

UNDERSTANDING THE PARTNERS IN POLICYMAKING PROGRAM AND  
THE IMPACT OF PARTICIPATION ON PARENTS OF CHILDREN  
WITH DEVELOPMENTAL DISABILITIES IN MISSOURI

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MICHELLE C. REYNOLDS

Masters of Occupational Therapy, Rockhurst University, 1999  
Bachelor of Arts, Rockhurst University, 1996

Kansas City, Missouri  
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Michelle C. Reynolds, Candidate for the Doctor of Philosophy

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ABSTRACT

Parents are critical partners in the lives of individuals with developmental disabilities; however, they often lack an understanding of available resources or they do not know how to navigate the disability service system to obtain the services they need. Advocacy and leadership skills along with basic knowledge of best practices can assist individuals with disabilities and their families in obtaining the services they need while limiting societal and systematic hurdles which may prevent them from living their lives as fully participating citizens.

The Partners in Policymaking program, which exists both nationally and internationally, trains 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. Previous research into the effectiveness of the program has shown increased advocacy activities of the participants; however, these studies do not seek an understanding beyond the anticipated outcomes nor identify what features may lead to these outcomes.

Using grounded theory, a substantive theory is presented to describe program features and identify outcomes of the Partners in Policymaking program in Missouri. Fourteen parents of children with developmental disabilities who participated in the program were selected using theoretical sampling to participate in semi-structured interviews. Inductive and constant comparison is used to interpret the data until saturation of themes was reached.

Seven themes are presented as the key elements which made the Partners in Policy program meaningful for the parents which are: (1) being ready, (2) respect, (3) changed perceptions, (4) membership, (5) understanding possibilities, (6) navigating a future, and (7) decreased intimidations. These themes impacted parents in such a way that they were transformed by their participation in the program.

These findings are significant because they provide additional details about the impact of the Partners in Policymaking program from the perspective of the parents beyond the results of previous studies. This study will assist in the development of future training programs and can be used as a foundation to further research on family support. The result of this study is a substantive theory that concludes that *parents “ready” to participate in the Partners in Policymaking program in Missouri experience a transformation in their perception about the future for their child with a disability.*

## APPROVAL PAGE

The faculty listed below, appointed by the Dean of Graduate Studies, have examined a dissertation titled “Understanding the Partners in Policymaking Program and the Impact of Participation on Parents of Children with Developmental Disabilities,” presented by Michelle C. Reynolds, candidate for Doctorate of Philosophy degree, and certify it is worthy of acceptance.

### Supervisory Committee

Joan V. Gallos, Ph.D., Committee Chair  
Department of Public Affairs & Administration

Linda M. Breyspraak, Ph.D.  
Department of Sociology

Patricia J. Kelly, Ph.D.  
Department of Nursing

Robert D. Herman, Ph.D.  
Department of Public Affairs & Administration

David O. Renz, Ph.D.  
Department of Public Affairs & Administration

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Reaching this destination is just the beginning of a lifelong journey of discovery and exploration to enhance the lives of individuals with developmental disabilities and their families. I am grateful to everyone that has traveled with me to this point and excited about where we are headed together in the future.

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for my husband, Steve and my two sons, Preston and Brayden,  
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## CHAPTER 1

### INTRODUCTION

#### **Statement of the Problem**

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 the needs of the families are being met.

#### **Purpose of the Study**

The Partners in Policymaking is a widely recognized program in the United States that was created to support families as they build their capacity to serve in this role. 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. My study seeks to understand the meaning of the experience from the perspective of the participant and to gain a deeper understanding into what is causing the powerful impact. My research study will serve to begin to fill this gap by the use of grounded theory to identify the vital aspects of the Partners program that facilitate change.

### **Overview**

To understand the Partners in Policymaking program, it is important to understand the context and history of our understanding and response to disability and to families, in general. The perceptions of society, trends, practices and policies that have evolved over the years have determined the nature, settings and types of interventions and supports for persons with disabilities and their families. Amidst this evolution, families have remained the constant in the lives of persons with disabilities however the needs, strengths and desires of the family have not always served as the catalyst to the systems and policies that have been designed and put into practice.

Chapter One provides a historical overview of both the framework used by professionals to respond to disability and for understanding families raising a child with a disability, highlighting the origin of family support and the theories that serve as the foundation for providing family support using a family-centered approach. This chapter lays the groundwork for understanding the context of when, why and how the Partners in Policymaking program was developed. It concludes with an overview of the state and

federal disability policies, provided chronologically within the context of the family support movement.

### **History of Disability**

The development of services and supports for individuals with developmental disabilities and their families has progressed from removing individuals with disabilities from their families and society and warehousing them in institutions for training and protection to now empowering individuals with disabilities to work, play and live in the community as any other citizen (Braddock, 2002). What began as a medical model focused on a need to fix an individual with a disability, dictated by physicians and strengthened by the advances in science and medicine (Bazyk, 1989; Larimore, 1993; Turnbull & Turnbull, 1990) has evolved into a model where disability is understood within a social context where it is the environment that needs to be changed (Marks, 1997). The medical model focused on individual pathology and attempted to prevent disabilities or to cure people who had them, viewing disability as a personal tragedy (Johnstone, 1998; Marks, 1997). Services and supports using this model were designed to fix the person and to make the disability go away. Research focused on discrete behaviors or syndromes with positivistic, often experimental designs in controlled environments such as hospitals or clinics (Mary, 1998; Scheerenberger, 1987).

In the mid-twentieth century the model for understanding disability began to be viewed within a societal context. That is, barriers in society were what needed to be fixed or changed not individuals (Braddock, 2002; Fougeyrollas & Beauregard, 2001; Oliver, 1990; Shakespeare, 1997). For example, while a person in a wheelchair was once viewed as not having the ability to navigate a flight of steps which prevented him or her from entering a

building, the focus has shifted to the lack of an accessible entrance as the reason they are unable to enter.

The social construct view of disability has had a major impact on the way services and supports are provided to individuals with developmental disabilities and their families. Goals of programming are now focused on creating meaningful lives for people with disabilities, as opposed to defining activities to fix or rehabilitate the person. This shift has also changed the language of the disability field and the delivery of services; persons are no longer identified using their diagnosis but are recognized as a *person first* and services are controlled by the person receiving them as opposed to medical professionals. The social construct view also changed where services are provided to individuals with disabilities; services are no longer being provided in controlled medical settings but rather in the community with non-medical professionals providing care. This paradigm shift brought about the recognition that parents and caregivers needed services and supports that would enable them to successfully raise their family member at home. These services and supports are recognized in the disability field as family supports. Table 1 distinguishes the differences between the medical model and the social construct model as applied within the disability field.

Table 1

*Medical Model vs. Social Construct*

<b>Categories</b>	<b>Medical Model</b>	<b>Social Construct</b>
Focus	Fix or cure the individual	Adapt or make accommodations to environment
Locus of Control	Dictated by doctors and professionals	Person with disability and families make decisions
Emphasis	Focused on discrete behaviors and syndromes	Focuses on creating meaningful lives and relationships
Interventions	Controlled environments, such as hospitals and institutions	Living in community in homes, apartments, with families
Providers	Medical professionals provided care	Direct care staff, personal care attendants, and family members provide support
Language	Patients or by diagnosis	Person first language

**History of Family-Centered Services and Supports**

The era of deinstitutionalization and the acknowledgement of the rights of individuals with disabilities (Jacques, 2003) created a positive change to how professionals responded to disability and the impact it had on families. In the nineteenth century the moral blame for childhood disability was assigned to the parents (Ferguson, 2002) and in an effort to stop this cycle, professionals removed the child from the family and society. Then in the early 1900s attention shifted to how children with disabilities inevitably damaged the family and professionals focused on treatments that would cure the child (Ferguson, 2002). In the 1950s professionals began focusing on interventions that would not only fix the child but that would also assist the mother in overcoming the burden and grief they were experiencing from having a child with a disability to care for.

