

## **Information Brief: Highlighting the Impact of the Partners in Policymaking Program**

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### **Overview**

Families of adults with developmental disabilities serve as a critical source of care and support. In 2006, an estimated 4.7 million Americans had intellectual and developmental disabilities (Larson et al., 2000) and approximately 60% of these individuals lived with family caregivers (Fujiura, 1998). Family members not only provide day-to-day support but also play key roles in securing opportunities for persons with developmental disabilities and assisting in making decisions that reflect the person's desires, goals and dreams (Beach Center on Disability, 2007b; Everson & Zhang, 2000; Neely-Barnes, Graff, Marcenko, Weber, & Warfield, 2008; O'Brien, O'Brien, & Mount, 1997).

Families also play a vital role in identifying, designing and advocating for services and supports across the lifespan of persons with developmental disabilities. This role is especially vital as the disability service system evolves and frees itself from its historical design of providing institutional care to a system that supports self-determination, freedom and choice for persons with disabilities. In order to ensure that persons with disabilities and families have a strong voice in this redesign, training programs must exist to develop their capacity to be informed, educated advocates. It is imperative that we understand the efficacy and impact of these training programs to ensure ongoing support and to ensure that families are gaining the skills they need to be effective social change agents.

The Partners in Policymaking program developed in 1986, exists both nationally and internationally, to train families of children with development disabilities and adults with disabilities to make changes in their lives and in their communities and ultimately become integrated citizens. It is designed to mobilize parents of children with developmental disabilities and adults with disabilities to participate in policies that support inclusion, independence, integration, self-determination, and productivity of individuals with developmental disabilities as set forth in the federal Developmental Disabilities Act.

### **Partners in Policymaking Program**

#### *Origins of the Partners in Policymaking Program*

The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 517) is the only federal law that focuses specifically on individuals with developmental disabilities and their families. This Act, also known as the DD Act, assures that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other

assistance and opportunities that promote independence, productivity, integration, and inclusion into the community. In the 1986 Reauthorization of the DD Act, the role of parents and family members in the provision of services and policies was further recognized and strengthened. This amendment required that programs develop and implement meaningful participation and training for parents and family members.

In response to the federal DD Act, the Minnesota Governor's Council for Developmental Disabilities recognized that parents of children with developmental disabilities needed specific information and skills to participate. Their response was to create the groundbreaking training program called Partners in Policymaking® to empower individuals with developmental disabilities and their families in obtaining the most appropriate supports and services for themselves and others (Kaliszewski & Wieck, 1987) and to assist them to become involved in the public policy arena (Wieck & Skarnulis, 1987). The mission of the program is to "provide information, training, resources and skill building in the area of developmental disabilities to families of young children with disabilities and to consumers with disabilities" (Zirpoli, Wieck, Hancox, & Skarnulis, 1994, p. 423). Participants are exposed to leading national figures in the areas of policy, research, and services for individuals with developmental disabilities (Balcazar, Keys, Bertram, & Rizzo, 1996) and are connected with policymaking and legislative advocacy opportunities (Kaliszewski & Wieck, 1987).

As the program quickly expanded to other states, the creators of the Partners program recognized the need to protect the integrity of the program. In 1997, the Minnesota Governor's Council trademarked the program to ensure that during implementation in other states that the standards, quality and values were maintained. They wanted to ensure that all programs were competency based; conducted over eight, two-day weekends with at least 1128 hours of training; covered specific topic areas and utilized the expertise of presenters with a national (as opposed to local) perspective and knowledge of best practices; and involves readings, homework, and a public policy project. Using their standard curriculum, the graduates who successfully completed the training program gain the following competencies:

- History of disability services and perceptions, including an overview of parents' movement and self-advocacy and independent movement.
- Benefits and values supporting inclusion and quality education for students with and without disabilities, and strategies to achieve inclusion and quality education.
- Importance of futures planning and self-determination for individuals with developmental disabilities and the role of the service coordination system in accessing services available.
- Information on state-of-the-art technologies for people with severe disabilities.
- Importance of supported, competitive employment opportunities.

- Understanding that a flexible, responsive system of supports for the families of children with disabilities across the lifespan is the corner stone for a true system of community supports for individuals with developmental disabilities.
- Basic principles and strategies being used to support individuals with developmental disabilities in their own homes across the life span.
- Successful techniques and techniques for advocating for services to meet needs, focusing on strategies for representing un-served and underserved individuals.
- Overview of how bills become law and skills for getting involved in the legislative process.

