Supporting Families: National Trends
We have the Opportunity to Reframe Our Thinking from Building Systems That Deliver Services to Systems That Support Families and Individuals
The Supporting Families Framework

• Discovery and Navigation
• Connecting and Networking with Others
• Services and Goods Directed to Family Unit
Why Support Families?

- Families are the core unit in our society, serving as a source of support for all of its members.
- Values about work, community and contribution come from families.
- For individuals I/DD, the role of family is unique and often central across the lifespan.
- Families play key roles in identifying and securing opportunities
  - to participate in meaningful ways with in their community
  - ensuring access to self-determined lives.
- Parents and other family members of individuals with I/DD often provide medical, behavioral, financial, and other daily supports beyond what most families provide.
- Yet, the vital role of families is not fully recognized and supported in disability policy and practices.
Why Support Families - Why Now?

- Families often are faced with emotional, social, physical and economic demands that they may not have experienced had their child not been diagnosed with a disability.
- 28% of children with disabilities live below the federal poverty threshold as compared with 16% of children without disabilities\(^4,5,6\).
- Parents of children with disabilities have lower rates of and diminished opportunities for employment and advancement than parents of children without disabilities\(^2,7\).
- Over 58% of parents/caregivers report spending more than 40 hours per week providing support for their loved one with I/DD, including 40% spending more than 80 hours a week\(^2\).
- A growing number of individuals with I/DD live in households where the primary caregivers are themselves aging.
- Yet, states are relying on families to provide a greater proportion of supports and services than ever before while committing less than 5% of spending toward supporting families.
Why Support Families? Why Now?

• Demands for services that support individuals with I/DD are increasing, while at the same time both state and federal funds are diminishing.
• State DD agencies are under enormous pressure to reconfigure systems to reduce expenditures and improve efficiency.
Let’s look at the data

As we look at each slide what is the story you can tell based on the data.
Significant Numbers are Waiting for Services

Low Estimate (State Reported State Agency Reports of People Needing Residential Services Within Next 12 Months): 122,870

High Estimate (Kaiser Family Foundation): 240,000

Data not reported by: MS, NJ, NC, OH, TX, or WA

Source: UMN RTC/ICI
REDUCTIONS IN STATE ONLY FUNDING: FY2009

State only funding includes state Medicaid matching funds, state general fund, special state funds and local government funding.

How does the average annual cost of providing Medicaid Waiver services to people with IDD differ by age and living arrangement?

For children and youth with IDD ages birth to 21 years:

- $19,310: Overall average annual Waiver expenditures across all living arrangements.
- $14,950: Average annual Waiver expenditures for people living in the home of a family member.
- $44,775: Average annual Waiver expenditures for people living in any other setting.

For adults with IDD ages 22 years or older:

- $43,493: Overall average annual Waiver expenditures across all living arrangements.
- $24,515: Average annual Waiver expenditures for people living in the home of a family member.
- $57,075: Average annual Waiver expenditures for people living in any other setting.
Re-evaluating current services – How many could be served?

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>Cost per Person</th>
<th>Cost to Serve the Waiting List</th>
<th>People Served with $5 M</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICF/MR</td>
<td>$128,275</td>
<td>$15,761,149,250</td>
<td>39</td>
</tr>
<tr>
<td>Non-family HCBS</td>
<td>$70,133</td>
<td>$8,617,241,710</td>
<td>71</td>
</tr>
<tr>
<td>Host Family</td>
<td>$44,122</td>
<td>$5,421,270,140</td>
<td>113</td>
</tr>
<tr>
<td>Own Family</td>
<td>$25,072</td>
<td>$3,080,596,640</td>
<td>200</td>
</tr>
</tbody>
</table>
A growing number of adults are living in the family home

Charlie Lakin UMinn RTC on Community Living/ICI
Families as Primary Care Givers

Place of Residence for Service Recipients with IDD 1998 - 2011

RISP 2011, RTC on Community Living UCED U of Minnesota

<table>
<thead>
<tr>
<th>Year</th>
<th>Own Home</th>
<th>Family</th>
<th>Host Home</th>
<th>1 to 6</th>
<th>7 to 15</th>
<th>16+</th>
<th>Nursing Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
<td>62,669</td>
<td>325,650</td>
<td>28,122</td>
<td>108,84</td>
<td>53,940</td>
<td>89,348</td>
<td>24,144</td>
</tr>
<tr>
<td>1999</td>
<td>65,006</td>
<td>355,190</td>
<td>31,884</td>
<td>114,54</td>
<td>52,863</td>
<td>82,718</td>
<td>25,533</td>
</tr>
<tr>
<td>2000</td>
<td>73,147</td>
<td>391,850</td>
<td>37,367</td>
<td>124,46</td>
<td>52,818</td>
<td>82,582</td>
<td>32,195</td>
</tr>
<tr>
<td>2001</td>
<td>80,242</td>
<td>451,670</td>
<td>40,688</td>
<td>135,32</td>
<td>54,333</td>
<td>77,180</td>
<td>34,820</td>
</tr>
<tr>
<td>2002</td>
<td>86,694</td>
<td>482,470</td>
<td>42,272</td>
<td>135,57</td>
<td>54,031</td>
<td>72,742</td>
<td>35,155</td>
</tr>
<tr>
<td>2003</td>
<td>90,597</td>
<td>500,000</td>
<td>45,759</td>
<td>135,56</td>
<td>54,325</td>
<td>72,474</td>
<td>35,005</td>
</tr>
<tr>
<td>2004</td>
<td>107,15</td>
<td>503,640</td>
<td>39,857</td>
<td>142,91</td>
<td>58,503</td>
<td>69,148</td>
<td>32,899</td>
</tr>
<tr>
<td>2005</td>
<td>101,14</td>
<td>533,040</td>
<td>35,386</td>
<td>156,61</td>
<td>52,888</td>
<td>66,501</td>
<td>30,027</td>
</tr>
<tr>
<td>2006</td>
<td>104,38</td>
<td>569,020</td>
<td>35,302</td>
<td>157,08</td>
<td>56,572</td>
<td>66,125</td>
<td>28,206</td>
</tr>
<tr>
<td>2007</td>
<td>115,65</td>
<td>576,160</td>
<td>36,972</td>
<td>157,76</td>
<td>59,002</td>
<td>62,496</td>
<td>26,013</td>
</tr>
<tr>
<td>2008</td>
<td>115,87</td>
<td>588,590</td>
<td>38,262</td>
<td>160,47</td>
<td>53,198</td>
<td>59,447</td>
<td>26,080</td>
</tr>
<tr>
<td>2009</td>
<td>122,08</td>
<td>599,150</td>
<td>40,967</td>
<td>158,62</td>
<td>58,235</td>
<td>59,604</td>
<td>29,608</td>
</tr>
<tr>
<td>2010</td>
<td>127,45</td>
<td>592,180</td>
<td>40,060</td>
<td>167,87</td>
<td>55,682</td>
<td>57,028</td>
<td>31,832</td>
</tr>
<tr>
<td>2011</td>
<td>120,31</td>
<td>610,290</td>
<td>44,214</td>
<td>172,76</td>
<td>57,486</td>
<td>55,572</td>
<td>33,661</td>
</tr>
</tbody>
</table>
State Profile 4: 2013 Waiver Recipients - Total and Living in Family Home