Then, starting in the 1980s, the field began to acknowledge that families found strength and joy having a family member with a disability. This new way of thinking was supported by two complementary but unique models, family systems and resiliency theory. Both of these models recognized that families should be understood as a system of strength and resilience. These models became widely recognized and accepted in the field and now serve as the foundation for policies and practices that support families raising children with developmental disabilities known as the family-centered approach. This approach to the delivery of services, built on family systems and resiliency theory, is the foundation for the delivery of family support in the field today (Antonovsky, 1993; Ferguson, 2002; Parish, Pomeranz-Essley, Hemp, Rizzolo, & Braddock, 2001; Summers, Behr, & Turnbull, 1989) and will be used as the framework for my study. Table 2 highlights how our understanding of families raising children with disabilities has influenced how family support is provided using a family-centered approach.

Table 2

*History of Disability: Moving Toward Family Support*

<b>Era</b>	<b>Impact of Disability</b>	<b>Professional Response</b>	<b>Model</b>
Nineteenth Century	Blame assigned to parents	Remove the child from society	Eugenics
Early 1900s	Child damaged the family	Remove from family and cure the child	Medical Model
1950s	Child was burden on the family	Coping and Adjustment Theory: Counsel and train parents; fix the child	Coping and Adjustment
1980s to current	Child recognized as positive contributor within resilient and capable family system, with strengths and needs	Partner to provide family support and services to family and child in natural environments in community	Family Systems theory and Resiliency Theory formed the foundation for the family-centered approach

## **Family Systems Theory**

The development of the family-centered approach began with professionals recognizing the family as a system that could not be separated into parts (Ferguson, 2002; Maul & Singer, 2009; Summers et al., 2005). Known as a systems framework, Bonfenbrenner (1979) used a social ecological model that suggests individuals and families exist within the context of wider relationships- from the micro system of their own families to the more distal macro system of society. This systems framework explained how components of a system interact with one another to form a whole, focusing on the relationships and interdependence of all of the parts. As it relates to the study of families, it recognizes that families are made up of members that have individual needs as well as needs of the entire family. This shifts the focus of disability services from focusing primarily on the child to focusing on the family as a whole system (Turnbull, Turnbull, Erwin, & Soodak, 2006; Bailey et al., 1998).

Specifically, as it relates to disability, the Family Systems Theory provides a framework for understanding how families function and accommodate across the lifespan to having a child with a disability. This theory is based on the characteristics of the family as a single entity, such as family size, form, cultural background, socioeconomic status, and geographic location (Turnbull et al., 2006). The family is recognized as a whole made up of subsystems (marital, parental, sibling and extended) which are separated by boundaries of cohesion and adaptability that define interaction within and outside of the family.

Family systems theory takes into account the interaction of the family characteristics and subsystems on how the family responds and functions in the area of affection, self-esteem, spirituality, economics, daily care, socialization, recreation and education. By

utilizing a theory that recognizes the characteristics, interactions and needs from the specific perspective of the family as a system, professionals can match the types of supports and services needed to support the person with a disability and ultimately support the entire family (Knox, Parmenter, Atkinson, & Yazbeck, 2000; Mitchell & Winslade, 1997; Turnbull, Summers, & Brotherson, 1983). This expanded the existing disability service system framework from only focusing on the needs of the child to also focusing on the parents and caregivers as a system.

### **Resiliency Theory**

In addition to expanding its focus on all of the family members, the family-centered approach focused on the strengths and capabilities of the families as opposed to only looking at the deficits and needs. For many years research evaluated a families' ability to function based on the levels of stress and depression of the parents using a model known as the stress and coping perspective. (Floyd & Gallagher, 1997; Greenberg, Seltzer, Krauss & Kim, 1997; Pearlin, 1989; Pruchno, Patrick & Burant, 1996; Risdal & Singer, 2004; Thoits, 1995). This model focused on the presumed negative impact on family life caused by the burden of care giving (Crnic, Friedrich, & Greenberg, 1983; Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996). As research into families raising children with disability evolved, research moved away from the pathological dysfunction of families and began to recognize the resourceful ways that families adapt and provide care.

This contrasting research suggested that most parents of a child with a developmental disability demonstrated a pattern of resiliency in their well-being (Costigan, Floyd, Harter, & McClintock, 1997; Seltzer, Greenberg, & Krauss, 1995) and were able to positively cope and adapt (Glidden, 1989; Ramey, Krauss & Simeonsson, 1989; Turnbull, Blue-Banning,

Turbiville, & Park, 1999). According to McCubbin and McCubbin (1989), families develop “resiliency or an ability to respond to and eventually adapt to situations and crises encountered over the family life cycle” (p.6). Families are able to develop strengths and capabilities in order to achieve balance and harmony for optimal family functioning.

The Resiliency Model recognizes that families can function competently and overcome crises through a process of adaptation (Patterson, 2002). Expanding on the family stress model developed by Reuben Hill in 1949, McCubbin and McCubbin (1989) proposed that a family’s strengths (cohesion, adaptability, family hardiness, family time and routines), resources, positive appraisal of the situation, and the depth of coping and problem-solving strategies are all positively related to the family’s ability to adapt to a situation. For families that have a child with a disability, this theory recognized their ability to adapt, grow and respond to hardships or changes and gain harmony and balance in their life.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### **Types of Family Support Services**

Although researchers opinions have been mixed throughout history regarding the positive and negative impacts of having a child with a disability, there is consensus that having a child with a disability creates a new and different set of challenges for families (Affleck, Tennen, & Gershman, 1985; Cho, Singer, & Brenner, 2001; Heller, Miller, & Factor, 2003; Horwitz, Reinhard, & Howell-White, 1996; Schwartz & Gidron, 2002; Singer, 2002). Families often are faced with emotional, social, physical and economic demands that they may not have experienced had their child not been diagnosed with a disability (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Itzhaky & Schwartz, 2000; Mak & Ho, 2007; McCollum & Hemmeter, 1997). In response to these additional demands, family support policies and services were designed to strengthen the family unit as they support their family member with a disability across the lifespan.

Family support is recognized as being inclusive of the entire range of formal and informal services provided by governmental and nongovernmental entities to support the entire family to keep their family member with a disability at home (Turnbull & Turnbull, 2000). Family support can consist of such services as respite, financial assistance, case management, home modifications, behavioral training or after-school programs (Bradley, 1992; Parish, Pomeranz-Essley, & Braddock, 2003). It also acknowledges informal relationships which consist of accessing spouse/partner, siblings, grandparents, friends, neighbors, co-workers, and other parents for information, emotional and care giving support (Thompson et al., 1997; Turnbull & Turnbull, 2000).