### *Outcome and Impact of the Partners in Policymaking Program*

The growth and expansion of the program is an indication of both the need and the anticipated positive advocacy efforts expected after graduation. Since the program's inception, the founders and other program implementers have collected both qualitative and quantitative demographic information on all participants including evaluations of each topic and post-evaluation reports outlining the types of advocacy activities in which the graduates participated. In addition, anecdotal comments were collected about their advocacy efforts from the participants.

The strength of the evaluation studies of the Partners in Policymaking program is the consistent longitudinal data that supports the findings of an increase in advocacy actions on the part of the participants after graduation, which is the expressed mission of the program. This data can be found dating back to the first class of the Minnesota program and can also be compared to the many states that have implemented the program. The following table highlights findings from three different states: Minnesota, Iowa and New York.

<b>Evaluative Reports of Partners in Policymaking Programs</b>	
Minnesota: Year One Ziropoli et al. (1989)	35 participants in six month survey reported: -57% <i>improved self-advocacy skills</i> -89% <i>obtained services for self or family</i> -68% <i>contacted policy officials</i>
Minnesota: First Five Years Ziropoli et al. (1994)	130 participants surveyed reported: -57% <i>improved self-advocacy skills</i> -62% <i>obtained services for self or family</i> -62% <i>contacted policy officials</i>
Iowa: 1990 – 1993 Conconan-Lahr et al. (1996)	Mixed methods (mailed survey, semi-structured interviews, and focus groups) found: - <i>Satisfaction with program</i> - <i>Increase participation in advocacy activities</i>
New York: 1990 - 1996 Kate Toms and Asst. (1997)	

Despite identified limitations, such as lack of diversity of participants (Conconan-Lahr & Brotherson, 1996; Zirpoli et al., 1989), lack of baseline data on participants (Zirpoli et al., 1989) and lack of control group (Balcazar, Garate-Serafini, & Keys, 1999), numerous and consistent findings all conclude that the program increases participants advocacy actions and ability to obtain services for self or family. As is evident with these findings, it can be concluded that this program results in positive satisfaction and outcomes for the participants.

### **Current Study**

According to the Minnesota Governor's Council, since 1987 over 15,000 people have graduated from the Partners program representing over 46 states, two US territories, the Netherlands and the United Kingdom. Since its inception, both quantitative and qualitative data have proven satisfaction with and positive outcomes related to visiting legislators, testifying, or writing letters to newspapers. However, little is known about the impact of the program on the participants beyond these activities and the aspects of the program that facilitated these changes.

Using grounded theory, this study delves into the specific impact of the Missouri Partners in Policymaking program on the participants and how features of the program impact the outcomes. This methodology focuses specifically on selective sampling or key informants, as opposed to a random sample selection. In qualitative research, it is important that participants have direct experience with the phenomena being studied either by observing in it or participating directly with it and they also must be available and willing to share their experience.

Parent participants were recruited from the Missouri training program which has graduated 299 participants (186 parents and 113 self-advocates) over the last sixteen years. Fourteen parents participated in semi-structured interviews. Twelve of the study participants were mothers (86%) and two were fathers (14%.) Participant's education ranged from attending at least one year of college with almost half holding Master level degrees (43%). Participant's children represented varying and multiple cognitive, physical, medical and chromosomal disabilities such as Autism, Down syndrome, Rett syndrome, Shaken Baby syndrome and Cerebral Palsy. Three of the study participants (21%) graduated Partners in Policymaking before 2000 while eleven (79%) graduated in classes from 2001-2010.

### **Results**

The Partners in Policymaking Program, for many of the parent participants, was a *life-changing experience; it was monumental, it was a shift in my mindset and it forever changed and molded who I am*. One parent compared it to the first time they saw the ocean, *you hear people talk about it but until you go, you just cannot take it all in and grasp the gravity of the opportunity*. Another parent explained how it *truly has taken my child and his life and his potential and just expanded it*. For some parents it

was not until several months after graduating that they *were fully aware of the impact or importance of* what they experienced.

The following describes the key elements of this life-changing transformation for Missouri Partners in Policymaking parent graduates within seven themes: *being ready, feeling respected, changing perceptions, finding membership, understanding possibilities, navigating a future, and decreasing intimidations*. Within the themes, direct quotes from parents are italicized.

