the committee members to consider.

It was also suggested that we add information regarding another perspective and background from a different perspective in the section stating the background of SDM. Laurie was asked to draft this and send to Pat for consideration by the committee members.

A list of recommendations has been included. Stefanie Lancaster has done a great job capturing this information within the minutes. Those recommendations have been included within the report. Members went through each to review and discuss.

1. Develop and provide information opportunities to the primary targeted audience categories of direct service providers, legal medical, education and the public as reflected in the Education Plan.
2. Develop and deliver a PR Campaign to include all of the decision making options – for all citizens in Delaware.
3. DHSS should communicate with the Delaware Bar Association that they could use the “Practical Tool for Lawyers: Steps for Supported Decision Making” 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 see advisement on difference areas such as.
4. Develop and add an information pamphlet reflecting each decision making option to the DHSS website with all other pertaining documents in a variety of languages with a variety of formats including the use of pictures, to include a template of the SDM Agreement, the Endless Possibilities continuum of options document, and a Spectrum of Capacity document. All documents should be made available in printed format and available at DHSS worksites.
5. The Agreement must be on the website in a fillable format so those who need to use the computer/technology to complete the document are given the access that they deserve.
6. Add a link to the engrossed version of the law to the DHSS website.
7. DHSS should include a question and answer document on the website for persons to use as a guide for the process for people who want to use this option and for supporters to understand what supported decision making is.

8. The presentation being developed for the LIFE Conference 2017 should be used as the core training tool and more slides can be added to provide information tailored to a targeted audience. Include this tool on the DHSS website.
9. Have the informational training materials available in a webinar, PowerPoint and video format on DHSS's website and be fully operational by February 2017. Styles of learning should be considered.
10. DHSS Case Managers should NOT be supporters.
11. DDDS should incorporate an optional "Supported Decision-Making" module into their electronic records system for persons served by DDDS who choose to have one or more Decision Maker Supporter(s). This module should serve as an accessible on line record for the individual, their family and staff, for the purpose of verifying and sharing their "Supported Decision Making Agreement" with physicians, other medical professionals and others as pertinent.
12. DHSS should investigate educational tools for all of the options on the continuum of Decision Making in Delaware.

VIII. Adjourn – The meeting adjourned at 12:00 p.m. The next and last meeting will be held on December 12th from 10 a.m. until 12:00 p.m. at the Smyrna Rest Stop. Information for the last meeting in December will be sent to everyone approximately two weeks in advance for everyone to review and come prepared to finalize the recommendations to DHSS at the final meeting.

Supported Decision-Making

S.B. #230

Committee Meeting Minutes

December 12, 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 – present via phone), Barbara Monaghan (Delaware People First), Terri Hancharick (EPIC), Jamie Wolfe (State Council for Persons with Disabilities – present via phone), Lexis McFassel (Office of the Public Guardian), Brian Hartman (Disabilities Law Program), Thomas Cook (Ability Network of Delaware), Debra Miller (CHIMES), Terry Olson (The Arc of Delaware), Vicki Haschak (Elwyn), Cynthia Campbell (parent), Wendy Strauss (Governor's Advisory Council for Exceptional Citizens), Emmanuel Jenkins (self-advocate), Michael Pasquale (self-advocate), Verna Hensley (Easter Seals), Vivian Turner (CERTS), Laurie Ramonwich, Cynthia Campbell

Guests Present: Bill Monaghan, Micki Edelson, Patricia Justice (Division of Services for Aging Adults with Physical Disabilities)

- I. Welcome & Introductions- Members of the committee and public decided there was no need to introductions. Pat stated that there were some handouts in the packets of information provided to those present regarding what Texas is currently doing in regarding education for the supporter and principal. This is for informational purposes only.
- II. Review of Agenda – There were no updates or additions requested to the agenda at this time. The agenda was approved as written.

