## Keeping the Community Promise: Lifting the Cap on Long-Term Care in Wisconsin



"Please think seriously about what the cap will mean to thousands of families just like mine. I pray you will find the right reasons for doing what you know is right."

- Lynda Babino, Waupaca

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The Survival Coalition is comprised of over 40 statewide groups representing people with all disabilities and all ages, their family members, advocates, and providers of disability services. For over 20 years, Survival has been at the forefront of promoting cost effective, community-based services and supports for people with disabilities.

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# **Keeping the Community Promise: Lifting the Cap on Long-Term Care in Wisconsin**

W isconsin is at a crossroads in the journey to reform long term care. For decades we have made bipartisan progress in keeping our older adults and people with disabilities in their homes and out of costly institutions. As Governor Tommy Thompson predicted years ago, we have been leading the nation with our values and investment.

It was the evening of January 20, 1998 when then Governor Thompson proclaimed he was introducing a revolutionary new program called Family Care that would give families "security, peace of mind and hope for the future" – setting the standard for the nation.

Since that time Family Care and its sister community-based long-term care programs like IRIS, Partnership, legacy waivers and long-term care waivers for children have accomplished much of this original vision in the eyes of families. Before the legisla-

In 1998, Governor Thompson introduced Family Care, which he said would give families "security, peace of mind and hope for the future."

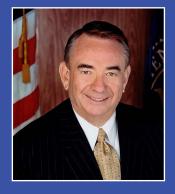
ture voted to establish a right to long-term care in the community, people languished on wait lists and many found their only option was to be forced into a nursing home. A recent review by the Legislative Audit Bureau confirms that the popular Family Care program has improved access to long-term care in the community and offers people with disabilities and older adults choices that meet their needs.

Even before 1998, bi-partisan Wisconsin legislatures made a commitment to community-based long-term care in a "Community Promise", partly because care in the community had proven its cost-effectiveness.

Family Care alone has been carefully evaluated. Various external studies reveal consistently that the alternative to care in the community, a bed in a nursing home, costs significantly more and Wisconsin's innovative models of managed care and self-direction have great potential.

Like Governor Thompson, Governor Walker had been a champion of community care. It was just August 2010 when soon-to-be Governor Scott Walker, while highlighting his own state Assembly vote for Family Care said, "If I did nothing else I wanted to make sure Milwaukee County expanded Family Care to people under the age of 60 with developmental and physical disabilities, so that they in turn could see that waiting list eliminated like we did for older adults in this community."

We clearly can eliminate the waiting list and we have an opportunity in the 2011-2013 biennium.



Former Governor Thompson

**1998 State of the State Address**State Capitol
January 20, 1998

Governor Thompson: "The greatest hope of our families is for a compassionate system of high quality choices so they can give their parents the very best care possible. Tonight, we unveil a revolutionary new program to meet the needs of our aging and ease the worries of their children. We call it Family Care...Family Care gives families security, peace of mind and hope for the future. It will set the standard for the nation."

\$2,800 vs. \$4,000: The average cost of Family Care is \$2,800 per month, whereas the average cost of a pursing home is \$4,000 per month. the average cost of a nursing home is \$4,000 per month.

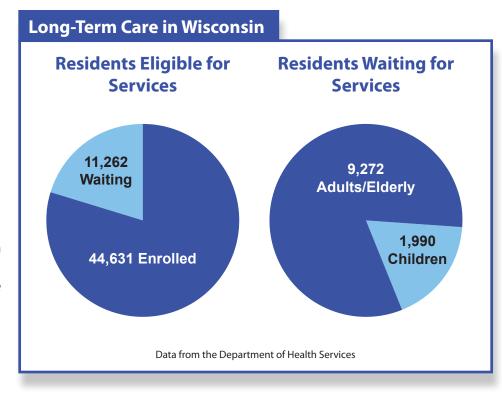
The 2011-2013 biennial budget now proposes to cap enrollment on all major long-term care programs, except nursing homes, even though the data shows the average cost of Family Care is \$2,800 per month versus the average nursing home cost of \$4,000 per month.

Older adults who have spent their personal retirement funds on private long-term care as their health and daily needs increase, now wonder if the Community Promise will hold true for them when they need it. Will they be able to stay in their homes?

Families of young adults with disabilities leaving high school fear they will graduate to nothing.

Those who have waited with the hope of their name being called off a list in a year or a few months are now in limbo indefinitely.

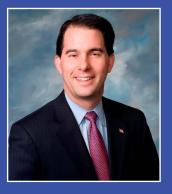
We can still keep the Community **Promise for Wisconsin.** 



This report serves to illustrate the value of the Community Promise, both in dollars and quality of life, and share the stories of the thousands of older adults, adults and children with disabilities who depend on our state's commitment to community-based long-term care.

A right to long-term care in the community is not only what is right for older adults and people with disabilities; it is right for the taxpayers of this state.

**Keep the Community Promise.** 



Governor Walker

### **2010 Primary Election Victory Speech** Milwauke<u>e</u> September 14, 2010

Candidate Scott Walker: "Before I took office, there was literally a waiting list of 3,000 older adults waiting for long-term care in our community. Today not one senior in our community is on a waiting list because we stood up and led the way. We can do it for the state as well."