### ***Being Ready***

Many parents used the phrase “*being ready*” when talking about considering and applying for Partners. Although the experience of *being ready* was different, it was a very concrete and vivid experience for each. One parent was ready to apply for Partners after she was able to *transition from denial and grieving to realizing (her child) was a beautiful person, not something to be fixed*. For another parent being ready meant *moving beyond living day to day to now thinking about the future and where (their child) would end up*. Another parent was ready when she couldn’t ignore the *constant grumbling in her heart that something wasn’t right about her child being segregated in a special education classroom*. Two other parents described their experiences of how they were ready after they witnessed the *metamorphosis of attitude and change of belief systems about individuals with disabilities* from other parents who had attended. The sense of being ready appears to be an important factor in why and when someone applies to the program and possibly how much the program affected them.

### ***Feeling Respected***

Many parents explained their experience as a parent of a child with a disability as entering a *whole different world or different ball game*. For some parents, the experience of parenting was stressful and overwhelming because of the *ongoing challenges at every stage of the game with a kid with a disability*. One parent explained that *family members and people in the community treat you as if you are crazy for fighting for inclusion of your child with a disability into their school*. For others, caregiving was not what was stressful it was *the challenge of getting what your child needed* from professionals and the disability system.

The Partners in Policymaking program is one of the first times for many parents, since becoming a parent of a child with a disability, where “*respect*” served as the foundation for the program and many of their interactions. One parent commented that *the respect that we received was amazing; I was treated like a businessperson. I had never received that type of respect as a mother, let alone a mother of a person with a disability*. Parents conveyed how respectful and committed the program staff was in hosting the program, as well as all of the presenters. It was an environment for participants to *be able to learn and grow but they did not baby people and they do not feel sorry for you*.

Parents felt the program design and schedule was very respectful of their time and other commitments. From the travel arrangements to the resource papers, the training was always well organized and *you knew what to expect so it was worth the trip*. This is especially important to parents who often feel like they are constantly struggling or battling to get what their child needs and that professionals do not understand or respect where they are coming from as a parent.

### ***Changing Perceptions***

Many parents recognized that although they had a child with a disability, they had thought very little, beyond their own child, about individuals with disabilities and their lives before participating in Partners in Policymaking. Parents admitted individuals with disabilities *were absent from (their) view, they were a mystery* or that they had *looked right through them*. For some parents, they *didn't even give it a thought*. One parent explained that *disability wasn't even on my radar screen, probably like the rest of the general public.....and then I had my child*. For most of the parents, having a child with a disability introduced them to a *world they were completely unaware of*.

Many parents thought back to their childhood and recalled how uncommon it was to see a peer with a disability in their schools. Several parents remembered *busing the children to a different school* or one parent referred to the *mystery hallway* as the place where children with disabilities attended. One parent said *I have to say I honestly was scared if I did see someone out in the community with a disability. I was scared of them and just felt I wouldn't be able to talk with them*. Another parent regrettably admitted that they saw *right past them like they were not human and they did not have an opinion*.

Several parents' recall having a negative perception about the life individuals with disabilities lead; they *really did not have a quality of life* or that they *were not doing anything, they were just cared for*. Parents admitted that they were *unsure what individuals with disabilities did or how they were supported*; one had the *notion that all individuals with disabilities live in institutions*, for another *employment in the community wasn't even a possibility*. One parent explained *before Partners, I didn't give it a whole lot of thought about independence and about living life to its fullest*. For parents who had experience with disability, Partners validated or reaffirmed their assumptions, beliefs and views about disability.

Partners in Policymaking exposed parents to the current and past realities of disability. Starting in the first weekend with an overview of the history of disability and the presentation titled "Disability is Natural" and throughout the entire program with interaction and inclusion of individuals with disabilities as classmates was the cause for their transformation. This shift seemed immediate for some parents and for others it wasn't until after Partners, *the more it made sense*. Many parents felt after the first session

their *whole mind shifted*. One parent explained how she came home after the first session and *apologized to her son for all of the stuff that she had put him through*; it was the first time that she began thinking about how the different therapies and interventions had the potential to cause her son pain and isolation.

For many parents, it was their first exposure to the history of disability. For some, this emotional experience provided the history and explanation for institutions and sheltered workshops and *the great leaps and strides from what it was 10, 20 years ago*. For others, this session brought *guilt, sadness and tears*. One parent explained *how I have cried hard lots of times obviously but watching the videos and learning about the history made me cry*. Another parent expressed how she *wept and wept* because she could not believe that people with disabilities experience such cruelty.