- III. Review of Minutes – Cynthia Campbell noted a few minor edits to the minutes. These edits are as follows:
- On members present, Laurie Ramonowich was mistakenly left off. Please add her to the list of those present.
 - Under #3 of the recommendations list on page 5, it states “people to see advisement on difference areas such as”. It should read “seek advisement on different areas such as the continuum of options”.
- IV. Review DRAFT Documents Revised – All copies of the revised forms were provided to members present. A copy of the LIFE Conference presentation was provided to everyone present. The committee reviewed the presentation page by page. Some edits were found and are as follows:
- Page 1 – The capacity to make decisions for yourself. Terry Olson suggested stating it as “supported decisions”
 - Add the LIFE Conference information and date to the cover page.
 - Remove dates on the bottom of each page.
 - Periods should be added to all bullet points throughout the entire presentation.
 - Page 3 – “all or nothing” should reflect “all and/or nothing” phenomenon.
 - Page 4 – 1st bullet – Determined could be changed to “evaluated by a physician”. Lexie will check if this is cited from another document.
 - Page 4 – 3rd bullet – Terry Olson had a concern with “manipulate information” and felt that another term should be used such as “use”. Lexie will check if this is cited from another document. She will update after checking the source.
 - Page 5 – 1st bullet - “evidence” should be changed to state “express a choice”. Also, under 3rd bullet – edit to read “ability to appreciate the situation options and their likely consequences”.
 - Page 7 – “all or nothing” should be listed as “all and/or nothing”.

- Page 7 – the sentence that reads “whether the situation you are in is within your abilities or exceeds them”. Terry suggested rewording to read “whether the decision you are making is within your abilities or exceeds them”.
- Page 8 – add period at the end of the sentence.
- Page 9 on the Spectrum of Capacity chart, under 3rd column in first sentence it states “may still execute an documents”. It should be “any documents”. 3rd column, 2nd paragraph, simple and complex – please adjust to and/or. This is in more than one area on that page so all simple and complex statements should reflect and/or. It was also recommended to adjust the font colors on the headings so that the yellow section is more legible and to provide a “key” somewhere within the presentation to reflect what some of the acronyms mean such as AHCD and POA/DPOA. There was some discussion regarding concern of the third column “significant impairment of capacity” is unclear. It was decided that this would be explained in more detail and provide examples during the educational training. The colors (red, yellow, green) of the headings are purposeful and the yellow column reflects that this is always the grey area and a person should use caution in this area.
- Page 10 – It was recommended by Terry to bold or underline the headings on this page.
- Page 11 – It was recommended to spell out DDDS, DLP and DD Council or add these acronyms and descriptions to a key in the document.
- Page 12 – There was a question regarding “communicate to other decisions about the individual’s life”. It was asked whether this was a direct citation or if it should read “others”.
- Page 12 – at the bottom of the page, “brief” is spelled incorrectly. It is listed as “ei” and should be “ie”.
- Page 13 – effectuate should be changed to implement.

- Page 14 – 1st bullet – should not be bulleted and should be bold. Add “formal” to supported decision making agreement. Also, under the last bullet – should read “types of decisions” not “decision”.
- Page 15 – 3rd bullet – should add “eligible” to adult witnesses. Also, under 4th bullet, it was recommended to revise this to read “Individuals who can serve as witnesses are limited by section 9405A (e) of the statute”.
- Page 16 – There was some discussion relating to the “You” term used rather than the “individual, principal or supporter”. Lexie will review this and edit as appropriate. It was also recommended to spell out FERPA and HIPPA or add it to the key. There was also a brief discussion also relating to a “good faith statement” for those who are supporters to highlight their duties. Lexie will also add this within the presentation as well.
- Page 17 – 1st bullet - “you” should be substituted with the appropriate word chosen to keep it the same throughout the presentation. Under the 2nd bullet, “the form just formalizes a relationships you may already have” should be edited to read “the agreement just formalizes a relationship you may already have”. Within the 3rd bullet, “supported” should read “supporter” while also changing the comma at the end to a period. Under the 4th bullet, “principle” should be edited to read “principal”.

V. Review DRAFT Report to DHSS – There were two versions provided to the committee to review. Version 1 is the version Pat provided and Version 2 is the 2nd draft that Terry provided. It was recommended to go page by page throughout the documents to try to blend the two together. The recommendations are as follows:

- Page 1 – the first three paragraphs were agreed to keep as is from Version 2.
- It was recommended to keep the names of individuals on the committee within the report not as an Appendix. It was

recommended to alphabetize these names and move it forward in the report.