## **Long-Term Care in Wisconsin**

### **Number of People Served and Waiting for Services by County**

Partnership/PACE   IRIS   CLT   Adults/   Clifforn   Children	County	Enrollments by Program,				People Waiting for Services,				
Adams NA	County									
Ashland   154			Partnership/PACE	IRIS	CLTS	Elderly		<u> </u>		
Barron   307	Adams	NA	NA	NA	33		11	24 months	25	
Beyfield   103	Ashland	164	NA	40	9	81 <sup>1</sup>	3	12 month	84	
Brown   NA	Barron	307	NA	67	48		24	8 month	177	
Buffalo	Bayfield	103	NA	14	15	81 <sup>2</sup>	0	0 months	81	
Burnet	Brown	NA	NA	NA	286		148	13 months	785	
Calumet         182         2         17         94         52         0         0 months         52           Chippewa         214         415         26         98         0         12         11 months         12           Clark         213         NA         26         31         280³         8         3 months         28           Columbia         372         42         41         71         0         39         60 months         39           Crawford         161         NA         5         24         27         0         Not reported         27           Dane         NA         961         NA         452         314         62         19 months         376           Dodge         314         29         50         68         40         55         Not reported         95           Dodg         314         29         50         68         40         55         Not reported         95           Dodg         318         33         11         10         5 months         124           Bull         40         33         1112         12         36 months         124	Buffalo	65	NA	34	18	280 <sup>3</sup>	0	Not reported	280	
Chippewa	Burnet	NA	NA	22	19	40	0	2 months	40	
Clark         213         NA         26         31         280 <sup>4</sup> 8         3 months         288           Columbia         372         42         41         71         0         39         60 months         39           Crawford         161         NA         524         277         0         Not reported         27           Dane         NA         961         NA         452         314         62         19 months         376           Dodge         314         29         50         68         40         555         Not reported         95           Door         NA         NA         NA         NA         10         5 months         34           Douglas         385         NA         50         33         1112         12         36 months         124           Dun         144         288         32         49         23         0         6 months         52           Eau Claire         350         984         109         148         27         28         0 months         55           Florence         NA         NA         NA         NA         NA         9         5 <td>Calumet</td> <td>182</td> <td>2</td> <td>17</td> <td>94</td> <td>52</td> <td>0</td> <td>0 months</td> <td>52</td>	Calumet	182	2	17	94	52	0	0 months	52	
Columbia         372         42         41         71         0         39         60 months         39           Crawford         161         NA         5         24         27         0         Not reported         27           Dodge         314         29         50         68         40         55         Not reported         95           Door         NA         NA         NA         NA         10         5 months         34           Douglas         385         NA         50         33         112         12         36 months         124           Dunn         144         288         32         49         23         0         6 months         23           Eau Claire         350         984         109         148         27         28         0 months         55           Florence         NA         NA         NA         NA         148         127         28         0 months         0           Forest         NA         NA         NA         NA         NA         NA         NA         12         0         0         0 months         0           Green         1,068	Chippewa	214	415	26	98	_	12	11 months	12	
Crawford         161         NA         5         24         27         0         Not reported         27           Dane         NA         961         NA         452         314         62         19 months         376           Dodg         314         29         50         68         40         55         Not reported         95           Door         NA         NA         NA         NA         NA         10         5 months         12           Door         NA         NA         NA         50         33         112         12         36 months         124           Dun         144         288         32         49         23         0         6 months         23           Forel Green         AN         NA         NA         NA         12         0         0         0 months         0           Forest         NA         NA         NA         12         0         0         0 months         0           Forest         NA         NA         NA         9         5         56°         52 months         61           Grant         248         NA         7         45	Clark	213	NA	26		280 <sup>4</sup>	8	3 months	288	
Dane         NA         961         NA         452         314         62         19 months         376           Dodge         314         29         50         68         40         55         Not reported         95           Dour         NA         NA         NA         26         74         10         5 months         84           Doun         144         288         32         49         23         0         6 months         23           Eau Claire         350         984         109         148         27         28         0 months         55           Florence         NA         NA         NA         NA         NA         10         0         0 months         55           Florence         NA         NA         NA         NA         10         0         0 months         0         0         0 months         0         0         Forest         NA         NA         NA         13         12         0         0         0 months         0         1         6         1         4         20         NA         13         13         11         1         1         1         1         1 <td>Columbia</td> <td>372</td> <td>42</td> <td>41</td> <td>71</td> <td>0</td> <td>39</td> <td>60 months</td> <td>39</td>	Columbia	372	42	41	71	0	39	60 months	39	
Dodge         314         29         50         68         40         55         Not reported         95           Door         NA         NA         NA         NA         26         74         10         5 months         84           Doun         144         288         32         49         23         0         6 months         23           Eau Claire         350         984         109         148         27         28         0 months         55           Florence         NA         NA         NA         12         0         0         0 months         0           Fored         NA         NA         NA         12         0         0         0 months         0           Forest         NA         NA         NA         9         5         56 <sup>5</sup> 52 months         61           Green Lake         158         NA         7         45         60         14         20 months         22           Green Lake         158         NA         7         13         41         11         9 months         52           Iowa         90         NA         13         17         55 <td>Crawford</td> <td>161</td> <td>NA</td> <td>5</td> <td>24</td> <td>27</td> <td>0</td> <td>Not reported</td> <td>27</td>	Crawford	161	NA	5	24	27	0	Not reported	27	