Family support is designed to empower and meet the needs of families as they serve in the role of caregiver (Bradley, 1992; Dunst, Trivette, & Deal, 1994; Knoll et al., 1992; Taylor, Knoll, Lehr, & Walker, 1989; Thompson et al., 1997) and to supplement and in some cases replace costly state run programs. Family support is also recognized as a strategy to advance autonomy and self-determination of both the family and ultimately the person with a disability (Wehmeyer & Palmer, 2000). The overall goal is to provide family support that leads to better psychological health (less stress, reduced anxiety, less depression) and increased levels of well-being and life satisfaction of all family members (Ireys, Chernoff, DeVet, & Young, 2001; King, Teplicky, King, & Rosenbaum, 2004).

Family supports delivered within the family-centered approach increases the families' sense of control and ultimately enhances the quality of life for the individual with a disability and the family as a whole (Bowman & Virtue, 1993; Knox et al., 2000; Summers, McMann, & Fuger, 1997; Summers et al., 2005; Wheeler, 1996). This is accomplished by recognizing the family as the constant in the family member with a disabilities' life and serves as the main unit for all planning and intervention. By focusing on the families' relationships, strengths, and perceptions and providing services in a culturally responsive manner the family is able to adjust to and develop a positive future for all family members (Bradley, 1992; Dunst, Trivette, & Deal, 1988; Friesen & Koroloff, 1990; Johnson, McGonigel, & Kaufmann, 1989).

To better understand the complexity of family support, the literature identifies three broad categories for the types of services that are offered to the family: instrumental, emotional and informational/educational. Instrumental supports are the services needed in the home to meet the day-to-day demands of caring for the person with a disability. Emotional

and informational/educational supports assist the caregiver and family in increasing their understanding about the disability and strategies for navigating the community services. These two supports also enhance a families knowledge of how and what is possible when planning a future for their child and family. Figure 1 describes the framework for family support through the combination of these three main categories of family support and the family-centered philosophical approach.

<p><b>Family Support is a family-centered value-based approach:</b>          - driven by the family and family member with ID/DD,          - focuses on the strengths, capacity, and diversity of family,          - builds on networks of all family members and community, and          - recognizes the family as a system</p>		
<p><b>Instrumental Supports:</b> Day-to-Day Needs</p>	<p><b>Emotional Supports:</b> Mental Health and Self-efficacy</p>	<p><b>Information and Training Supports:</b> Knowledge and Skills</p>

*Figure 1: Framework for Family Support*

**Instrumental Supports**

Families indicate it is the day-to-day caregiving needs which require the most support (Dyson, 1991; Frey, Greenberg, & Fewell., 1989; Friedrich & Friedrich, 1982; Kazak & Marvin, 1984; Mahoney & O’Sullivan, 1992). The demands of caregiving are substantially greater for children with disabilities than for children without disabilities (Erickson & Upshur, 1989; Harris & McHale, 1989, Mahoney & O’Sullivan, 1992). These demands

entail additional time and support needed for feeding, bathing, dressing, as well as transportation, special equipment, and additional medical care needs (Itzhaky & Schwartz, 2000).

In addition, having a child with a disability can sometimes bring greater financial instability for families because of additional medical, therapy and support costs (Parish et al., 2009). In the US, 28% of children with disabilities live below the federal poverty threshold as compared with 16% of children without disabilities (Emerson, 2007; Fujiura & Yamaki, 2000; Parish et al., 2009). This is often compounded because parents of children with disabilities have lower rates of and diminished opportunities for employment than parents of children without disabilities (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).

Instrumental supports are the most common types of supports to assist the family and the child with a disability overcome the day-to-day challenges. These can be defined as concrete services such as respite or child care, community supports, specialized professional supports and therapies as well as financial assistance and connection to recreational opportunities (Bailey, Blasco, & Simeonsson, 1992; Bradley, 1992; Friesen & Koroloff, 1990; Singer & Irvin, 1989). These types of supports are designed to reduce the impact of having a child with a disability on the family in terms of the caregiving and financial responsibilities

Although empirical studies specific to instrumental supports are limited, positive outcomes have been identified by some researchers. In one descriptive study, family caregivers who participated in family support programs in Iowa, Illinois and Michigan reported positively about the availability of cash vouchers and subsidies, but they emphasized the need for information, advice and assistance on navigating service systems

regardless of resource availability (Agosta, 1992). These outcomes were further supported in findings from other states where families reported less unmet needs than families who did not participate in the family support program during the same time period.

In a more recent study conducted over a nine year period, Caldwell, Heller, and Taylor (2007) found other positive outcomes such as higher satisfaction with services, increased communication participation and decreased caregiver burden from families that participated in a consumer-directed program that allowed families to control and direct an individualized budget. To further describe instrumental supports, longitudinal data has been collected from every state that provides family support services and compared in the *State of the State in Developmental Disability* (Braddock, 2002). This report provides an overview of service use and cost but it does not provide details on the outcomes of these services. Table 3 highlights the studies found that focus on instrumental supports for families raising children with disabilities.

Table 3

*Instrumental Supports: Day-to-Day Needs*

<b>Research</b>	<b>Findings</b>
Evaluating family support services: Two quantitative case studies, Agosta (1992)	Positive response to cash vouchers and emphasized need for information and advice on navigation and resources available
Longitudinal outcomes of a consumer-directed program supporting adults with d.d. and their families, Caldwell et al, (2007)	Nine year study of 38 families showed decrease in unmet needs, increase in service satisfaction, increased community participation and decreased caregiver burden
State of the State in Developmental Disabilities, Braddock (2002)	Longitudinal and state comparison data on service use and cost of elements of family support

## **Emotional Supports**

In addition to the extra day-to-day demands, parents of children with disabilities often report more parenting stress and mental health problems than parents without children with disabilities (Beckman, 1991; Dyson, 1991; Emerson, 2003) which is exacerbated by the isolation and stigma associated with disability (Bradley, 1992). Many families indicate experiencing a recurring sense of loss of the person whom their child might have become along with the ongoing fear for what the future may bring for their child (Blacher, Lopez, Shapiro, & Fusco, 1997; Freedman, Krauss, & Seltzer, 1997; Hassall, Rose, & McDonald, 2005; Lefley, 1996; Turnbull et al., 1993). To cope with these stressors, families often seek emotional supports to assist them as they adapt to new situations.

Families can meet their emotional needs through formal supports provided by professionals such as counseling or therapy and informal supports provided by other parents or peers who are also experiencing raising a child with a disability. In addition, organizations run by families who have children with disabilities have been established to provide peer support opportunities in both one-on-one and group situations (Davidson & Dossier, 1982; Santelli & Marquis, 1993; Santelli, Poyadue, & Young, 2001; Santelli, Turnbull, Marquis, & Lerner, 1997). Currently, there are more than 2,000 national family organizations with many of them having state and local groups (Turnbull & Turnbull, 2001). Whether it has been offered by professionals or family organizations, emotional supports are beneficial for decreasing the isolation and additional stress that parents may experience (Bailey et al., 1992, Friesen & Koroloff, 1990; Gartner, Kerzner-Lipsky, & Turnbull, 1991; Singer et al., 1999; Summers et al., 1989).