- Page 2 – in Version 2, remove the last sentence of the 2nd paragraph that reads “Additional input was gathered in between these meetings”.
- Page 3 & 4 – the background section will be removed as a separate section but the explanation of Supported Decision Making will remain in the report. All other background information will be removed. Cynthia had some concerns about removing background of how SDM was brought to Delaware completely and wanted it notated that she didn’t agree within the minutes.
- Page 5 – After some discussion, it was agreed to keep Version 2’s layout of the SDM Committee Review process. It was also asked that it be included to reference that meeting minutes are attached for more detail.
- Page 6 – Review of a Best Practice SDM Resource Tool for Attorneys, Lexie’s name should reflect one L. Under “review of documents” heading, it should be referenced that the committee members reviewed the draft documents – not “some of the draft documents”.
- Page 8 – In Version 2, there was some discussion regarding “Selection of Supporters” and the attestation statement. This is asking that a person attest that they do not have the items listed – not actually paying/funding this option and making them have criminal background checks. It was stated that there is no way to enforce this and the fact that this is not needed or requested with Powers of Attorney. It doesn’t seem appropriate to require it of something in a lower level of decision making. There was some concern by Cynthia and Laurie regarding oversight on this piece. Some members feel there is no authority within this committee to provide additional oversight on this piece and some members feel that the committee was tasked to provide this support. The minutes reflect this statement.

- Page 9 – It was agreed to keep all of Version 2's as listed with a few minor edits. #5 – Edit to read “A core training tool should be developed similar to the presentation used at the LIFE Conference”. #6 – it was discussed to remove “to the College of Direct Support and should” and replace with “and” so that the sentence reads “DHSS’s website in a link and be fully operational by February 2017”. With regards to adding a training tool (such as a PowerPoint presentation) to the College of Direct Supports website was another area that the committee was unable to agree upon and it was recommended to notate this within the minutes. #7 – keep this recommendation however edit it to read “illustrate the differences between each decision making option”.
- Page 10 - #8 – This should be revised to read “Supporters should be informed in the instructions for the SDM Agreement that they should view the webinar described in #6 via the link provided”. Remove the 2nd sentence. A sentence should be added to #9 and revise to read “It is recommended that all educational materials regarding Supported Decision Making include a section dedicated to discussion of due diligence and appropriate caution in selecting an individual to assist in accessing and discussing the principle’s information and records”.
- Under Item C – SDM Implementation - #4, it was recommended to revise it to read “Current DHSS Case Manager and/or any person acting in the capacity of a case manager should be prohibited from becoming a supporter to avoid conflict of interest. Under #5, remove “Therap currently, and CS360 in the future).
- Under Item D – SDM Oversight – it was recommended to remove that section completely.

VI. Adjourn – The meeting adjourned at 12:15 p.m.

SUPPORTED DECISION-MAKING AGREEMENT

Delaware Code Title 16, Chapter 94A, Section 9401A

This form is to be read aloud or otherwise communicated, in the presence of the witnesses and parties to the agreement. The form of communication shall be appropriate to the needs of the individual with the disability, that individual's language (an interpreter must be present for foreign languages and alternative forms of communication) and sensory processing wants or needs.

This form is to be used for the appointment of a person(s) to help me make decisions. A Supported Decision-Making Agreement is a written agreement between me and my appointed person(s). The person(s) I appoint helps me make decisions. **My appointed person(s) does not make decisions for me.** A Supported Decision-Making Agreement is effective if I am at least 18 years of age and able to understand the nature and effect of this agreement. I can revoke this agreement at any time and with notice to the appointed Supported Decision-Maker(s). This agreement takes effect as soon as it is signed by all the required individuals. This agreement supersedes any other Supported Decision-Making Agreement made by me. This agreement is not durable and would not survive a determination of incapacity under Delaware Code.

1. This is the Supported Decision-Making Agreement of:

Name _____ Date of Birth _____
 Address _____
 Phone _____
 Email _____

2. My Supported Decision-Maker

I appoint the following person(s) to be my Supported Decision-Maker(s):

Supported Decision-Maker:

Name _____
 Address _____
 Phone (wk) _____ (hm) _____ (cell) _____
 Email _____

3. Alternate Supported Decision-Maker (Optional) – **if there is no Alternate, please cross out this section.**

If my Supported Decision-Maker named above declines to help me or is unable or unavailable to help me within a reasonable time period, I want the following person to help me as my Supported Decision-Maker:

Name _____
 Address _____
 Phone (wk) _____ (hm) _____ (cell) _____
 Email _____

APPENDIX B

4. Areas I Want My Supported Decision-Maker to Help Me

I want my Supported Decision-Maker(s) to help me make decisions in the following areas:

a) Health Affairs ☐ _____ initials

Access or obtain any information that will help me make decisions. Help me make appointments with health care providers. Help me keep track of information about my health care, including my medical records and help me with creating my health care plan and activities of daily living. Help me understand information about health care decisions I have to make, now or in the future, so that I can make my own decisions about my health care. Communicate or assist me in communicating my decision to other persons. My Supporter may see my private health information under the Health Insurance Portability and Accountability Act of 1996, and I will provide a signed release.

Add any additional information:

b) Supportive Services ☐ _____ initials

Defined as a coordinated system of social and others services supplied by private, state, institutional, or community providers designed to help maintain the independence of an adult. Communicate or assist me in communicating my decision to other persons. For more specifics see DE Code, Title 16, Ch. 94A. Access or obtain any information that will help me make decisions. My Supporter may see my educational records under the Family Education Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g), and I will provide a signed release.

Add any additional information:

c) Financial Affairs ☐ _____ initials

Access or obtain any information that will help me make decisions. Help me obtain information and understand information about financial affairs, including but not limited to assets and resources and their use and management for my clothing, support, care, comfort, education, health care and shelter. Communicate or assist me in communicating my decision to other persons.

Add any additional information:

5. Areas I DO NOT Want My Supported Decision-Maker(s) To Help Me (if any)

I do not want my Supported Decision-Maker(s) to help me in making these kinds of decisions:

APPENDIX B

6. Signatures (me, my Supported Decision-Maker(s) and the witnesses must sign together at the same time)

Adult

I am at least 18 years of age and I understand the nature and effect of this agreement.

Print Name

Signature

Date

Supported Decision-Maker #1

Print Name

Signature

Date

Alternate Supported Decision-Maker (optional) - if there is no Alternate, please cross out this section.

Print Name

Signature

Date

Witnesses

Two adults must witness my signature and the signature(s) of my Supportive Decision-Maker(s) and sign together in my presence. The witnesses CANNOT be a Supported Decision-Maker of the adult. They also CANNOT be an employee or an agent of the Supported Decision-Maker. As well, they CANNOT be a spouse, child or parent of the Supported Decision-Maker or an employee of the Supported Decision-Maker.

Print Name

Witness Signature

Date

Print Name

Witness Signature

Date

Concerns about adults who may be in need of protective services should be evaluated and reported in accordance with Title 31 chapter 39.

A person, who in good faith acts in reliance on an authorization in a supported decision-making agreement, or who in good faith declines to honor an authorization in a supported decision-making agreement, is not subject to civil or criminal liability or to discipline for unprofessional conduct.

For further guidance please see Title 16, chapter 94A.

SUPPORTED DECISION-MAKING AGREEMENT DECLARATION

My relationship to the principal is

I am willing to act as a supporter.

I acknowledge the duties of a supporter under DE Code Title 16, Chapter 94A.

Supported Decision-Maker #1

Print Name

Signature

Date

Alternate Supported Decision-Maker (optional) if there is no Alternate, please cross out this section.

Print Name

Signature

Date

APPENDIX C

ENDLESS POSSIBILITIES

A COMPARISON OF DECISION MAKING OPTIONS IN DELAWARE

Who Completes the Form	Supported Decision Making (Proposed)	Surrogate Decision Making	Advanced Health-Care Directive	Power of Attorney	Guardianship
	The adult, two witnesses, and the Supporter.	Determination is made by the attending physician if patient lacks capacity, or stated by the patient if able.	The adult, with or without medical or legal consultation.	The adult, with or without legal consultation.	A petition and multiple forms must be filed by the person seeking guardianship with the Court of Chancery.
Type of Document	Document executed and witnessed indicating what type of assistance is needed and what the supporter has permission to do.	Documented by the physician in the patient's health record as to who is designated by the patient, or who is available to serve.	Legal document stating a person's future health care treatment if the adult loses decision-making capacity, and may appoint an agent.	Legal document appointing an agent to manage financial affairs on behalf of the adult prior to or when the adult loses capacity.	Court Order specifying the powers of the guardian and what, if any, rights are retained by the individual.
Intended Population	Individuals who need help in gathering and assessing information, and making informed decisions.	Patients in the health care setting with or without decision making capacity.	All adults that have even a modest level of capacity, who are aware and able to understand the nature and effect of the document. (Testamentary capacity)	All adults that have even a modest level of capacity, who are aware and able to understand the nature and effect of the document. (Testamentary capacity)	All individuals assessed by a physician to have no decision making capacity, or those at risk of harm or exploitation.