Door         NA         NA         NA         26         74         10         5 months         84           Douglas         385         NA         50         33         112         12         36 months         124           Dun         144         288         32         49         23         0         6 months         23           Eau Claire         350         984         109         148         27         28         0 months         55           Florence         NA         NA         NA         142         0         0         0 months         5           Forendulac         1,068         NA         46         83         NA         0         0 months         0           Forest         NA         NA         NA         132         27         218         15         12 months         219           Green         293         NA         7         45         60         14         20 months         52           Iowa         90         NA         13         41         11         9 months         52           Icon         52         NA         9         10         2         0	Dane	NA	961	NA	452	314	62	19 months	376	
Douglas         385         NA         50         33         112         12         36 months         124           Dunn         144         288         32         49         23         0         6 months         23           Eau Claire         350         984         109         148         27         28         0 months         55           Florence         NA         NA         NA         NA         12         0         0         0 months         0           Forent Lake         NA         NA         NA         9         5         56° 52 months         61         66         67 <t< td=""><td>Dodge</td><td>314</td><td>29</td><td>50</td><td>68</td><td>40</td><td>55</td><td>Not reported</td><td>95</td></t<>	Dodge	314	29	50	68	40	55	Not reported	95	
Dunn         144         288         32         49         23         0         6 months         23           Eau Claire         350         984         109         148         27         28         0 months         55           Florence         NA         NA         NA         12         0         0         0 months         0           Fored         NA         NA         NA         46         83         NA         0         0 months         0           Forest         NA         NA         NA         NA         9         5         56°         52 months         61           Grant         248         NA         32         27         218         1°         12 months         219           Green         293         NA         7         45         60         14         20 months         74           Green Lake         158         NA         7         13         41         11         9 months         52           Iowa         90         NA         13         17         55         1°         12 months         56           Iowa         90         NA         13         17	Door	NA	NA	NA	26	74	10	5 months	84	
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Florence	Dunn	144	288	32	49	23	0	6 months	23	
Fond du Lac         1,068         NA         46         83         NA         0         0 months         0           Forest         NA         NA         NA         NA         9         5         565         52 months         61           Grant         248         NA         32         27         218         1°         12 months         219           Green         293         NA         7         45         60         14         20 months         74           Green Lake         158         NA         7         13         41         11         9 months         52           Iowa         90         NA         13         17         55         1°         12 months         52           Iowa         90         NA         13         17         55         1°         12 months         52           Iowa         90         NA         9         24         4168         13         24 months         22           Jackson         183         NA         9         24         4168         13         24 months         22           Jackson         183         16         66         40         1	Eau Claire	350	984	109	148	27	28	0 months	55	
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Iowa         90         NA         13         17         55         17         12 months         56           Iron         52         NA         9         10         2         0         0 months         2           Jackson         183         NA         9         24         4168         13         24 months         429           Jefferson         684         66         40         116         174         90         72 months         264           Juneau         146         NA         17         28         45         2         6 months         47           Kenosha         1,006         52         83         149         NA         2         12 months         2           Kewaunee         NA         NA         NA         58         3         0         0 months         3           Lafayette         68         NA         3         12         27         1         18 months         28           Lafayette         68         NA         3         12         14         8         24 months         22           Lincoln         NA         NA         0         27         19         0 <td>Green</td> <td>293</td> <td>NA</td> <td>7</td> <td>45</td> <td>60</td> <td>14</td> <td>20 months</td> <td>74</td>	Green	293	NA	7	45	60	14	20 months	74	
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La Crosse         1,922         NA         58         138         NA         58         36 months         58           Lafayette         68         NA         3         12         27         1         18 months         28           Langlade         119         NA         5         12         14         8         24 months         22           Lincoln         NA         NA         0         27         19         0         0 months         19           Manitowoc         571         NA         64         88         261         0         0 months         261           Marathon         975         NA         80         80         294         61         24 months         355           Marinette         NA         NA         NA         23         148         47         3 months         195           Marquette         134         NA         7         18         8         0         0 months         17           Milwaukee         8,728         1,174         1,093         635         2,817         478         27 months         3,295           Monroe         345         NA         20         31	Kenosha	1,006	52	83	149	NA	2	12 months		
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### **Long-Term Care in Wisconsin**