In a meta-analysis of the effectiveness of group-based parenting programs for improving maternal psychosocial health, the author found 23 studies from 1970 to July 2000, which had control trials with an experimental and control group and at least one standardized instrument (Barlow, Coren, & Stewart-Brown, 2002). Despite some limitations such as lack of pre-test, the results were positive in that they supported a statistical difference favoring the intervention group for a decrease in depression and anxiety and an increase in confidence, self-esteem and relationship with partner. This study provides promising evidence that emotional support services can have a positive impact on caregivers who are raising children with disabilities.

These findings are consistent with a study conducted between the years 1989-1993 with responses from over 375 local parent-to-parent programs and 600 parents who requested parent-to-parent support or parents who served as mentors. Santelli and colleagues (1997) reported that over 60% of the parents surveyed reported the most important aspects of the match were the emotional support of sharing an experience with another parent and receiving information about the specific disability along with receiving strategies for coping with the day-to-day caregiving needs of the child. Table 4 summarizes the findings of these studies on emotional supports.

Table 4

*Emotional Supports: Mental Health and Self-efficacy*

<b>Research</b>	<b>Findings</b>
Meta-analysis of the effectiveness of parenting programmes in improving maternal psychosocial health. Barlow, Coren, & Stewart-Brown, 2002	23 studies from 1970 to 2000 with control trials with experimental and control groups and one standardized instrument Found decreased depression and anxiety, increased confidence, self-esteem and relationship with partner
Parent-to-Parent programs: A resource for parents and professionals, Santelli et al, 1997.	375 local P2P program administrators and 600 referred and veteran parents from 43 of 50 states from 1989 – 1993 participated in survey 60% mention emotional support of sharing experiences, receiving info about disability and day-to-day as most important part of match.

**Informational and Educational Supports**

Informational and educational opportunities for families and individuals with developmental disabilities are crucial form of family support (Bailey, 2001; Bailey et al., 1999; Heller, Caldwell, & Factor, 2007). Families often report lack of information or misinformation as one of the main barriers to supporting their child and their family (Freedman & Boyer, 2000; Westling, 1996). They often seek information about the disability itself and the types of interventions, therapies and services available to assist their child and their family (Bailey, 2001; Bailey et al., 1992).

Families also need to develop skills to assist them in navigating, identifying, accessing and advocating for needed services within the educational, vocational, housing and financial planning arenas (Friesen & Koroloff, 1990; Heller et al., 2007). By developing the capacity of parents and caregivers to solve problems, develop coping strategies and advocacy skills, families become more independent and have increased levels of self-efficacy (Singer

& Irvin, 1989). These crucial skills are charted as outcomes of government services for families receiving early intervention, child mental health, and educational system services (Bailey et al., 1998; Mahoney et al., 1999; Turnbull & Turnbull, 1996).

As the field has come to recognize the significant role of families, the focus of parent education programs has evolved with it. The first educational training programs were designed to fix parents that had given birth to a child with a disability and then evolved to helping the parent overcome the tragedy of having a child with a disability. Then training moved to using the parent as an instrument of intervention. The focus is now on assisting families to develop the skills and confidence needed to understand their child's disability, navigate the resources available, and to partner with professionals in obtaining services for their child (Turnbull & Turnbull, 2000).

Although studies focusing on instrumental and emotional supports are limited, a plethora of educational training program studies can be found in the literature (Singer, 2002). Schultz et al. (1993) tested the group-based intervention, Caring for Parents Caregivers program. This multi-component intervention consisted of six weekly sessions focusing on stress-management, relaxation, problem solving, accessing social support, networking, and awareness of self and others. Parents were randomly assigned to a treatment and control group and 12-month evaluation data were analyzed. Results showed significant improvements in psychological well-being in the treatment group for both mothers and fathers. The outcomes of this study are encouraging given the strong internal validity of the study.

Researchers focusing on autism have evaluation programs that focused on parent education and behavioral changes in the child. Bitsika and Sharpely (2000) described

outcomes of an eight week stress management group intervention for parents. Parents reported positive outcomes related to the group experience and the techniques learned. Although pre to post self-rated anxiety and depression scales did not significantly change within the control group, there was a difference compared to the group of parents that did not participate in the program. In another study, Bristol and colleagues showed parents involved in a training and education program for their child with autism reported reduced depression 18 months after treatment (Bristol, Gallagher, & Holt 1993). This study highlights how educational training can show positive changes for parents and the child with a disability.

Numerous studies have shown positive outcomes using parent education based on self-efficacy. In an experimental study Koegel, Symon and Koegel (2002) evaluated a parent education program that used motivational techniques that were incorporated into their daily interactions with their children. The results demonstrated gains during interactions with the parents compared to the pre test in their home environment. Brookman-Frazee (2004) also investigated parent education programs but she compared two facilitation models: one directed by a clinician and one facilitated in partnership with the parent. Parent stress, parent confidence, child affect, and child responses to engagement were measured using standardized instruments completed by two researchers that were blind to the experimental conditions. Mothers in this study were observed to demonstrate lower levels of observed stress and higher levels of observed confidence during the partnership condition compared to the clinician directed condition. Children also had a positive response to the partnership condition compared to the clinician directed condition. Although the small sample size was a limitation to this study, this research does support the notion that empowering parents to

participate in collaborative problem-solving with professionals may relate to parent confidence and stress.

More recently, researchers have expanded their focus to move beyond decreasing levels of stress and anxiety for parents to identifying how family support services can impact the levels of self-efficacy and empowerment of the parent and the child with a disability (Dempsey & Dunst, 2004; Heller, Miller, & Hsieh, 1999; Wehmeyer, 1992). The literature defines empowerment as a parent's willingness and confidence in learning new skills, managing life routines, and being active in their child's treatment as well as community and political systems (Heflinger, Bickman, Northrup, & Sonnichsen 1997; Koren, DeChillo, & Friesen, 1992). Empowerment interventions, such as parent education, shift the locus of control to the family to enable them to acquire the skills to solve their own problems and meet their family goals (Jones, Garlow, Turnbull, & Barber, 1996; McDowell & Klepper, 2000).

One such study identifies the empowerment effects of teaching leadership skills to adults with a severe mental illness and their families. Hess and colleagues (2001) trained 160 participants in five different training sessions. The responses from the participants over a two-year survey indicated that training supported collective advocacy activities beyond the time of the project. Although this study focuses on a different target group it is very similar to the Partners in Policymaking program and the findings support the positive impact that both of these program can make in terms of political advocacy. Table 5 summarizes the studies regarding the impact of information and educational supports.

