Systems Change to Promote Rights: A Supported Decision Making Initiative and National Core Indicators Data
National Core Indicators (NCI)
State Members 2014-15

- 42 states
- District of Columbia
- 22 sub-state regions

CA* - Includes 21 Regional Centers
OH* - Also includes the Mid-East Ohio Regional Council
# Exercising Rights

<table>
<thead>
<tr>
<th>Rights</th>
<th>No guardianship</th>
<th>Limited guardianship</th>
<th>Full guardianship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can be alone with friends or visitors at home</td>
<td>81%</td>
<td>75%</td>
<td>71%</td>
</tr>
<tr>
<td>People ask before entering home</td>
<td>91%</td>
<td>89%</td>
<td>88%</td>
</tr>
<tr>
<td>Uses phone or internet without restriction</td>
<td>92%</td>
<td>90%</td>
<td>87%</td>
</tr>
</tbody>
</table>

Source: NCI-DD Adult Consumer Survey data 2013-14
## Exercising Choice

<table>
<thead>
<tr>
<th>Choice – Made decision or had some input into decision</th>
<th>No guardianship</th>
<th>Limited guardianship</th>
<th>Full guardianship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>62%</td>
<td>46%</td>
<td>41%</td>
</tr>
<tr>
<td>Roommates</td>
<td>54%</td>
<td>42%</td>
<td>35%</td>
</tr>
<tr>
<td>Staff (day &amp; residential)</td>
<td>69%</td>
<td>64%</td>
<td>60%</td>
</tr>
<tr>
<td>Daily schedule</td>
<td>90%</td>
<td>79%</td>
<td>77%</td>
</tr>
<tr>
<td>What to buy</td>
<td>93%</td>
<td>83%</td>
<td>81%</td>
</tr>
</tbody>
</table>

Source: NCI-DD Adult Consumer Survey data 2013-14
# Employment

<table>
<thead>
<tr>
<th>Employment</th>
<th>No guardianship</th>
<th>Limited guardianship</th>
<th>Full guardianship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrated employment goal in service plan</td>
<td>30 %</td>
<td>22 %</td>
<td>21 %</td>
</tr>
<tr>
<td>Had community paid job during past 2 weeks</td>
<td>19 %</td>
<td>13 %</td>
<td>12 %</td>
</tr>
</tbody>
</table>

Source: NCI-DD Adult Consumer Survey data 2013-14
## Relationships

<table>
<thead>
<tr>
<th></th>
<th>No guardianship</th>
<th>Limited guardianship</th>
<th>Full guardianship</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Has friends who are not family or staff</strong></td>
<td>78%</td>
<td>74%</td>
<td>73%</td>
</tr>
<tr>
<td><strong>Can date without restrictions</strong></td>
<td>71%</td>
<td>68%</td>
<td>58%</td>
</tr>
</tbody>
</table>

Source: NCI-DD Adult Consumer Survey data 2013-14
## Personal Characteristics

<table>
<thead>
<tr>
<th>Co-occurring:</th>
<th>No guardianship</th>
<th>Limited guardianship</th>
<th>Full guardianship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild level ID</td>
<td>49%</td>
<td>33%</td>
<td>28%</td>
</tr>
<tr>
<td>Use speech to communicate</td>
<td>85%</td>
<td>72%</td>
<td>65%</td>
</tr>
<tr>
<td>Live with parents or other relatives</td>
<td>38%</td>
<td>29%</td>
<td>33%</td>
</tr>
</tbody>
</table>

Source: NCI-DD Adult Consumer Survey data from 2013-14
NCI Guardian Status Tracking

2015 New Question
If under guardianship, guardian’s relationship to person:
- Family
- Friend
- Employee of state or guardianship agency
- Other

NCI 2013-14
Adults with I/DD receiving services in NCI states:
- No guardian - 48%
- Limited guardian - 7%
- Full guardian - 43%
- Don’t know - 2%
Massachusetts SDM Pilot

- Partnership between CPR & Nonotuck Resource Associates
- Among the first SDM demonstrations in the nation
- Individuals with I/DD enter into Agreements with supporters in areas such as health, relationships, finances, employment
  - CPR provides legal representation as necessary
  - Nonotuck care managers act as liaisons between the individual, his/her network and the community
- Advisory Council reviews progress, offers guidance
- Independent evaluation
SDM Pilot Advisory Council

Representatives include:
• People using state services
• Legal scholars in disability issues
• Judges
• Attorneys
• Medical professionals
• Directors of social service organizations
My Role as a SDM Facilitator

- Care Manager for 5 of 8 participants
- Provide information to families and supporters about SDM
- Facilitate SDM meetings with participants, CPR-Nonotuck team
- Help SDM participants understand SDM and SDM Agreement
- Assure person’s voice is heard and person is satisfied
- Collect information on how SDM is used
- Participate in pilot evaluation
My Role as an SDM Supporter

- Support decision-making: demonstration, role-playing
- One-on-one conversations laying out pros and cons
- Know how person makes decisions (for example, wait 6 minutes for Amanda’s response)
- Respect person’s values and preferences ... and decisions
- Lots of meetings! Lots of conversations!
Amanda’s SDM Arrangement

Decision Support Areas:
Health care, Legal, Finances, Home and Personal Life

Chose 4 Supporters:
- Mother
- Live in caregiver since 2009
- Respite worker
- Care Manager-friend-respite worker
Resources

- SDM Pilot website: www.supporteddecisions.org
  (Website is expected to launch in July 2015.)

- SDM Pilot Handouts:
  - Representation Agreement
  - Brochure

- National Core Indicators (NCI) website: www.nationalcoreindicators.org

- NCI data brief on Rights & Respect. Explores extent to which public I/DD services are delivered in ways that respect service recipients' privacy, choices, and control. Highlights significant differences by race and ethnicity, guardianship status, residence type, and other variables. Presents promising innovations and programs preserving rights and respect:
  www.nationalcoreindicators.org/resources/data-briefs
Contact Us!

Elizabeth Pell, Policy Associate  
Human Services Research Institute  
2336 Massachusetts Ave  
Cambridge, MA 02140  
617-844-2307  
epell@hsri.org

Maggy Walto, Care Manager & Supporter  
Nonotuck Resource Associates  
14 Park Place  
Lee, MA 01238  
413-588-2971  
walto@nonotuck.com

Deborah A. Dorfman, Senior Attorney  
Center for Public Representation  
22 Green Street  
Northampton, MA 01060  
413-586-6024  
ddorfman@cpr-ma.org

Amanda Benoit  
SDM Pilot Participant  
Nonotuck Resource Associates  
Contact Amanda through Maggy

Paige Emerson  
SDM Advisory Council member  
Nonotuck Resource Associates  
Contact Amanda through Maggy