#### **Number of People Served and Waiting for Services by County**

County	Enrollments by Program, DHS early 2011 data				People Waiting for Services, most current DHS data			
	Family Care	Partnership/PACE	IRIS	CLTS	Adults/ Elderly Waiting	Children Waiting	Children's Average Wait Time	Total Waiting
Portage	955	NA	20	85	NA	42	36 months	42
Price	147	NA	15	26	34	0	6 months	34
Racine	1,098	123	80	118	NA	46	12 months	46
Richland	374	NA	19	28	NA	8	24 months	8
Rock	NA	NA	NA	172	157	69	63 months	226
Rusk	142	NA	19	27	106	14	36 months	120
Saint Croix	271	27	133	135	147	88	67 months	235
Sauk	344	58	29	69	107	21	24 months	128
Sawyer	123	NA	26	8	70	0	2 months	70
Shawano	NA	NA	NA	48	36	0	0 months	36
Sheboygan	812	NA	46	74	47	0	10 months	47
Taylor	NA	NA	NA	18	1	0	0 months	1
Trempealeau	267	NA	19	33	41	17	Not reported	58
Vernon	247	NA	19	22	416 <sup>12</sup>	8	30 months	424
Vilas	NA	NA	NA	46	77	56 <sup>13</sup>	52 months	133
Walworth	389	NA	97	75	167	0	120 months	167
Washburn	176	NA	21	12	56	7	8 months	63
Washington	604	23	20	84	173	19	12 months	192
Waukesha	1,479	70	144	314	173	177	20 months	350
Waupaca	266	43	25	60	177	1	12 months	178
Waushara	207	NA	17	13	51	0	0 months	51
Winnebago	859	NA	172	183	318	0	0 months	318
Wood	785	NA	36	49	177	9	6 months	186
Totals	31,541*	4,492	3,292	5,306	9,272	1,990	Total Waiting	11,262

#### Notes

- 1. The Waitlist amount reflects a consolidation of the Ashland and Bayfield Counties Waitlists by DHS.
- 2. The Waitlist amount reflects a consolidation of the Ashland and Bayfield Counties Waitlists by DHS.
- 3. The Waitlist amount reflects a consolidation of the Buffalo, Clark, and Pepin Counties Waitlists by DHS.
- The Waitlist amount reflects a consolidation of the Buffalo, Clark, and Pepin Counties Waitlists by DHS.
   The Waitlist amount reflects a consolidation of the Forest, Oneida, and Vilas Counties Waitlists by DHS.
- 6. The Waitlist amount reflects a consolidation of the Grant and Iowa Counties Waitlists by DHS.
- 7. The Waitlist amount reflects a consolidation of the Grant and Iowa Counties Waitlists by DHS.
- 8. The Waitlist amount reflects a consolidation of the Jackson, Monroe, and Vernon Counties Waitlists by DHS.
- 9. The Waitlist amount reflects a consolidation of the Jackson, Monroe, and Vernon Counties Waitlists by DHS.
- 10. The Waitlist amount reflects a consolidation of the Forest, Oneida, and Vilas Counties Waitlists by DHS.
- 11. The Waitlist amount reflects a consolidation of the Buffalo, Clark, and Pepin Counties Waitlists by DHS.
- 12. The Waitlist amount reflects a consolidation of the Jackson, Monroe, and Vernon Counties Waitlists by DHS.

  13. The Waitlist amount reflects a consolidation of the Forest, Oneida, and Vilas Counties Waitlists by DHS.

#### **Descriptions of Wisconsin Long-Term Care Medical Assistance Programs:**

- Family Care integrates home and community-based services, institutional care, Medicaid personal care, and home health. Family Care does not pay for acute/primary health care costs, e.g. hospital stays, ER visits, medications.
- Partnership and PACE integrate a person's long-term care services, health and medical services (acute/primary care), and prescription medications. All medical care is integrated into the benefits.
- IRIS (Include, Respect, I Self-Direct) is a self-directed, long-term care option for elderly people and adults with disabilities where resources are creatively used to help the individual achieve the life they want with the support they need.
- Children's Long-Term Support (CLTS) waivers provide children with a variety of individualized services including in-home intensive treatment services.
- Legacy waivers are community-based long-term care programs (including the Community Options Program COP, and the Community Integration Program CIP) that are available to eligible individuals in counties prior to full implementation of Family Care or IRIS.

<sup>\*</sup> The total number of individuals served by Family Care and Family Care Partnership/PACE reflects all individuals served by county in addition to individuals receiving services that live outside of county service areas. Individuals receiving services outside of the county are not reported in this chart, but are included in the overall Family Care Enrollment and Family Care Partnership/PACE Enrollment.

## History of Long-Term Care in WISCONSIN

#### Late 1970s ◆

Wisconsin creates flexible long-term care services as an alternative to nursing homes. COP and CIP "legacy waivers" begin.

#### 1990s

Seniors, people with disabilities, counties and state officials develop a vision for the "Community Promise."

#### 1998

Governor Thompson introduces Family Care in the 1999-2001 budget; there is bi-partisan support in the Legislature; waiting lists begin to be eliminated in seven pilot counties.

#### 2000s

Wisconsin's investment in Family Care results in unprecedented levels of federal match funding for community-based care. New jobs are created in the long-term care industry.

#### 2003

The children's long-term care home- and community-based waiver program is created to provide family-centered services to children with developmental disabilities and other long-term care needs.

#### 2006

Governor Doyle announces plans to expand Family Care and eliminate waiting lists for community-based long-term care programs in all counties during the next five years.

