Supported Decision-Making in Maine

Margaret Cardoza, Self-Advocate
Nell Brimmer, Esq., Managing Attorney, Disability Rights Maine
Agenda

MAKING SDM A REALITY IN MAINE - GRASSROOTS ADVOCACY AND DISABILITY RIGHTS LAW

- History
- Impact
- Challenges
- Work To Do
Who we are

MARGARET CARDOZA
SELF ADVOCATE

NELL BRIMMER
MANAGING ATTORNEY
DISABILITY RIGHTS MAINE
History of Self Advocacy in Maine

- Pineland: Maine's institution
  - closed by a class action lawsuit in 1996

- As a result, people discovering their world for the first time
  - de-programming
  - fighting institutional thinking
The Maine Self-Advocacy Movement

PAIGE BARTON, CREATOR OF SPEAKING UP FOR US (SUFU)

Paige received independent living services. Today, SUFU is Maine's largest self-advocacy organization.

PAIGE LEFT HER POSITION WITH A SERVICE PROVIDER TO WORK IN THE STATE'S DHHS

Hired to do self-advocacy work on behalf of DHHS

MARGARET TOOK OVER PAIGE'S POSITION IN 1997 AT THE SERVICE PROVIDER
Margaret's Work

THE WORK OF SELF-ADVOCACY

- ACCESSIBILITY
- ACCOMMODATIONS
- COMMUNITY INVOLVEMENT
  - Transportation in Maine - advocating for commuter train
- ALWAYS AN IDENTIFIED PROBLEM WITH GUARDIANSHIP
  - Difficult working relationship with guardians
  - Confronted with guardians and the line was drawn; guardian authority was law
### Introduction to SDM - Self-Advocacy

<table>
<thead>
<tr>
<th>MARGARET SEES JENNY HATCH ON TV - REACHES OUT TO JONATHAN MARTINIS</th>
<th>RESEARCH AND WORK TO DESIGN SDM TRAININGS FOR SELF ADVOCATES</th>
<th>SELF ADVOCATES AND DISABILITY RIGHTS MAINE ATTORNEYS VISIT PROBATE JUDGE</th>
<th>MARGARET CONCLUDED WORK AS RESULT OF MEETING HER MISSION</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do we bring this to Maine?!</td>
<td>Started SDM trainings as Self-Advocate Coordinator</td>
<td>Discussion of SDM as an alternative to guardianship</td>
<td>She knew SDM was the solution</td>
</tr>
</tbody>
</table>

www.supportmydecision.org
Introduction to SDM: Disability Rights Maine

**DRM ATTORNEY RETREAT SUMMER 2013**
Committee Formed: Seeking to identify alternatives to guardianship

**RESTORATION OF RIGHTS**
Representation of Clients in Probate Court to Terminate Guardianships

**COLLABORATION**
Self Advocacy and DD Network

**SUPPORTED DECISION-MAKING COALITION**
Formed in 2015

www.supportmydecision.org
Dear Friends;

The Disability Rights Center is applying for a $5000.00 grant from the National Resource Center for Supported Decision-Making and we want your partnership!

The Disability Rights Center has been working hard to get people out from under or stop people from going under unnecessary and destructive guardianship. But we want more. DRC wants guardianship in Maine to be replaced with supported decision making, a model offering natural and professional supports to assist people in making independent decisions. And we need a team of partners!

DRC lawyers are representing individuals in terminating or limiting their guardianship and our Guardianship Team has trained hundreds of individuals and guardians about alternatives to guardianship but we realize we could keep doing these individual cases forever! So we are creating materials and developing more trainings, creating a continuing legal education course for attorneys working with individuals threatened with guardianship, and advocating for supported decision making as the first consideration before anything that limits self-determination.

We know $5000. will not go very far but we also know we can use the writing of this proposal to figure out who is with us and how to expand our work! We are excited.

I’ll tell you more about what we are proposing but first, the ask! Will you come or send someone to a meeting in May or June, to share ideas about how to move supported decision making in Maine. Basically, will you join Maine’s Supported Decision Making Coalition? We will need quarterly meetings I think.

Please let me know by the end of this week if you can be involved in this vitally important coalition!

Thank you! And feel free to forward this to others I’ve missed. Just be sure to ask them to get back to me. Thank you again.
## Timeline of SDM Work in Maine

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
</table>
| 2015 | - Maine Supported Decision-Making Coalition Formed to Bring SDM to Maine  
- DRM receives seed grant from the National Resource Center on Supported Decision-Making (NRC-SDM) |
| 2016 | - OCFS includes SDM in its Guide to Transition Services in Maine  
- supportmydecision.org launched |
| 2017 | - Maine Probate and Trust Law Advisory Committee (PATLAC) recommends inclusion of SDM in the Probate Code  
- DRM receives 2nd seed grant from the National Resource Center on Supported Decision Making (NRC-SDM) |
| 2018 | - Maine passes legislation to include SDM in Probate Code  
- Knox County Probate Court terminates guardianship in favor of SDM  
- OADS awarded ACL grant to enhance APS system by incorporating SDM |

www.supportmydecision.org
Key Partnerships

NATIONAL RESOURCE CENTER FOR SUPPORTED DECISION-MAKING (NRC-SDM)

Maine was a 2 time grant recipient

SUPPORTED DECISION-MAKING NEW YORK (SDMNY)

Delegation from Maine went in September 2018 to learn from their work on facilitation

TRAININGS AND OUTREACH

National Disability Rights Network Annual Conferences, Online Trainings, Recent Developments
Trainings

- Individuals who receive services
- Transition-age young adults and their families
- Judiciary/members of the bar/Probate Court staff
- State Actors: Office of Aging and Disability Services/Adult Protective Services (act as public guardian in Maine)
- Case Managers
- Parent Groups
# The Work of Outreach

## Building Capacity in Maine

<table>
<thead>
<tr>
<th>Person Centered Planning (PCP) Meetings</th>
<th>Collaboration and Connection</th>
<th>SDM Workbook</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attorneys and Advocates providing materials at meetings to individuals and their teams</td>
<td>Continuation of partnership and community building</td>
<td>Creation of a User's Guide - ability to provide materials that can be used to facilitate the process of SDM</td>
</tr>
</tbody>
</table>
Maine signs the new Probate Code into law March 2018 with a promulgation date of July 2019.

Maine's Probate Code has not been updated since the 1970's.

Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act

A desire for SDM to be a protective device with court oversight

Substantive changes proposed
Considerations

MAKING CONNECTIONS AND AND CREATING SUPPORTS

Creating supports naturally is preferable to calling them "natural supports"

ISOLATION

Maine is a large, rural state with long winters

HOW TO ENSURE THE DECISION-MAKER'S DECISIONS ARE HONORED

Am I making the final decision?
Ensuring Decisions Are Honored

When seeking out help for a decision, all people want these qualities in a supporter:

- Be UNBIASED, NON-JUDGMENTAL, and NOT PERSUASIVE
- Provide access to information
- Provide ACCOMMODATIONS to communicate and understand each other
- Is the RELATIONSHIP balanced or is one person paid? Is the relationship mutual or are there ulterior motives?