Having self-advocates as classmates provided parents with a glimpse into the life of an adult with disability. For one parent *it was nice to be able to hear what their experiences were and how they managed their own lives and the supports that they had to do it*. It was the up-close and personal exposure to day-to-day life such as communication or ways of walking or using wheel chairs. One parent explained that if individuals with disabilities were not included as equal peers, they *would not have believed it as much because it was all theoretical to me without self-advocates sitting in the room with me, learning with me*.

This inclusive dynamic allowed parents to talk, interact and communicate with self-advocates, many for the first time. Parents were also able to watch and observe *how their experience has shaped them and things that they have gone through in their life that brought them there*. For other parents, self-advocates provided encouragement and hope. *It put things into perspective* in terms of what the future might look like for their child. It helped them *realize that (their child) is going to be an adult someday and that it is okay*.

Many parents felt like their perspective of the strengths and opportunities for individuals with disabilities was the biggest change. One parent was able to *see beyond the disability and see how capable individuals with disabilities are. It just really opened my eyes to what their lives were like*. A number of parents mentioned that it was the first time that they *realized individuals with disabilities dream*. For other parents, they recognized that *individuals with disabilities are able to communicate their wants and needs*; that *they are gifted and capable and they want to be a part of the community*.

Parents articulated how this changed perception carried over to their view about their own child. One parent said that what changed for them was that *it let me look at my daughter and realize it is not just pity; it is not self-doubt or inability. It was almost entirely the opposite. It was hoping, dreaming, loving, liking and disliking just like everybody else does*. For other parents, it opened their eyes to the reality that their child had potential and that they were going to grow up as an adult with rights. One

parent explained that *it's really horrifying to me to think had I not had Partners in my life, my child would really be so limited.*

Learning alongside self-advocates as they talked about their experiences was a major factor for creating this new perspective. Parents were able to see beyond their role of nurturing and protection to seeing the importance of their child taking risks, making mistakes and sometimes failing. One parent recognized by listening to a self-advocate's story that *Mom and Dad have to let go at some point and allow stuff to happen.* By including self-advocates as classmates, parents were able to see that *individuals with disabilities are out there trying to have a sense of independence and have their own life.*

### ***Finding Membership***

The feeling of isolation of being a parent of a child with a disability was an overwhelming emotion of many of the parents. The feeling of isolation came from the feeling that *you feel like you are the only one out there that has a child with a disability.* These feelings, for some occurred immediately after their child was born; *after a typical baby is born, people give advice but after your baby is born with a disability, they do not know what to say.* For others, it occurred when advocating or standing up for your child as they interact with different settings and people. The explanation provided by one parent was through the comparison with the segregation of how children feel when isolated in special education resource rooms; *just be a parent with a child with a disability, it is almost equally isolating.*

The experiential group learning process was an important feature of the Partners program both in terms of individual learning but also in connecting the group to one another. One parent explained that *there were 30 other people that were getting to know each other, sharing stories, and discussing strategies for moving forward, not just for their own loved one but for other people in the state as well.* Parents felt that having other parents and self-advocates in the group created a safe environment for learning, brainstorming and developing skills. Parents felt like they could share their dreams and nightmares with each other. One parent explained *you didn't feel alone and you didn't feel like you were crazy. When you cried it was okay because they understood why you cried. You were with a group of people that understood.* For many of the parents, Partners provided them for the first time with a connection or network to other parents or self-advocates in the same situation.

The feeling of connecting with others who are experiencing similar situations is reinforced with speakers that were parents of children with disabilities; *they were living it, not people that were just out talking about it.* Another parent explained it as:

*When someone who feels so strongly about something gets up and speaks, it's real easy to listen to that. It's real easy to go with that person and to listen to what their life experience or dreams were and their efforts that they made along the way to make those dreams real.*



Partners not only connected with each other during class, it also opened up a network for connection after the class. The listserv and the alumni training serve as a support system for sharing concerns, ideas or telling success stories. For some parents it created new lifelong friends and for others it was a safety net if they needed some assistance. One parent explained *there's virtually no network in the school district between parents with disabilities and I don't depend on Partners daily, I just know they're there and I know that they'll understand*. However, a few of the parents interviewed do not stay in touch with other Partners, nor participate in the listserv or attend the alumni training because they did not feel that doing so would meet their on-going needs specific to their families.

### ***Understanding Possibilities***

For most of the parents, they expressed the desire to increase their knowledge to *know as much about everything that they could*. Parents wanted information about their child's specific diagnosis or disability and about the different types of services available locally and statewide. They lacked information about what was possible or available for their child. Parents wanted information that would help them *look at the future* and learn about *what to expect*.