#### 2008

The Department of Health Services, with bipartisan support from the Legislature, creates the nation's most progressive self-directed long-term care option called IRIS. IRIS becomes available in every county offering Family Care.

#### 2010

As of June 2010, Family Care operated in 53 counties and served 28,885 participants. Program expenditures totaled \$936.4 million in fiscal year 2009-10. A December analysis shows two expansion counties would save money in Family Care.

#### 2011

Governor proposes to cap long term-care and reinstate waiting lists for older adults and people with disabilities in the 7 "No Wait" counties. Long-term supports are frozen for legacy waivers and children. DHS projects an increase in nursing home and institutional spending resulting from the cap.

#### 1980s

Demand for community-based services grows; Waitlists for support exceed 15,000.

#### 1995

The Department of Health Services begins an intensive process to redesign Wisconsin long-term care. Wisconsin was spending 50% more than the national average on each Medicaid-eligible elderly person and using nursing homes at a rate of 45% above the national average.

#### 1999

Wisconsin still relies heavily on expensive nursing homes. The state has 67.9 nursing home beds per 1000 population aged 65 or older, compared to 52.3 beds per 1000 elderly in the United States. Counties report that approximately 3,200 children were waiting for Family Support Services.

#### 2001

Counties report 9,478 adults waiting for long-term care services, 576 of whom were residing in nursing homes or other institutions. Length of wait time varies significantly among counties.

#### 2005

A federally required study of Family Care finds the program produced substantial savings for Wisconsin's Medicaid program.

#### 2006

The Legislature, with strong bipartisan support, adds funding to the 2007-2009 biennial budget to continue Family Care expansion.

#### 2009

County-based Aging and Disability Resource Centers complete long-term care eligibility determinations for 12,818 individuals.

#### 2011

Family Care and IRIS now operate in 57 counties. Approximately 42,300 people will be enrolled in the state's various long-term care programs as of June 2011. Several county adult wait lists are at zero. More than 3,000 children statewide wait for long-term supports.

#### 2011

Legislative Audit Bureau reports that Family Care has improved access to community-based long-term care and prevented people from being forced into expensive institutions. No fraud was found; consumer satisfaction is high. Family Care saves money compared to standard Medicaid. Cost-effectiveness is inconclusive.

### **Stories from Real Wisconsin People**



I am a substitute Sunday school teacher, I read to children at my local school, and I serve on community boards and speak at conferences as an advocate. I am also a person with a disability and I do have extensive medical needs. The people who help me through Family Care help me get dressed, make my meals and help me get into bed at night. I am grateful for this help. I have a full life! If you start putting caps on funding for people like me it is just going to lead to people getting sicker faster, going into nursing homes, which is not going to save the state a dime. I don't think I should be put into a nursing home when I am 44 years old. I live with that fear every day.

**Tami Weber, River Falls** 

Stuart Rabin, who is 25, has significant developmental disabilities and he lives with his family in an apartment in our home. As he has a severe condition, he has challenging support, behavior and medical needs. We are delighted with his quality of life using the IRIS program. Over the past three years, he has gone from using a wheelchair and a ramp with an expensive lock system (\$20,000+) in our van to using a walker and a less expensive auto access chair in the van (\$6,577). This more functional and less expensive option is a direct result of the Medicaid supports and services we have been able to use flexibly under his IRIS plan. While Stuart has intensive care needs, we keep in mind that we are responsible for decisions in using his budget wisely. I have many ideas on how to make this program better and more cost-effective. Please preserve this program for Stuart and other people with disabilities.







For many years my sister was in a nursing home supported by the tax dollar - about two times more expensive than the residence she lives in now. She has her own apartment with 24 hour care through Family Care. For many other people with disabilities (like my sister), on waiting lists for Family Care, the only other alternatives are the much more expensive nursing homes. Without Family Care, my sister would be unable to work - and thus not be contributing at all to the private business sector because she would instead be in a nursing home. Lifting the proposed budget caps on Community Long-Term Care Services is actually just common sense. Christopher A. Sigl, Hartford

I live in Mukwonago. I live in an adult family home. Before that I lived in a nursing home. It was really difficult to go into a place where you had to be institutionalized. What I mean by that is they schedule the way you think, the people you see, everything is the same order over and over and over again. It could have been called a prison. And I didn't deserve that. I am young I have things to do, people to see. I help out at ACAP. I am so free and I know this because I was in a place that was terrible and with all my heart I do not want to go back to that kind of thing. It would absolutely destroy me.

My son will be turning 18 this year. I adopted him at the age of 6 and for the last 11 years have lived with behaviors that many have said I should have given him back to the state because it was just too much. I love my son and would never even consider surrendering him back to the state, but I am living with fibromyalgia and chronic pain and his father is disabled. Both he and I will no longer be able to care for our son within our home... but he has the ability to live, with help, in the community as independent as possible. But because of this cap, he might not be able to get the services needed for him to live on his own.

