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MINNESOTA PARTNERS IN POLICYMAKING® BASELINE SURVEY

YEAR XXXI (CLASS 35)

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PREPARED BY

NANCY MILLER METROPOLITAN STATE UNIVERSITY October 3, 2017

Partners in Policymaking[®] Baseline Survey – Minnesota Program Class 35 Report: 2017-2018 October 3, 2017

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Total started survey: 34*

*The Survey Monkey results are based on participants <u>starting</u> the survey. This is used as the number for the total results. It is understood that some participants decided to withdraw from the class after starting the survey and others may also have started the survey twice.

1. Gender:

Female	26	76%
Male	8	24%
Total	34	100%
2. Race or Ethnicity:		
African American	3	9%
Native American	1	3%
Hispanic American	0	0%
Caucasian	29	85%
Other	1	3%
Total	34	100%

Partners in Policymaking® Baseline Survey – Minnesota Program Class 35: 2017-2018

3. Age:

Total	34	100%
50+	7	20%
40-49	3	9%
30-39	17	50%
20-29	5	15%
Under 20	2	6%

4. Place of residence:

Total	34	100%
Rural	4	12%
Non Metro Area	6	17%
Suburban	16	47%
Urban	. 8	24%

5. Income (family income if Class member is parent):

Less than \$12,000	9	27%
\$12,000-\$19,999	5	15%
\$20,000-\$29,999	1	3%
\$30,000-\$39,999	4	12%
\$40,000-\$49,999	0	0%
\$50,000 +	14	43%
Total	33	100%

Skipped question: 1

6. Level of Education:

Total	34	100%
Doctoral degree	1	3%
Post Master's degree	1	3%
Master's degree	3	9%
Partial graduate work	2	6%
Four years of college	10	29%
Two years of college	7	21%
High school graduate	9	26%
Less than high school	1	3%

7. Specific disability for yourself (if participating as self-advocate) or family member

(if participating as parent):

- 1. Slight autism/anxiety disorder.
- 2. Mild cerebral palsy, learning disability and I have more but I am not sure what.
- 3. Mild autism, Mild anxiety disorder.
- 4. Son is globally delayed inverted duplication and deletion of 8p.
- 5. Quadriplegic.
- 6. Schizoaffective disorder, diabetes Type 2.
- 7. Mental health bipolar, anxiety, depression.
- 8. Autism Spectrum Disorder.
- 9. My son has Autism.
- 10. I have one son who was born at 24 weeks and 800grams with multiple challenging outcomes, plus 2 that were diagnosed with FASD. But truly, of the six special needs adoptions we have done, it is the issues of their mental health issues both from genetic pieces or from the effect of abuses suffered that are the biggest challenges.
- 11. Legally Blind, Depression, Anxiety.
- 12. Cerebral palsy. Premature birth. Learning difficulties.
- 13. Autism, Anxiety, ADHD, Learning Disabilities in the areas of Reading, Writing and Motor Planning.

- 14. Poor balance, neuropathy.
- 15. Family Member my son 8- Noah has autism and my brother 27-Chris has autism.
- 16. N/A
- 17. Son has Down Syndrome.
- 18. I am the parent of two children with special needs, with one of their diagnoses being DD.
- 19. PTSD , bpd, development delay.
- 20. Autism, ADHD, Anxiety.
- 21. Autism.
- 22. Going blind from Retinitis Pigmentosa; PTSD.
- 23. I am Deaf.
- 24. Ehlers-Danlos Syndrome (Hypermobility, otherwise called HEDS), which is a rare genetic disorder that affects the connective tissue, joints, etc. It can, because it's genetic, have two other disorders that present with it that I also have, known as Mast Cell Activation Syndrome (MCAS) and Post Orthostatic Tachycardia Syndrome (POTS). Along with those I have PTSD and severe, treatment resistant Bipolar Disorder.
- 25. Autism and bipolar disorder.

26. Autism.

- 27. Son: Autism Daughter: ADHD; Anxiety.
- 28. I am the mother a six year old with severe, nonverbal autism.
- 29. Cerebral palsy, Russel Silver Syndrome, Hydrocephalus, micro-preemie.
- 30. My 9 year old son has been diagnosed with Autism Spectrum Disorder, Sensory Processing Disorder and Central Nervous System Delays. My 7 year old son has been diagnosed with ADHD and Sensory Processing Disorder and Generalized Anxiety.
- 31. My oldest son has Autism Spectrum Disorder, my daughter has Bipolar Disorder and a Non-Verbal Learning Disability, and my youngest son has ADHD.