APPENDIX C

Signatures required	Document must be signed by the adult, two witnesses, and the appointed Supporter.	Confirmed in writing by the physician if patient lacks capacity, or by the physician and the witness if decision maker designated by patient.	Person and two witnesses meeting specific requirements.	Document must be signed, witnessed and notarized.	Court Order signed by a Judicial Officer.
Appointment of Authorized Representative	Appoints an individual to gather information and assist in assessing information. Supporter does not have individual authority.	A person may designate a surrogate decision maker by informing the health care provider in the presence of a witness, or if unable to do so, the health care provider may recognize an individual pursuant to the law. (16 Del.C. §2507)	Title 16, Chapter 25 provides a form which must be executed to set out the wishes of the person and appoint an agent who may act when the individual becomes incapacitated.	Title 12, Chapter 49A provides a statutory form and directions for appointing an agent.	The Court of Chancery appoints a guardian upon the petition. Title 12, Chapter 39.
Role of Representative	To provide support to the adult, including help in assessing information, options, responsibilities and consequences of the adult's life decisions, including those about health care, financial decisions, and support services.	To make decisions about health care in place of the individual.	To make decisions about health care in place of the individual in conformance with their wishes.	To make decisions in place of the individual about financial matters.	To assume all decision making in place of the individual, who retains not ability to make decisions for themselves. Authority extends to both person and property depending on the order of the Court.
Termination of Power	May be revoked by individual.	A competent person may disqualify a surrogate in writing or by communicating	May be revoked in writing or another means of effective communication the	May be revoked by the individual.	The guardianship may be terminated upon review by the Court of Chancery, or terminates upon death.

APPENDIX C

		with the care provider.	intent to revoke.	
--	--	----------------------------	-------------------	--

APPENDIX D - SPECTRUM OF CAPACITY IN DECISION-MAKING

Judgment about an adult's "mental incapacity" will call for a review on the facts of each adult

An adult is considered to have capacity to make decisions until the Court of Chancery of Delaware determines the adult lacks mental capacity



APPENDIX E

Education Plan

<u>Agency/Organization</u>	<u>Format for materials</u>	<u>Possible Partners</u>	<u>By When</u>	<u>Person Responsible</u>
People with Disabilities		State Agencies, DPF, NAMIDE, DDC, S	Dec-17	
Seniors at Senior Centers		State agencies	Dec-17	
Families		State Agencies, ARC	Dec-17	
Potential Supporters		State Agencies	Dec-17	
Medical Clinicians		HCC, OPG, DLP, Cory	Dec-17	
Service Providers		State Agencies	Dec-17	
Educators/Higher Ed		OPG, DLP, GACEC, DOE	Dec-17	
State Employees		State Agencies, OPG, DLP, DDC	Dec-17	
The Judiciary		OPG, DLP	Dec-17	
Other Members of the Public		DDC, OPG, DLP, GACEC, SCPD, State A	Dec-17	
DSBA		OPG, DLP	Dec-17	
Elder Law Bar		OPG, DLP	Dec-17	
Health Law		OPG, DLP	Dec-17	
Estates & Trusts Law		OPG, DLP	Dec-17	
ACLU		OPG, DLP	Dec-17	
Public Defenders		OPG, DLP	Dec-17	
Attorney General Staff		OPG, DLP	Dec-17	
Medical Society		OPG, DLP	Dec-17	
Hospital Association		OPG, DLP	Dec-17	
Christiana Care Social Workers		OPG, DLP	Dec-17	
Nemours Social Workers		OPG, DLP	Dec-17	
Westside Health		OPG, DLP	Dec-17	
Henrietta Johnson		OPG, DLP	Dec-17	
School District Spec Ed Directors		DLP, GACEC, PIC	Dec-17	
School District Transition Coordinators		DLP, GACEC, PIC	Dec-17	
Health Information Management		Nemours	Immediately	Cory Nouri



Supported Decision Making

Making decisions for yourself, with assistance.