Lynda Babino, Waupaca

Laura Nicosia, Mukwonago

### **Stories from Real Wisconsin People**

My son Tyler is no different than most 13 year old boys except that he has Down syndrome and autism. He enjoys going to school, playing baseball, and serving mass. I am concerned that if Family Care, IRIS, or any other program is frozen, the waiting list will grow to the point that my son Tyler will have to wait years to be able to live his dreams. I am also a consultant in the IRIS program. I see first hand how individuals with the ability to self direct their supports and services are much happier with their life. Self direction allows these individuals to hold down jobs. In some cases real jobs, not just sub minimum wage jobs. With the money that they earn, they put some of that back into the economy. Tyler has dreams and I have dreams for Tyler.



**Kevin and Tyler Fech, Cudahy** 



My son Stephen and I are just about to enter the world of adult services. Stephen will be turning 18 late in May 2011. I have been waiting for Family Care support so that I can return to full-time work. I take care of Stephen five days and five nights a week by myself and sometimes work on the weekend when my husband is home from his job out of state. He was one of many employees cut from Kohler two years ago and there are no jobs for him around here. Stephen needs someone with him to keep him safe and remind him to do the care that he can for himself. He needs assistance in preparing meals and taking his medication. If you cap long-term care and my son gets put onto a waiting list, he will be stuck sitting at home during the summers and after graduation. He will be stuck doing nothing and I will be needed at home 24/7. Isn't it more democratic to allow him to be as independent as possible and also to allow me to assist in our income?

Carla Scofield, Plymouth

My name is Laura Strebe. I live in my own apartment. IRIS pays for staff to help me with menu planning, grocery shopping, cleaning, and laundry. They make sure that I am doing things safely. IRIS pays for me to learn new skills and jobs. The money that I earn helps me pay my bills. I work at First English Church. The people there are very nice to me. IRIS helps me do all of these things. I am afraid that if I do not get support from IRIS that I would not be able to live by myself anymore. Some of my friends don't have any support at all and I am afraid that they will never be able to move out. Please don't cancel this program. Laura Strebe, Appleton



The Family Care program allowed my family to keep our parents in our home for the duration of their lives. It was much more cost effective than nursing home care and enriched all of our lives. To think this program would not be available to help other seniors is very sad. Please work to reinstate and retain the Family Care program for all.

Maureen Creed, Milwaukee

My son, Andy is a 21-year-old adult who has an intellectual disability. While growing up, Andy was on and off waiting lists for support. When he was 18, we were relieved to hear the state had moved forward with a bi-partisan long-term support Medicaid Waiver. Now, with the support of the IRIS program, Andy has created his own business. He now sells his worm compost product at the Eau Claire Farmers Market. He loves working in his community. His life has meaning. I have always said it has been a dream that Andy would be included and be able to earn enough money to reduce his need for publicly funded supports. It is critical that there not be a funding cap placed on any long-term care programs.

Terri Larson-Baxter, Eau Claire

Heather Bruemm Chair

Beth Anderson

Karen Avery

Judy Braun Lynn Breedlove

Teri Buros Devon Christianson Dana Cyra

# Wisconsin Council on Long Term Care

RESULUTION
In Support of Continuing Statewide Implementation of Family Care, IRIS,

DAGE and Doublements:

WHEREAS Family Care was initiated in 1999 by Governor Tommy Thompson to WIENERS Failing Care was inmated in 1777 by Governor Toming Thompson |

Provide greater choices to long-term care consumers, and to provide more cost
optimize long term care carriage and

WHEREAS an independent assessment by APS Healthcare in 2005 found that effective long-term care services, and Family Care had a high consumer satisfaction rate, and saved the state's Medical

Assistance program on average \$452 per person per month, and WHEREAS Family Care and IRIS have been fully or partially implemented in all

### RESOLUTION

**In Support of Continuing Statewide Implementation** of Family Care, IRIS, **PACE and Partnership** 

WHEREAS Family Care was initiated in 1999 by Governor Tommy Thompson to provide greater choices to longterm care consumers, and to provide more cost-effective long-term care services, and

WHEREAS an independent assessment by APS Healthcare in 2005 found that Family Care had a high consumer satisfaction rate, and saved the state's Medical Assistance program on average \$452 per person per month, and

WHEREAS Family Care and IRIS have been fully or partially implemented in all but 15 counties in Wisconsin, and

WHEREAS a Legislative Audit Bureau report indicates that Family Care "has improved access to long-term care by allowing participants to avoid institutional care, and in many instances, to remain in their own homes..." and that "the implementation of this large, complex program has generally proceeded as planned...", and

WHEREAS the Council supports the Department of Health Services' commitment to address areas of concern identified in the Legislative Audit Bureau's Evaluation Report and the Family Care Financial Evaluation completed by APS Healthcare, and

WHEREAS the cap on long term care will result in cost-shifting in the form of increased nursing home admissions, hospitalizations, admissions to psychiatric facilities, admissions to correctional facilities, and Medicaid card costs, and

WHEREAS Family Care holds the promise of eliminating waiting lists, reducing institutional care, reducing other Medical Assistance costs, such as hospitalization and emergency care use, and

WHEREAS Family Care continues to be a cost-effective model for long-term care reform in Wisconsin and the Country,

THEREFORE BE IT RESOLVED that the Wisconsin Council on Long Term Care urges the Governor, the Department of Health Services, and the Legislature to lift the caps and continue statewide implementation of Family Care, IRIS, PACE and Partnership on its original schedule in the 2011-2013 state budget.