Table 5

*Information and Educational Supports: Skills and Knowledge*

<b>Research</b>	<b>Design</b>	<b>Findings</b>
Psychoeducational supports for parents of children with intellectual disability: An outcome study. Schultz et al (1993).	Random Control trial of multi-component group-based intervention.	Improvements in psychological well-being
The effectiveness of parent management training to increase self-efficacy in parents of children with Aspergers syndrome. Sofronoff and Farbotko (2002)	Random Control Trial ; 45 mothers and 44 fathers participated in training with pre and post tests	Decreased in problem behaviors in child compared to control group and increase in self-efficacy of parents overall
Collateral effects of behavioral parent training on families of children with d.d. and behavior disorders. Feldman and Werner (2002)	Quasi-experimental ; survey of 18 families participated in behavioral parent training five years post discharge	Decrease in child behavior problems, and family stress and increase in quality of life and self-efficacy
Empowerment Effects of Teaching Leadership Skills to Adults with a Severe Mental Illness and Their Families. Hess, Clapperm Hoekstra, and Gibison (2001)	Descriptive; 160 Academy Participants (92 with consumers and 68 family members) surveyed over a two-year period of 5 Academy Training sessions	Positive qualitative outcomes that support collective advocacy action of participants beyond scope of project
Autism: Pivotal response intervention and parental empowerment. Koegel, Symon, and Koegel (2002)	Experimental; 10 children and their families participated in a multi-phase intervention	Gains during interactions with the parents compared to the pre test in their home environment
Using parent/clinician partnerships in parent education programs for children with autism. Brookman-Fraze (2004)	Experimental; 3 boys and their mothers participated in this study measured using standardized instruments completed by two researchers that were blind to the experimental conditions	Mothers demonstrated lower levels of observed stress and higher levels of observed confidence during the partnership condition compared to the clinician directed condition. Children also had a positive response to the partnership condition compared to the clinician directed condition

CHAPTER 3:  
EVOLUTION OF DISABILITY POLICY AND THE PARTNERS IN POLICYMAKING  
PROGRAM

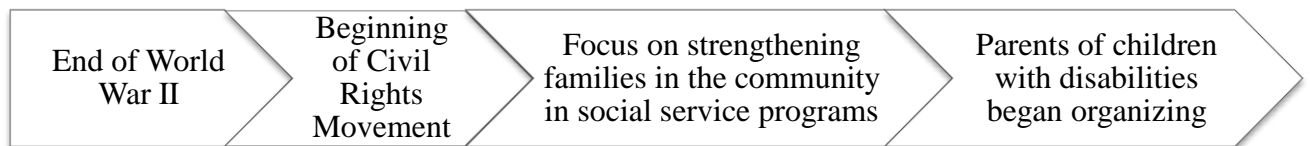
**Family Support Movement**

The origin of the family support movement in the disability field is rooted in the United States larger societal context and events of the 1950s. As the war was ending, the country began to prosper. Women were working outside of the home, families were buying homes, medicine was improving and the economy started to boom. At the same time, the civil rights movement was starting where citizens were demanding equal rights and standards across the country. These political, economic and societal factors set the stage for what is recognized as the family support movement.

The larger social service family support movement began with the general social services movement in the 1960s, with self-help and grassroots efforts advocating for the development of community-based programs and supports to strengthen family functioning (Dunst, Johanson, Trivette, & Hamby 1991; Weissbourd, 1987; Weissbourd & Kagan, 1989; Zigler & Black, 1989). This movement focused on families in particular social or economic categories; such as poverty, joblessness, poor health, or other factors (Kagan & Weissbourd, 1994). The family support movement evolved to adjust to the changing composition and needs of families.

During this same time, the parent movement in the disability field was gaining strength and momentum. Parents organized to support each other and to speak out for their sons and daughters with disabilities (Braddock, 2002). Families strongly supported the idea that their child was not broken and did not need to be removed from their home to be fixed

(Bazyk, 1989; Cournoyer, 1991; Dunst et al., 1988; Turnbull & Turnbull, 1990). These parent groups were the first to bring disability issues of segregation, lack of education and training, and lack of support services to legislators, educators and the public (Goode, 1999). The parents highlighted the need to create a system of support that would enable their sons and daughters to go to school and receive the services necessary to continue living as a family. Figure 2 highlights the context for the development of the family support movement.



*Figure 2: Foundations of the Disability Family Support Movement*

This momentum created the first recognized disability family support movement. Families began identifying and campaigning for the development of programs that would support their child within community schools and the disability service system resulting in considerable progress in public policy for individuals with disabilities (Silverstein, 2000). These included the passage of Title XIX of the Social Security Act (Medicaid) which funded intermediate care facilities as opposed to funding only institutions; the ruling in the *Wyatt v. Stickney* case that found that individuals with disabilities had a constitutional right to treatment; passage of Section 504 of the Rehabilitation Act which protected individuals with disabilities against discrimination; and the landmark passage of the Education of All Handicapped Children Act (now known as IDEA). Also, during this time the Developmental Disabilities Services and Facilities Construction Amendments of 1970, P.L. 517 was passed, the first congressional effort to address the needs of a group of individuals with

disabilities designated as developmentally disabled. This Act would later become the Developmental Disabilities Act (DD Act). These new policies laid the foundation allowing parents to care for their child at home and in their communities.

State governments establishing policies and programs to support and strengthen families of young children (Weiss, 1989) represent the next wave of the family support movement. States recognized that families needed assistance to support their child at home. In the early 1970's Pennsylvania developed one of the earliest state-funded family support initiatives for children with intellectual disabilities. Over the next two decades, all other states and the District of Columbia fielded some type of family support for children, each offering different types of services and supports intended to do "whatever it takes" to assure that children could grow up with their families (Daniels, Butz, Goodman, & Kregel, 2009). The following table summarizes the third wave of disability family support.

Federal legislation soon followed, representing a third wave of family support that refocused federal departments and initiatives on family-oriented and community based programs. Early intervention Special Education legislation (IDEA Part C) passed in 1986 that mandated states develop systems that utilize individual family service plans to integrate health, education and social service systems. Part C recognizes that the "family is the most important constant in a child's life and the family environment is the richest context for social, emotional, cognitive and physical development" (Hooper & Umansky, 2004, p. 92). IDEA reauthorization also indicated parents were to be viewed not only as recipients of services but as the accountability mechanism to monitor professionals as they implemented IDEA requirements (Turnbull & Turnbull, 2000; Turnbull, Turnbull, & Wheat, 1982). The same year the Developmental Disabilities Act mandated its funded entities to develop a

meaningful role for families in the provision of services and policies. This significant mandate is the impetus to the development of the Partners in Policymaking program and is described below in greater detail. Then, the Department of Health and Human Services-Division of Maternal and Child Health, soon following in 1989, adopted the philosophy that services for children with special health care needs should be family-centered, community-based, coordinated, comprehensive, and culturally competent with passage of P.L. 101-239 Omnibus Budget Reconciliation Act. (Brewer, McPherson, Magrab, & Hutchins, 1989; Hutchins & McPherson, 1991; Shelton, Jeppson, & Johnson, 1987). These federal policies represented the transformations that were occurring across the country related to family support and to the recognition and rights of families. Figure 3 shows the progress of disability family support in public policy.