Parents appreciated the speakers who are recognized experts in the field and who are very knowledgeable and passionate about the information that they provide. The speakers provided resources *beyond the typical written resources* and provided information about *how they did things and how they went about it*. Parents felt that they could apply this directly to their lives and *use it in a real way*. Specifically parents liked receiving tools related to advocating during an individual education plan (IEP) meeting and legislatively.

Partners provided parents with information about different options and types of services available locally and statewide, along with strategies for navigating those services. Partners *created a picture for your child's future*. It helped many parents know what to *expect and demand at school* and it provided options about life after school. For some parents, this information expanded their understanding not only about what is available but also provided information beyond the segregated settings that were familiar. One parent explained:

*when you don't know what's out there, your options are very limited, but when you hear what people are doing in other areas and how they went about it and how you can do it, I think that that just helps you grow and helps your child.*

### ***Navigating a Future***

Parents' also expressed immense confusion and frustration with the new role of navigating and interacting with different systems such as the medical, educational or disability service systems to get what they needed for their child. For some parents, it was the *lack of respect from professionals* and for

others the *political dimensions and policies* that made it difficult to get the services they needed. For one parent, when they attended an individual education planning meeting they *felt like the professionals were talking a different language and following a different set of rules*. Advocating for even basic things that most people take for granted was something that most parents are now facing.

Parents felt they needed training to assist them in advocating for their own child by having a *basis of knowledge to react to or to cooperate with the people that are trying to help him*. They expressed the need to learn strategies that would assist them in discussions with the doctors, educators and other professionals. Parents wanted to *learn strategies that assist them to gain the respect and attention of professionals*. Parents wanted professionals to understand that they *know the child best* and that they were advocating for what was best for their child and family.

Partners provided parents with specific tools and skills for advocating for their child. *It gave me the skills and helped me be prepared*. It provided strategies for communicating and speaking up on behalf of their child. Parents learned *what was appropriate and how far to push it*. It built parents courage so that they could say *my child has rights*. One parent felt that *without Partners, I would not have learned to speak up and to expect to be heard*.

In subsequent meetings after the training, parents felt that they were more prepared to bring people to collaborate on meeting the needs of their child. The training provided a *basis of knowledge to react to or to cooperate with the people that are trying to help*. Partners provided an understanding of the special education laws and rights of the child and parents along with a structure for advocating within the law. Parents *knew what was possible* and they felt *armed, that they did not have to settle* when they attended their individual education planning meetings.

### ***Decreasing Intimidations***

Some parents had a desire to become more knowledgeable about how to advocate at the policy and systems level, both locally and statewide for all individuals with disabilities. By attending Partners, parents felt that they not only could learn new advocacy skills but also given opportunities for using those skills. Several parents recognized the need to *make a difference not only for their own child but for other kids and families*. One participant explained that *not all parents are strong enough to advocate, they do not necessarily have the ability or the drive to always stand up for their child so I find myself fighting for all of them*.

Several parents also expressed how the advocacy they learned for their own child also had an impact on other children and their community. Partners provided encouragement and tools to reach out beyond their own families and advocate for change within their schools and other services in the

community. By learning how to challenge and improve things for their own child, they were also *setting the tone for the next kids coming up the block.*

Parents felt Partners provided them with an understanding of the legislative process at the local, state and national levels such as how a bill becomes law and specific strategies for influencing the process. This information increased parents' assertiveness and confidence and made the process of advocating for policy change less intimidating. Parents are now more comfortable writing letters, making calls, or visiting with legislators. By understanding the political dynamics, parents feel they were able to focus their efforts to make a bigger impact in legislative advocacy. One parent explained that *it does not matter how passionate you are or even how much information you have if you do not approach it in the right way.*

Parents provided examples of how they became involved in systems activities as a direct result of their participation in Partners. One parent worked in their local county to establish a tax levy that would support funding for individuals with disabilities and their families. Another parent talked about their role with the parent teacher advisory board as a member and as an officer while another parent explained her positions on the state, regional and national board for Head Start. Several parents serve as peer mentors for other parents providing emotional and informational support. Almost all of the parents interviewed discussed how Partners had opened different opportunities for creating change beyond their own family.

The listserv and the alumni training also keep parents motivated and knowledgeable about current issues. The listserv also served as a tool for mobilizing advocacy efforts. One parent gave the example of emailing an issue they were having with their child that could potentially impact other children in the same situation and several Partners graduates participated in the letter writing campaign.