Adopted at the May 3, 2011, meeting of the Wisconsin Council on Long-Term Care in Madison, Wisconsin.

### **Statewide Support**



**Over 70 statewide and regional agencies have signed on** in support of the May 3, 2011 resolution from the Wisconsin Council on Long-Term Care which urges the Governor, the Department of Health Services, and the Legislature to lift the caps and continue statewide implementation of Family Care, IRIS, PACE and Partnership on its original schedule in the 2011-2013 state budget. The following agencies support the resolution:



#### **Statewide Agencies**

**AARP Wisconsin** 

Aging & Disability Professionals Association of Wisconsin

**Autism Society of Wisconsin** 

Board on Aging and Long Term Care

Brain Injury Association of Wisconsin, Inc.

Coalition of Wisconsin Aging Groups

Disability Rights Wisconsin

Family Voices of Wisconsin

Greater Wisconsin Agency on Aging Resources, Inc

Lutheran Social Services of Wisconsin and Upper Michigan, Inc.

Mental Health America of Wisconsin

People First Wisconsin

Wisconsin Alliance for Retired Americans

Wisconsin Association of Area Agencies on Aging

Wisconsin Association of Benefit Specialists

Wisconsin Association of Family & Children's Agencies

Wisconsin Board for People with Developmental Disabilities

Wisconsin Branch of the International Dyslexia Association

Wisconsin Coalition Against Domestic Violence

Wisconsin Coalition Against Sexual Assault

Wisconsin Coalition of Independent Living Centers, Inc.

Wisconsin Council on Children and Families

Wisconsin Council of the Blind & Visually Impaired

Wisconsin Council of Churches

Wisconsin Counties Association

Wisconsin County Human Services Association

Wisconsin FACETS

Wisconsin Family Care Association

Wisconsin Personal Services Association



### **Regional Agencies**

Alzheimer's Association - Greater Wisconsin Chapter Alzheimer's Association of Southeastern Wisconsin

Arc - Winnebago County Disability Association

ARC of Greater Milwaukee

Autism Society of Southeastern Wisconsin

Badger Association of the Blind and Visually Impaired

Bell Therapy, Inc.

Carefinders, Inc

**Catholic Charities** 

**Community Advocates** 

Easter Seals Southeast Wisconsin

Genesis Behavioral Services, Inc.

Geriatric Support/Pathway Care

Grand Avenue Club, Inc.

GT Independence

IndependenceFirst

Independent Living Resources, Inc.

Interfaith Older Adult Programs

Jewish Community Relations Council of the Milwaukee Jewish Federation

**Jewish Family Services** 

JFS Housing, Inc.

La Causa, Inc.

Legacy Center, UA - Corporate Guardianship Services

Legal Aid Society of Milwaukee

Milwaukee County Disability Resource Center Oversight Committee

Milwaukee Mental Health Task Force

Midwest Community Services, Inc.

Milwaukee County Aging and Disability Resource Center Board

Milwaukee County Combined Community Services Board

Milwaukee County Commission on Aging

Milwaukee County Department of Family Care

Milwaukee Mental Health Task Force

NAMI Greater Milwaukee

North Country Independent living

Options for Independent Living

Project Access, Inc.

Society's Assets

St. Croix Valley Disability Coalition

Stowell Associates SelectStaff Inc.

The Arc of Racine County, Inc.

**Transit Express** 

**Transitional Living Services** 

United Cerebral Palsy of Southeastern Wisconsin

Wisconsin Community Services, Inc.

Wisconsin Latino Action Coalition

Wisconsin Upside Down

Women's Psychotherapy Centre of WI, LLC



Over 2,100 Wisconsinites have signed the "Keep the Community Promise: Lift the Cap on Community Long-Term Care" petition.

### The petition states:

The proposed state budget freezes for two years all major long-term care programs except nursing homes (which are more expensive than in-home care). This includes programs like Family Care, IRIS, Partnership, PACE, and the Children's Waivers. Older adults and children and adults with disabilities will go without essential services unless this cap is lifted. The cap will not save money because it will lead to an increased use of expensive and preventable institutional care. Community services mean people with disabilities and seniors can stay in their homes and maintain their independence.

We, the undersigned, ask state legislators to lift the cap on community long-term care services because they are more cost effective than institutions and better for people. Keep the community promise: remember there's no place like home! "My father, who is 84 years old, has been battling Alzheimer's for 2 years. My mother is struggling with keeping him at home. We need [this] to be able to help our parents and other parents suffering from this disabling disease.

Ann Negovan, Madison

"I have been on the Family Care waiting list since 2002 and I was hoping to get services very soon. Now I am worried because the budget will not fund more people in Family Care."

Nealy Rothe, Milwaukee

"Without long term supports, any family like ours would feel a significant impact on their quality of life. Long term care lets people live." Lauri Malnory, Eau Claire

"I am a mom of two special needs teens. Our son is supposed to be transitioning at the age of 18 so we need this cap lifted so he can receive his adult services. We depend on these services. We need them to continue getting the help they desperately need."