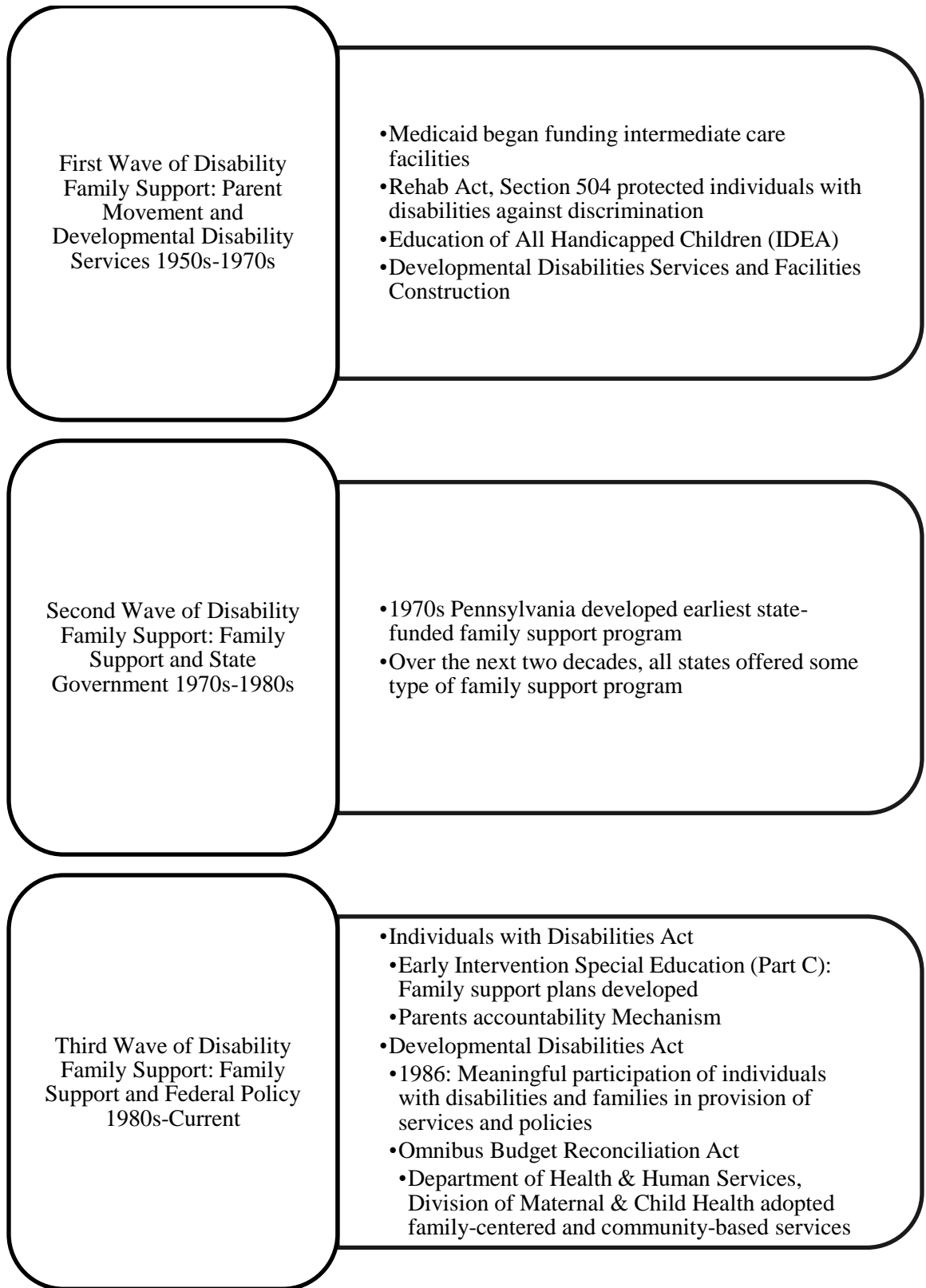


Figure 3: Progress of the Disability Family Support Policy

## **The Developmental Disabilities Assistance and Bill of Rights Act**

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), originally titled the Developmental Disabilities Services and Facilities Construction Amendments of 1970, P.L. 517, was the first federal legislation specific to developing services for persons with developmental disabilities, with its original focus on the development of facilities and programs. However, by 1986, the DD Act had evolved along with our understanding of disability, to recognizing the significant role that families play in the everyday support for individuals with disabilities and in the development of policies that most impacts their lives and services. The following section will highlight how the concept of family support threads throughout this federal legislation and how the DD Act served as the impetus to the development of the Partners in Policymaking program.

The DD Act is designed to assure 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. The Administration of Developmental Disabilities serves as the federal agency that oversees the DD Acts implementation. The goals of the DD Act are accomplished through funding provided to four distinct but

integrated entities in almost every state and territory; Councils on Developmental Disabilities, Protection and Advocacy Services, University Centers on Excellence in Developmental Disabilities, and Projects of National Significance. Table 6 describes the overall goal and structure of the DD Act.

Table 6

*DD Act: Goal and Structure*

<b>Goal: Assure that individuals with developmental disabilities and their families participate in 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.</b>	
University Centers on Excellence	Interdisciplinary training for students and professionals, cutting edge research, technical assistance and direct services and supports
Protection and Advocacy Services	Protect legal and human rights of individuals with disabilities through legal and administrative means
Developmental Disabilities Councils	Develop innovative and cost effective strategies to promote systems change in states
Projects of National Significance	Support local and state projects that can be replicated across the country

The DD Act identifies Councils on Developmental Disabilities in each state and charges them with developing innovative and cost effective strategies to promote systemic change. The role of Protection and Advocacy Systems are to protect the legal and human rights of individuals with developmental disabilities through legal, administrative and other appropriate remedies. University Centers for Excellence in Developmental Disabilities (UCEDDs) provide interdisciplinary training to students and professionals, engage in cutting-edge research, provide technical assistance, and direct services and supports to individuals with disabilities and their families. While Projects of National Significance support local and state projects which address emerging areas of concern that can be replicated across the nation. Each of these entities also identifies strategies for coordinating activities that would accomplish the overall goals of the DD Act, such as joint demonstration projects, shared information dissemination strategies or collaborative systems change initiatives.

With each reauthorization of the DD Act, the role of the family and individuals with developmental disabilities has grown in significance. Beginning in 1986 the reauthorization language was amended to recognize and mandate the role of parents and family members in the provision of services and policies for those with developmental disabilities. This amendment required that programs develop and implement meaningful participation and training for parents and family members. This is accomplished using a myriad of strategies; such as hiring family members and self-advocates in key roles, developing community advisory boards with family and self-advocate leaders from the state and infusing family-leaders into interdisciplinary training opportunities.

In 2002 the DD Act was again reauthorized, this time it wasn't just the role of families but the concept of family support overall that was elevated within the Act as Title II: Family Support. Family support was now explicitly recognized as an area of need and focus for research, education and services however no funding was appropriated (Beach Center on Disability, 2007a; Daniels et al., 2009). In response to this, the Administration on Developmental Disabilities used funding from the Projects of National Significance program to develop family support initiatives for individuals with developmental disabilities and their families (Knoll et al., 1990). These initiatives were designed to emphasize the important role of family and community members in the lives of individuals with disabilities with the provision of necessary support services (US Senate Report 100-113, 1987).

Although funding continues for several projects across the country, professionals within the field recognize the need to develop an integrated, cohesive system of support for families that moves beyond what the past projects have focused on. Currently however the Administration on Developmental Disabilities is engaging stakeholders in conversations to

facilitate the development of a national agenda and policy recommendations to further elevate the importance of and funding for family support. This is especially important as families are demanding services in the community, as opposed to segregated services in the community and as fiscal constraints are changing the scope and nature of services provided.

### **Partners in Policymaking Training Program**

In response to the federal DD Act and the increased role of families it mandated, 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). The program also educates participants about current issues and state-of-the-art approaches to community services and supports.

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. Specifically in Missouri, the Missouri Council for

Developmental Disabilities has been hosting the Partners in Policymaking training program. Two hundred and ninety-nine participants have graduated from the program over the last 16 years.