- Total Waiver Recipients
- Waiver Recipients in Family Home
Implication for Policy

Developmental disability service systems transformation:

1. Disability policies must acknowledge the family as a vital partner,

2. Disability policies must include the recognition of the family for their key role across the lifespan

3. Policies must create pathways for the supports necessary for the family to serve in this often lifelong role.

4. Supports to the family unit must be a fundamental consideration in budgetary and long-term care policy as our nation moves forward.
Defining Family Support
National Agenda on Supporting Families Family Support Defined

“Family Support is a set of strategies targeting the family unit but that ultimately benefit the individual with I/DD. Strategies must be designed, implemented and funded in a manner directed by the family unit. They should be flexible, comprehensive, and coordinated.”

http://www.familysupportagenda.org/FSNA/
People with disabilities and their families...

have access to resources and supports, that are person and family centered and directed, that enhance individual lives and maintain the family well-being.
## Strategies for Supporting Families

<table>
<thead>
<tr>
<th>Discovery and Navigation</th>
<th>Connecting and Networking with Others</th>
<th>Services and Goods Directed to Family Unit</th>
</tr>
</thead>
</table>
| • Best practices and values within and outside of disability services | • Family-to-Family Support  
  • Self-advocacy organizations  
  • Sib-shops  
  • Support Groups  
  • Professional Counseling  
  • Non-disability community support | • Planning for current and future needs  
  • Respite/Childcare  
  • Adaptive equipment  
  • Crisis prevention and intervention  
  • Systems navigation  
  • Home modifications  
  • Health and wellness management |
| • Accessing and coordinating community supports |                              |                                            |
| • Advocacy and Leadership skills |                              |                                            |
| • Useful information |                              |                                            |
STRATEGIES FOR SUPPORTING FAMILIES ACROSS THE LIFESPAN

Goal: To support families, with all their complexity and diversity, in ways that maximizes their capacity, strengths and unique abilities so they can best support, nurture, love and facilitate the achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life for their family members.

working definition from AIDD National Agenda on Family Support Wingspread Conference, 2011

<table>
<thead>
<tr>
<th>Discovery and Navigation</th>
<th>Networking and Community Connections</th>
<th>Services and Goods Directed to the Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge and Skills</td>
<td>Emotional Supports</td>
<td>Day-to-Day Needs</td>
</tr>
<tr>
<td>• Information on disability</td>
<td>• Family-to-Family Support</td>
<td>• Futures planning</td>
</tr>
<tr>
<td>• Information about generic supports</td>
<td>• Self-advocacy organizations</td>
<td>• Service Coordination</td>
</tr>
<tr>
<td>• Knowledge about best practices and values</td>
<td>• Sib-shops</td>
<td>• Personal assistance</td>
</tr>
<tr>
<td>• Skills to navigate and access services</td>
<td>• Support Groups</td>
<td>• Employment services</td>
</tr>
<tr>
<td>• Ability to advocate for services and policy change</td>
<td>• Professional Counseling</td>
<td>• Respite</td>
</tr>
<tr>
<td></td>
<td>• Non-disability community support</td>
<td>• Adaptive equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Home modifications</td>
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<tr>
<td></td>
<td></td>
<td>• Paying family caregivers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Financial planning/trusts</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Promote health and wellness</td>
</tr>
</tbody>
</table>

What is DHS currently doing to support these strategies?

- CYSHCN Regional Centers
- B-3 Coaching approach
- Exploration of family training
- CLTS website
- WI First Step
- ADRCs
- CYSHCN Parent-to-Parent Program
- Guide by Your Side Program
- Circles of Life Conference
- WI Community of Practice on Autism
- Wisconsin Statewide Parent-Educator Initiative (WSPEI)
- Wisconsin Statewide Transition Initiative
- Foster Care Medical Home
- Children’s Waivers
- Children’s COP
How do we use Supporting Families strategies?

• Medical settings
• Schools
• Community supports
• Birth-3
• Our families
Staying Connected

• Community of Practice for Supporting Families of Individuals with IDD
  http://supportstofamilies.org/cop/

• Wingspread Report