Decision Making

- ▶ The law presumes that an adult has capacity.
- ▶ There is a spectrum of legal and informal tools available to assist individuals who may need help making decisions.
- ▶ One size does not fit all.
- ▶ Important to assess individual's abilities and needs.

What is “Capacity”

- ▶ “Capacity” is evaluated by a physician. The Court of Chancery makes a final legal determination if petitioned.
- ▶ Refers to a physician’s assessment of a person’s psychological abilities to make rational decisions.
- ▶ Specifically, the individual’s ability to understand, appreciate, and use information and formulate rational decisions.

Assessing Decision Making Capacity

The abilities that consistently appear to be relevant to a person's capacity to make reasoned decisions regarding treatment:

- ▶ Ability to understand relevant information
- ▶ Ability to appreciate the situation, options, and its likely consequences
- ▶ Ability to manipulate information rationally
- ▶ Ability to express a choice

Myths about Decision-Making Capacity

- ▶ Decision-making capacity and legal competency are the same.
- ▶ Lack of decision-making capacity can be presumed when patients go against medical advice.
- ▶ There is no need to assess capacity unless the patient goes “against” medical advice.
- ▶ Decision-making capacity is an “all or nothing” phenomenon.
- ▶ Cognitive impairment equals lack of decision-making capacity.
- ▶ Lack of decision-making capacity is a permanent condition.
- ▶ Patients with certain psychiatric disorders lack decision-making capacity.
- ▶ Patients who are involuntarily committed lack decision-making capacity.
- ▶ Only mental health experts can assess decision-making capacity.

Debunking these myths will prevent errors in the clinical assessment of decision-making capacity.

Why is assessing capacity so important?



1/2/2017

Because...

Decision-making capacity is NOT an “all or nothing” phenomenon.

To support your ability to make decisions, it is important to understand how comfortable you are making each decision, and when you need help.

Then you are able to seek the level of help you need...for each decision.

Capacity is a spectrum of ability...

SPECTRUM OF CAPACITY IN DECISION-MAKING

- ▶ Judgment about an adult's "incapacity" will call for a review on the facts of each adult. An adult is considered to have capacity to make decisions until the Court of Chancery of Delaware determines the adult lacks capacity.

No impairment of Capacity

Some impairment of Capacity

Significant impairment of capacity

Lacks decision-making capacity

- No restriction on decision making.
- Understands the nature and intent of documents and can execute documents, such as an AHCD, POA, Will, and contracts.
- Understands both simple and/or complex fact presentations and is able to process information.
- Can make decisions with or without assistance.
- May seek assistance if helpful.
- No restriction on decision making.
- May still execute documents including AHCD, POA/DPOA, Contract, Will and Supported Decision Maker Agreement; if adult understands the nature and intent of document.
- May need assistance with understanding or processing information to make simple and/or complex decisions.
- Attending doctor may determine that adult cannot make any medical decisions; if there is an AHCD, it takes effect and determines care. If no AHCD, doctor may select a surrogate for medical decisions
- May still execute any documents, after evaluation of ability to understand the nature and intent of the document, including AHCD, POA/DPOA, Contract, Will and Supported Decision Maker Agreement.
- May not be able to understand or process information to make simple and/or complex decisions.
- Attending doctor may determine that adult cannot make any medical decisions; if there is an AHCD, it takes effect and determines care. If no AHCD, Dr. may name a Surrogate Decision Maker for medical decisions only.
- If there is a DPOA, it takes effect.
- Court of Chancery of Delaware will make determination, if a petition is filed, of mental incapacity and may appoint a guardian of property and/or person
- Lacks sufficient understanding to execute any legal documents.
- Is not able to understand or process information to make simple and/or complex decisions.
- Attending doctor documents that adult cannot make medical decisions or decisions necessary to keep the person safe; if there is an AHCD, it takes effect and determines care. If no AHCD, Dr. may name a Surrogate Decision Maker for medical decisions only.
- If there is a DPOA, it takes effect.
- Court of Chancery of Delaware will make determination, if a petition is filed, of mental incapacity and may appoint a guardian of property and/or person

Alternatives for Decision-Making

When you can still decide some things:

- ▶ Supported Decision Making
- ▶ Representative/Substitute Payee
- ▶ Case/Care management systems
- ▶ Community advocacy systems/agencies
- ▶ Release forms
- ▶ Durable Power of Attorney (not for healthcare)

When you lack decision-making capacity:

- ▶ Healthcare Surrogacy
- ▶ Advanced Health-care directives
- ▶ Durable Power of Attorney
- ▶ Guardianship

Supported Decision Making

16 Del.C. Chapter 94A

- ▶ Supported Decision Making is a new method of assisting people in making decisions and functioning independently without using guardianship or delegating decision-making to someone else.
- ▶ A consortium of stakeholders including the Division of Developmental Disabilities Service, the Disabilities Law Program, the Developmental Disabilities Council, and the Office of the Public Guardian have guided legislation to create a legal structure for Supported Decision Making.
- ▶ Chapter 94A empowers a person who has capacity but needs help in making decisions to appoint a Supporter in a written agreement to assist that person in managing their affairs.

Definition of Supported Decision Making

- ▶ “a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate decisions about the individual’s life.”

-Robert Dinerstein, 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, 19 Human Rights Brief 8, 10 (Winter 2012).

Highlights of Supported- Decision Making

- ▶ Individual who needs assistance is provided the supports necessary to make a decision and communicate or implement that decision.
- ▶ Trusted individuals, including family members, friends, professionals, will commit to help explain to the person in simple language about possible choices and the impact of those choices.

Elements of Supported Decision Making

Adult may enter in to a supported decision-making agreement when the following apply:

- ▶ It is voluntary.
- ▶ The adult understands the nature and effect of the agreement.
- ▶ Designation of at least 1 supporter.
- ▶ Identify the types of decisions for which the supporter is authorized to assist.
- ▶ Identify the types of decisions for which the supporter may not assist.

Elements of Supported Decision Making

- ▶ The agreement must be in writing.
- ▶ The agreement must be dated.
- ▶ The agreement must be signed by each party in the presence of 2 eligible adult witnesses.
- ▶ Individuals who can serve as witnesses is limited by section 9405A(e) of the statute.
- ▶ The agreement must be accompanied by a declaration page, signed by each supporter and in the presence of witnesses.
- ▶ Declaration page must contain the supporter's relationship to the adult; the supporter's willingness to act as a supporter and supporter's acknowledgement of the duties of a supporter.

Selecting a Supporter

- ▶ Should be someone you trust, and who you are comfortable sharing information with.
- ▶ Who is available and willing to act, including able to contact people and gather information.
- ▶ Do your homework in selecting a supporter, and proceed with caution.
- ▶ The supporter should act in your best interests and in accordance with your wishes.
- ▶ You have every right to revoke the agreement if the supporter you chose is not helping you or a good choice for you. You may pick another supporter.

Additional Points



- ▶ Statute requires third parties to honor the Supported Decision Making Agreement.
- ▶ You may have to sign a HIPAA release form in some circumstances anyway...
- ▶ You may have to sign a release for educational purposes (FERPA)

How does this work in real life?

- ▶ It is difficult to know how this will work for you in real life.
- ▶ Remember it is just like something you likely already do, in asking people for help and advice, or having them sit with you at the doctor to listen to the instructions or other information. The form formalizes a relationship you may already have.
- ▶ As noted above, you may be asked to sign additional documents to enable your supporter access. This is similar to what occurs with other decision-making documents.
- ▶ Recommend Supporter accompany the Principal, if possible, at least the first time when presenting the agreement.

Glossary

- ▶ AHCD: Advanced Health Care Directive.
- ▶ FERPA: Family Educational Rights and Privacy Act.
- ▶ HIPAA: Health Insurance Portability and Accountability Act.
- ▶ Supporter: Means a person who is named in a supportive decision making agreement, and is not prohibited from acting.
- ▶ Principal: Means a n adult who seeks to enter, or has entered, into a supported decision-making agreement.

Resources

- ▶ Ten Myths About Decision-Making Capacity, A Report by the National Ethics Committee of the Veterans Health Administration”, September 2002; National Center for Ethics in Health Care, Veterans Health Administration, Dept. of Veterans Affairs.
- ▶ “Competency and the Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians”, Raphael J. Leo, M.D., Prim Care Companion J Clin Psychiatry 1:5, October 1999.



1/2/2017

21