Partners in Policymaking is an advocacy training program recognized internationally in the field of developmental disabilities by self-advocates, disability professionals and policymakers (Wang, Mannan, Poston, Turnbull, & Summers, 2004). The creators of the Partners program recognized the need to protect the integrity of the program as it quickly expanded into other states for implementation. To ensure the quality of the program, the Minnesota Governor's Council filed a trademark application in 1997 and received approval in December, 1999. This is significant to ensure the quality of the programs being implemented by other states and it also creates a standard for which to evaluate the program.

The Trademark application (1997) states:

“leadership training programs that bear the name Partners in Policymaking are expected to be a certain type of leadership program:

- Value based;
- Competency based;
- Teaches leadership skills, best practices, and how to influence public policy at all levels of government; conducted over eight, two-day weekends;
- Includes at least 1128 hours of training;
- Covers specific topic areas;
- Utilizes the expertise and experience of presenters with a national (as opposed to local) perspective and knowledge of best practices in the topic areas;
- Involves readings, homework, and a public policy project;
- Regularly updated and improved.

A comprehensive curriculum has been designed to meet the intended purposes of the Partners program and is updated to reflect current and best practices in the field of

disabilities. As stated in the curriculum, successful completion of the program will give

Partners graduates these competencies:

- Describe the history of services for, and perceptions of, individuals with developmental disabilities.
- Describe significant contributions of the parents' movement.
- Describe the history of the self advocacy and independent living movements.
- Describe the benefits and values supporting inclusion and quality education for students with and without disabilities.
- Outline specific strategies to achieve inclusion and quality education.
- Demonstrate knowledge of the service coordination system and what services may be available.
- Describe the importance of futures planning and self determination for individuals with developmental disabilities.
- Understand the principles of choice and control of resources in futures planning.
- Understand the reasons for and the importance of proper positioning techniques for individuals with disabilities.
- Describe examples of state-of-the-art technologies for people with severe disabilities.
- Describe the importance of supported, competitive employment opportunities.
- Understand that a flexible, responsive system of supports for the families of children with disabilities is the corner stone for a true system of community supports for individuals with developmental disabilities.
- Understand the need for all individuals to experience changes in lifestyle across the life span.
- Know/understand the importance of home ownership/control as one of the defining characteristics of adult life in our culture.
- Understand the basic principles and strategies being used to support individuals with developmental disabilities in their own homes across the life span.
- Create a vision for the year 2020 (and beyond) for individuals with disabilities.
- Understand how a bill becomes a law at the state and federal levels.
- Identify critical federal issues and the process by which they can personally address their concerns.
- Demonstrate successful techniques for advocating for services to meet the needs of unserved and underserved individuals.
- Draft and deliver testimony for legislative hearings.
- Learn how to meet a public official and discuss issues.
- Identify strategies for beginning and sustaining grassroots level organizing.
- Understand the role of when and how to use the media to effectively promote their issues.

- Demonstrate proper procedures for conducting a meeting.
- Gain a basic understanding of parliamentary procedure and serving on boards.

### **Results 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.

After the first year of the program, Zirpoli, Hancox, Wieck, and Skarnulis (1989) reported on the responses of the 35 participants six months after participation. They reported that 57% of the participants had improved their self-advocacy skills, 89% obtained appropriate services for themselves or family member, and 82% felt prepared to be effective advocates. Data was also collected on the advocacy after graduation with over 68.6% having contacted a local, state and national official by phone, letters or office visits; 80% were serving on boards or committees; and more than 28% had presented to parent groups, conferences or published a letter.

The findings from the first year were supported by a follow-up study that looked at the first five years of the program (Ziripoli et al., 1994). Surveys were mailed to the 163 participants with 130 surveys completed and returned. The results indicated that participants were satisfied and that they had similar levels of improvement of self-advocacy skills (57% reported excellent) and ability to secure services as a result of participation (62% indicated

definitely yes). The level of advocacy after graduation was also similar to findings in the first report; 62% had contact with local, state or national official and at least 59% had contact by letter, mail or phone since graduation.

Findings were further supported by a study conducted in Iowa following the implementation of the Partners in Policymaking program there (Conconan-Lahr & Brotherson, 1996). Data was collected using three methods: (a) by a mailed survey from 43 of the 64 participants from 1990 to 1993, (b) 17 semi-structured telephone interviews and (c) two interactive focus groups. This study also identified supports and barriers for advocacy action as reported by the participants.

In addition to articles in academic, peer-reviewed journals several states contracted third party evaluators to develop findings to share with their funding sources or their boards to justify the continuation of their programs and to ensure that the programs were meeting their stated goals. Kate Toms and Associates (1997) reported on the New York Partners in Policymaking Program from 1990 to 1996 and Systemwide Solutions, Inc. (2004) used an action research approach to evaluate six years of Partners hosted in South Carolina from 1997-2003. Both reports used a mixed methodology of quantitative and qualitative surveys, interviews, and focus groups. Both reports confirmed participants' satisfaction with the program along with confirmation of participants actively engaging in advocacy activities. Table 7 summarizes findings from studies on the Partners in Policymaking program.

Table 7

*Evaluation of the Partners in Policymaking Program*

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

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 followed the same format and curriculum. Studies also indicate there are limitations to these findings 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 to rule out other causes of advocacy efforts (Balcazar, Garate-Serafini, & Keys, 1999). However, despite these limitations, the Partners in Policymaking program continues across the world today and serves as the most recognized training program in the developmental disability community.

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, this program results in positive satisfaction and outcomes for the participants, however few studies exist that explore additional outcomes and the specific factors that cause these changes. My study seeks to identify this information.

## CHAPTER 4

### METHODOLOGY

#### **Rationale for Qualitative Inquiry**

For this study, I use a qualitative research method to gain a deeper understanding of the impact of the Partners in Policymaking program on the parents that attended. By utilizing qualitative research methods I am able to explore and understand the meaning individuals or groups ascribe to a social or human problem, as opposed to the emphasis of a quantitative approach on the measurement and analysis of causal relationships between variables, not processes (Creswell, 2009; Denzin & Lincoln, 2003). Qualitative methods enable me to collect, analyze and interpret rich and descriptive data from the perspective of the participant, the parents who participated in the program.

Specifically, the grounded theory of Corbin and Strauss (2008) serves as the foundational qualitative approach for my study. This approach is used to generate a substantive-level theory of the impact of the experience of participating in the Partners in Policymaking program on the individual. Grounded theory is recognized as a means for providing a systematic approach to theory development; describing specific methods for sampling, study procedures and data analysis (Bryant & Charmaz, 2007; Creswell, 1998; Patton, 2002; Strauss & Corbin, 1998). Table 8 demonstrates the differences between quantitative and qualitative inquire, specifically highlighting grounded theory.

Table 8

*Comparison Between Quantitative and Qualitative Inquiry*

<b>Quantitative Inquiry</b>	<b>Qualitative Inquiry: Grounded Theory</b>
Measure and analyze causal relationships between variables	Explore and understand meaning individuals or groups ascribe to a social or human problem
Deductive methods: -identify theory -develop hypothesis -collect data -analyze data using statistical methods -prove/disprove hypothesis	Inductive methods: -identify social or human problem -collect data -analyze using constant comparison -develop categories -formulate substantive or formal theory
Random sampling from representative population	Theoretical and purposeful sampling
Measure and analyze causal relationships between variables	Trustworthiness, authenticity, credibility, rigor, transparency

**Symbolic Interactionism Framework**

In qualitative research, a theoretical lens is described as an overall orienting lens or perspective for the study of questions of gender, class, and race or other issues of marginalized groups (Creswell, 2009). Since the focus of my study is on a program that seeks to empower and enhance the advocacy skills of a group of parents raising children with disabilities that are often disenfranchised from society, I feel it is important to identify a methodological theoretical lens that has the same goal and intent. For this study, I am using the symbolic interactionism, which focuses on the social interaction of actual people in the social world (Blumer, 1969). This perspective shapes the data collection, analysis and dissemination. Using symbolic interactionism, my hope is that the results are reflective of the voice of the participants and that they will be used as a call for action or change.