32. CP.

Skipped question: 2

Partners in Policymaking[®] Baseline Survey – Minnesota Program Class 35: 2017-2018

8. Prior to your participation in Partners, did you ever contact local, state or federal public officials about how you or a family member with a disability have taken personal responsibility to secure needed services or improve the quality of needed services? If yes for any or all of the items listed, enter the <u>estimated number of contacts</u> for each.

Yes, federal: 16

- Number of contacts: 88
- Average number of contacts: 6

Yes, state: 16

- Number of contacts: 359
- Average number of contacts: 22

Yes, local: 19

- Number of contacts: 93
- Average number of contacts: 5

Answered question: 20; skipped question: 14

9. If you contacted local, state, or federal public officials in the past 6 months, enter the <u>estimated number of each TYPE of contact</u> you made with those public officials.

Yes, letters: 12

- Number of letters: 37
- Average number of contacts: 3

Yes, phone calls: 15

- Number of phone calls: 223
- Average number of contacts: 15

Yes, office visits: 17

- Number of office visits: 75
- Average number of contacts: 4

Yes, Emails: 17

- Number of emails: 383
- Average number of contacts: 23

Answered question: 19 ; skipped question: 15

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10. What other opportunities have you had in the last 6 months to advocate for yourself or other individuals with disabilities, educate the public about the abilities of people with disabilities, or explain how the needs that individuals with disabilities may have can best be met through individual and local community decision making. If you have participated in any of these activities in the past 6 months, enter the <u>estimated number of times</u> next to that particular activity.

Yes, testified at public hearings: 15

- Number of hearings: 17
- Average number of opportunities: 1

Yes, presented to parent/other community group: 17

- Number of groups: 38
- Average number of opportunities: 2

Yes, presented at a conference: 13

- Number of conferences: 6
- Average number of opportunities: 0

Yes, served on a committee: 15

- Number of committees: 26
- Average number of opportunities: 2

Yes, appeared on TV or radio: 12

- Number of appearances: 5
- Average number of opportunities: 0

Yes, articles/editorials published: 14

- Number of articles/editorials: 131
- Average number of opportunities: 9

Answered question 21; skipped question: 13

Partners in Policymaking[®] Baseline Survey – Minnesota Program Class 35: 2017-2018

11. If you participated in any of the above activities in the past 6 months, evaluate your competency level for each of those activities by <u>checking one of the four competency levels.</u>

	Excellent	Good	Fair	Poor	Total
Testified at public hearing	1 (11%)	5 (56%)	2 (22%)	1 (11%)	9 (100%)
Presented to parent/comm. group	2 (15%)	8 (62%)	2 (15%)	1 (8%)	13 (100%)
Presented at a conference	2 (25%)	4 (50%)	1 (12.5%)	1 (12.5%)	8 (100%)
Served on a committee	3 (27%)	4 (37%)	3 (27%)	1 (9%)	11 (100%)
Appeared on TV or radio	2 (33%)	1 (17%)	1 (17%)	2 (33%)	6 (100%)
Articles/editorials published	4 (50%)	2 (25%)	2 (25%)	0 (0%)	8 (100%)

Answered question: 21; skipped question: 13

12. Other activities/comments:

- 1. Church, martial arts.
- 2. No.
- 3. Volunteer for the Twin Cities Marathon every year, donates blood often. Help people in time of need.
- 4. MN Department of Human Rights, US Dept. of Labor, MN Disability Law Center, Star Tribune articles, MN Ombudsman for Mental Health and Developmental Disabilities, MAARC, it goes on and on.
- 5. I am active with my sons school which specializes in children with disabilities and support groups in my local area.
- 6. I speak 3x yearly at a college, speaking to students in their Education department about their potential impact on children with special needs, and things that impact the family.

- 7. I keep a blog that talks about disability issues, but it's not the only thing that it talks about.
- 8. I am on the Board of Directors of the Autism Society of Minnesota.
- 9. I blog regularly about my experiences, and work at the Autism Society of Minnesota.
- 10. Director of self-advocacy and group homes with LSS.
- 11. Volunteered at events, raised funds, promoted inclusion.