**Robin Davis, Wisconsin Rapids** 

"My mother received Family Care for three years. We gladly paid our share and knew she was living as independently as she could... without being in a nursing home. These services that are slated to be stopped will affect the quality of life for many residents already on waiting lists."

Georgene Voutila, Milwaukee

### **Studies of Long-Term Care in Wisconsin**

### Wisconsin Family Care - Implementation Process Evaluation Report II Prepared for Wisconsin Legislative Audit Bureau by The Lewin Group; August 2001.

http://legis.wisconsin.gov/LAB/reports/01-0FamilyCare.pdf

"Our assessment of the CMO counties based on the fidelity measure suggests that the counties involved in the Family Care pilot are making good progress toward full implementation and stabilization." "CMOs appear to have created the conditions necessary for achieving choice and facilitating consumer

direction."

### Wisconsin Family Care Implementation Process Evaluation Report III Prepared for Wisconsin Legislative Audit Bureau by The Lewin Group; November 2002.

http://legis.wisconsin.gov/lab/reports/02-0FamilyCare.htm

"Waiting lists for home and community-based waiver services have been eliminated in each of the five counties operating CMOs."

"CMO staff unanimously expressed a preference for Family Care over the old system."

## Wisconsin Family Care Final Evaluation Report Prepared for Wisconsin Legislative Audit Bureau by The Lewin Group; June 2003; July 2003.

http://legis.wisconsin.gov/lab/reports/03-0FamilyCare.pdf

"Shows positive results beginning to emerge as the local CMOs adopt the management practices of managed care."

"Lewin found that expenditures were lower for community care services under Family Care than for nursing home care. When functional status was considered, average spending for long-term care services in the community was 74.3 percent of nursing home spending. However, if level of care was considered, the difference diminished as the level of care increased. At the intermediate level of care, average community costs were 53.6 percent of nursing home costs: \$1,128 per person per month in the community, compared to \$2,104 in a nursing home. At the skilled nursing level, average community costs were 75.4 percent of nursing home costs: \$1,913 per person per month in the community, compared to \$2,538 in a nursing home."

## Family Care Independent Assessment: An Evaluation of Access, Quality and Cost Effectiveness For Calendar Year 2002 performed by APS Healthcare, Inc.; September 2003.

http://www.dhs.wisconsin.gov/ltcare/Reports/IA.pdf

"This report concludes that Family Care is fulfilling its objectives with regard to improving access and assuring quality in all five counties, and that Family Care is restraining long-term care costs and other Medicaid costs in four of the five counties."

### **Studies of Long-Term Care in Wisconsin**

Family Care Independent Assessment: An Evaluation of Access, Quality and Cost Effectiveness for Calendar Year 2003 – 2004 performed by APS Healthcare, Inc.; November 2005.

http://www.dhs.wisconsin.gov/ltcare/pdf/FCIndepAssmt2005.pdf http://www.dhs.wisconsin.gov/ltcare/pdf/IACoverMemo.pdf

"A study of the state's long-term care reform initiative, Family Care, has produced substantial savings for Wisconsin's Medicaid program. The initiative saves the Medicaid program \$452 per month for each individual receiving services when compared to other programs...The study compares long-term care costs in 2003 and 2004 for people in Family Care and those receiving the same services in other programs. Average monthly spending for Medicaid-funded services for Family Care members in Fond du Lac, La Crosse, Portage and Richland Counties was \$452 lower per person. Spending was \$55 lower per person for Milwaukee County."

Understanding Self-Directed Care in Wisconsin: A Comparison of IRIS and Family Care Programs Prepared for Division of Long Term Care Wisconsin Department of Health Services by La Follette School of Public Affairs; May 2010.

http://legis.wisconsin.gov/LAB/reports/01-0FamilyCare.pdf

"Findings indicate that for a program in the early stages of development, IRIS does an exceptional job of providing Self-Directed Care in Wisconsin."

### Health Services: Family Care Expansion to Langlade and Lincoln Counties; Legislative Fiscal Bureau; December 2010.

http://legis.wisconsin.gov/lfb/Section1310/2010\_12\_14\_DHS\_Family%20Care\_6.pdf

"The administration's proposal to begin offering the Family Care benefit in Langlade and Lincoln Counties is estimated to generate net GPR savings in 2010-11 (\$746,000), 2011-12 (\$547,200), and 2012-13 (\$71,200), compared to maintaining the current MA supported long-term care programs in those counties. The savings are due to estimated reductions in MA-funded costs for current long-term care services available in those counties, including the MA waiver programs, GPR-funded COP services, nursing home services, and MA card services that will be funded as part of the capitation payments DHS will make to the MCO."

### An Evaluation - Family Care - Department of Health Services; Prepared by Legislative Audit Bureau; April 2011.

http://legis.wisconsin.gov/lab/reports/11-5full.pdf

"Family Care operated in 53 counties and had expenditures of \$936.4 million in FY 2009-10." Analysis indicates that the program has improved access to long-term care, ensured thorough participant care planning, and provided participants with choices tailored to their individual needs. Consumer satisfaction is high. Family Care saves money compared to the standard Medical Assistance program. Cost-effectiveness is difficult to assess.