### **Conclusions and Recommendations**

The Partners in Policymaking program transforms parent's old stereotypes and assumptions about individuals with disabilities to a more positive and hopeful perspective for the future of their child. Families' need opportunities, such as Partners in Policymaking, to connect to a larger support network that includes self-advocates and other families in order to discover and try new things. Information and skills are important; however, it is important to have a network of people to practice with, fail in front of and have as a support system in order for families to discover different options and ideas that challenge the historical societal perception of individuals with disabilities.

Future training programs for parents of children with developmental disabilities should provide exposure and interactions with individuals with developmental disabilities. Parents can receive information on the types of services and supports that are available however having contact with

individuals with disabilities will help them to successfully envision and apply the knowledge they received. Training programs should ensure individuals with developmental disabilities are in vital roles with key responsibilities in all facets of the program as classmates, trainers, and facilitators. This requires a commitment of programs to move beyond inclusion as a token or mandate, to inclusion as an equal professional.

Parents' undergo many stages of coping, adaptation, adjustment and pride throughout their life as it relates to raising a child with a disability. It is also important to present information to parents at a point when they are ready to accept the message or understand the need for the skill acquisition. Parents must interact with supports that offer a sense of hope and offer a glimpse of what the future might look like; through personal communication with other families or self-advocates, reading personal stories or viewing positive reflections of success in pictures or videos. Parents and family members must also serve in vital roles with key responsibilities. By including staff and volunteers who have lived experience, they will be able to adapt the information and relate to others in a family-centered manner.

This study highlights the importance of building parent training program on the tenets of respect, inclusion, empowerment, and participatory learning. By incorporating these aspects, parents are able to obtain the information and skills to make changes for their child and family and undergo the positive emotional changes to the assumptions they may be carrying about individuals with disabilities. Parents that participate in programs built on the key features identified in this study will have a greater sense of hope and a more positive vision for the future of their child with a developmental disability.

### **Limitations and Future Research**

Several limitations are recognized in this study. Use of qualitative research design and specifically grounded theory significantly limits the ability to make broader generalizations due to the use of a purposeful sample instead of a random sample group. However, the purpose of this study was exploratory and attempted to move beyond evaluating the measured effectiveness of the program. Grounded theory was purposefully chosen to seek a deeper understanding of the impact of participating in Partners in Policymaking and to understand the features of the program that had the greatest impact. Interviews were conducted with key informants not with the purpose of quantifying and generalizing outcomes to all participants but rather to seek a symbolic, descriptive explanation of what is occurring from each individual's perspective.

The sample size of this study was limited in both number and characteristics of the subjects chosen. Factors such as time availability of the researcher and prospective subjects as well as financial and logistical constraints further limited the subject pool. Using grounded theory, these factors were

minimized with the use of theoretical and purposeful sampling instead of random selection from a population and the methodology of saturation of themes.

The sample was limited because only parents of children with disabilities were selected and other participants in the Partners in Policymaking program were excluded. The decision to include only parent participants was intentional since parents of children with disabilities represent a specific target audience with unique demographics, needs, experiences, and understanding. Because individuals with developmental disabilities provide a distinct perspective it is important to separate their voices from other participants

Despite its limitations, this study has important implications for programs that provide information and training to families of children with disabilities. This study also provides greater depth into understanding the positive outcomes associated with graduating from Partners in Policymaking and for understanding the needs of parents of children with developmental disabilities.

Future studies should seek to understand what facilitates the concept of “readiness” for families to receive the information and how being ready for different types of information and interactions could influence the intensity and type of transformation that occurs for training participants. Other areas of future research should focus on understanding how historical perceptions and stereotypes of disability impacts the types of services and supports families access for their child with a disability. Future research must include the perspective of all family members, self-advocates, parents, sibling and others who identify as a family member.

Future studies should utilize advocacy and pragmatic worldviews of research which recognize the nature of reality as being multiple and political (Crotty, 1998). It is important that any research in this field is directly applicable to current policies and practices and includes individuals with developmental disabilities and their families as researchers in the development, design, analysis and dissemination. It is crucial that emancipatory and empowerment-based research methods, such as mixed methods, are employed in future disability studies in order to stop the negative perpetuation of stereotypes of individuals with developmental disabilities. In research, methodology, results and dissemination must serve as a means for creating equal, barrier free societies for all people.