Answered question: 11; skipped question: 23

13. Please evaluate your current leadership skills.

Excellent	1	3%
Good	21	64%
Fair	10	30%
Poor	1	3%
Total	33	100%

Skipped question: 1

14. Please evaluate your current ability to secure appropriate services for yourself or a family member with a disability.

Excellent	6	18%
Good	17	52%
Fair	7	21%
Poor	3	9%
Total	33	100%

Skipped question: 1

15. Do you expect to be better able to receive appropriate services as a result of the skills and information you will learn from the Partners program?

Total	33	100%
Definitely No	0	0%
Probably No	3	9%
Probably Yes	8	24%
Definitely Yes	22	67%

Skipped question: 1

16. As a result of your participation in the Partners program, what are your general expectations?

- 1. For me to learn to be a better self-advocate.
- 2. To learn more advocating skills.
- 3. To learn and be a better advocate for myself and others with my situation.
- 4. To be able to better advocate for my child and learn resources to do so.
- 5. To learn and pick up knowledge about policy making and partners.
- 6. I want to learn more about the government and more about the services such as education. Wants to continue with school.
- 7. I expect to have the ability to more appropriately tailor my story and share my experience with policy makers, of my observations of how people with disabilities are controlled by service providers, as the service providers then portray themselves as the unsung heroes struggling to give the very best care. Being squeezed by families on one hand, and by the state on the other hand. I will learn to make better descriptions/sentences of conditions for people with disabilities than I am now.
- 8. Learning about law making and leadership.
- 9. To expand my knowledge of the current process and programs and the decisions behind why some things run the way they do, and from here to network and advocate for changes that would help those of us living it day to day. I hope to serve on my sons school board and expand his schools model to other schools.
- 10. I do hope to feel more secure and knowledgeable about the ways to access the things available to make good choices for the best of my children, but also I really would love to be able to help others access services that will make a difference in their life.
- 11. Learn about disability advocacy. Learn how policies impact people with disabilities. Learn more about general policy. Learn about services and resources.
- 12. Learn to advocate for self and others.

- 13. Learning how to advocate better for people with disabilities in the workplace and in education.
- 14. That I learn more how Minnesota works and our DHS system and special education system. How to connect with City council as I have not been successful.
- 15. To educate myself on how to best advocate for my son and to find ways through community engagement, legislation, community service to improve the opportunities for those with disabilities.
- 16. To learn the state role in helping families with disabilities, this includes law, healthcare and state resource. I am seeking to advocate for those seeking or needing help to care for vulnerable individuals with unique needs.
- 17. To gain knowledge.
- 18. Since my county cannot provide information of all services, programs and help that is available for my child...I will do everything I need to in order to find that information myself.
- 19. Learn more about the policy process, make connections with other people experiencing the same issues as myself and my family.
- 20. Improve self-esteem and confidence.
- 21. Skills to advocate better for myself, for my son who is on the Autism spectrum, my other son who has Cystic Fibrosis, and within my community (Deaf, DeafBlind, and Hard of Hearing).
- 22. I have very open expectations, actually. I want to learn about the history of how we've approached disabilities in the state of Minnesota, but also learn how to be a better advocate. I, personally, would love to get more engaged as say, a peer support specialist, but I've found there's only 1-2 organizations offering this program and if you're disabled? It makes it very difficult to attend. I can't personally commit to 80 hours straight in two weeks given my disability, and they don't allow for much in the way of leeway. I'm hoping perhaps I can walk away from the program and be able to have a better idea of how to provide a structure support like that for the mentally ill but at the same time perhaps be able to coordinate with organizations like those that offer these programs to offer something that makes more sense for those of us who have other obligations due to our disabilities.
- 23. Greater ease and confidence when approaching elected officials and when attempting to network.
- 24. I hope to be able to advocate better not just for myself, but for others, to become more involved in legislative advocacy (not just personal advocacy), and to make connections with others.
- 25. To become more educated about ways to affect public policy and advocacy for both my personal and work life.
- 26. To learn more about policies, procedures, and legislation.
- 27. I want to learn more about the history of disability-related services, learn from professionals and policy-makers in the field, promote inclusion, learn more about the

legislative process and become a stronger advocate for people with disabilities in my community and state.

- 28. I want to better learn how to advocate for my children and the children I serve as a special education teacher. I want to learn how to affect positive change in laws to better meet the needs of individuals with disabilities.
- 29. To learn to better navigate the system and to build my network.

Answered question: 29; skipped question: 5