Similar to our evolution, symbolic interactionism theory is concerned with the constant changing and adjusting between the self and the social world. For symbolic interactionists the self is not fixed and inflexible but constantly adjusting to others. Individuals perceive themselves in terms of how others perceive them during interactions and in terms of the roles they play in society. Through these interactions, the interpretation of symbols, and the filtering process of the mind, the meaning of the world and self is acquired (Plummer, 2000). This theory enables, researchers to interpret and evaluate human interactions using methods that allow interaction between and among the participants in order to observe the behavior in naturalistic settings (Creswell, 1998).

Individuals with disabilities and their families have been adjusting and re-organizing the perception and role of individuals with disabilities in society since the beginning. This evolution is recognized in the delivery of services and in societies understanding and perceptions of individuals. Goals of programming are now focused on creating real meaningful roles for people as opposed to defining activities to fix or rehabilitate a person. Examples of meaningful roles include making friends, getting jobs, becoming a member of a church or participating in recreational activities as opposed to the more common historic goal of helping a person overcome any limitations of their disability.

The interaction of the societal perception of individuals with disabilities and the role they have in society is impacting current programs and policies. Concurrently, individuals with disabilities are being supported to have meaningful, productive roles while at the same time society is recognizing the rights and value of individuals with disabilities in our community. As individuals with disabilities become recognized as neighbors, peers,

colleagues and spouses, policies and programs will continue to adapt to this new perception and meet the new support needs of the individual.

Using symbolic interactionism, I sought to understand the impact and the meaning of participation in Partners in Policymaking from the perspective of the individual as opposed to merely explaining the experience from a more collective experience. Through in-depth interviews, I asked the participant not to just explain how they felt about the course but rather to discuss the meaning of the interaction and experience for themselves and those that they have contact with such as their child, their families, and community organizations. This approach allowed me to investigate how the Partners experience influenced their perceptions and meaning of “disability” and how that new meaning will change their interactions in the future.

### **Grounded Theory Research Design**

Grounded theory is a strategy of inquiry in which the researcher derives a general, abstract theory of a process, action, or interaction grounded in the views of participants (Creswell, 2009; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Strauss and Corbin (1994) describe grounded theory as “a general methodology, a way of thinking about and conceptualizing data” (p. 275). Grounded theory studies people in their natural settings, attempting to understand phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2007). Data is collected using theoretical sampling and analyzed throughout collection using a systematic approach of constant comparison which leads to the formation of categories which are interrelated to form a substantive or formal theory (Charmaz, 2006; Charmaz & Henwood, 2007; Corbin & Strauss, 1990, Creswell, 2009; Strauss & Corbin, 1998).

Grounded theory attempts to move beyond description to a deeper understanding of the process. Glaser and Strauss (1967) explained that theory “discovered through data could be more relevant and productive since it would at least fit the immediate problems being investigated” (p. 172-173). As opposed to starting with a hypothesis, grounded theory allows the data to drive the findings. It uses an inductive method defined as “a type of reasoning that begins with study of a range of individual cases and extrapolates from them to form a conceptual category” (Charmaz, 2006, p. 188). It moves from specific accounts that are descriptive and detailed to a more general, abstract, conceptual level.

Grounded theory methodology results in a substantive theory which may or may not result in the formation of a formal theory. Substantive theory is specific to a group or place and it does not have broad social applicability. Formal theory, consequently, is not specific to a group or place; instead it applies to a wide range of concerns and problems across situational contexts (Strauss & Corbin 1998). The purpose of my study is to establish a substantive theory specific to Missouri Partners in Policymaking program.

### **The Researchers Role**

One of the distinctive differences between quantitative research and qualitative research is the role of objectivity. In quantitative research, the researcher uses standardized instruments and tools to collect data, which are interpreted using statistical analysis in an attempt to keep the data and results as objective and unbiased as possible. In qualitative research and especially grounded theory, the researcher is part of the process and serves as a tool for inquiry. Researchers are the translators of another’s words and actions; they are the go-betweens for the participants and the audiences that they want to reach.

In qualitative research, sensitivity as opposed to objectivity is the important element of methodology and analysis. Sensitivity is a researcher's ability to understand and present the view of the participants; based on the researchers insight, experience and comparison back and forth from data collection and analysis (Corbin & Strauss, 2008). The researchers' bias, knowledge, training, perspectives and research paradigms are woven into the research process (Guba & Lincoln, 1989).

In grounded theory specifically, the researcher and participants interact and co-construct the research together (Finlay, 2002). Because of this interpretive nature, it is important for a researcher to identify their biases, values, background, history, culture or any other factor which may influence or shape the findings. The experience of whoever is engaged in inquiry is vital to the inquiry and its implicated thought processes.

### **Statement of Bias**

Because of the nature of the grounded theory methodology, it is important that the researcher share her perspective and experience so that the reader is able to understand what might frame the results. My research into families living with children with disabilities began at a very early age, it began the day my family adopted my little brother, Eric. He was thirteen months old when he came into our lives, but at birth his diagnosis was a genetic pre-disposition to cognitive and developmental disabilities that were exasperated by environmental conditions as an infant.

As a sibling, I was able to experience the day-to-day joys and struggles that families face, along with the role of navigating the services for individuals with disabilities. Growing up, I attended individual education planning meetings for Eric as he transitioned year-to-year through the special education school system. During this time, I was experiencing firsthand

the hoops, barriers and frustrations that families feel as they attempt to understand and advocate for what they feel is best for their child. As he got older, I continued and still do attend planning meetings to discuss how to build the kind of life Eric wanted and deserved and how the service system could support him and my family to help him achieve this.

Throughout the years, Eric (and my family) has experienced many different opportunities, placements and services in an attempt to find the supports that provide for a successful and happy quality of life. This is something that will never stop. As a family, we will continue to need to adjust, accommodate and identify new strategies for supporting Eric as he changes, the environment changes and the supports that are available change.

The daily and lifelong experience of identifying supports for Eric and providing on-going emotional and problem-solving support for my parents serves as the foundation for what I have done in my professional career. As I was completing my Masters in Occupational Therapy from Rockhurst University, I began working as a graduate student at the University of Missouri-Kansas City Institute for Human Development, University Center on Excellence in Developmental Disabilities. Currently, and throughout the process of starting and completing my doctoral work, I serve in the role of Director of Individual Advocacy and Family Support.

In this role, I am able to engage with self-advocates (adults with disabilities) and families to identify, develop and disseminate strategies for enhancing the lives of individuals with disabilities and their families. Specifically this occurs with two major initiatives, People First of Missouri (PFMO) and the Missouri Developmental Disabilities Resource Center (MODDRC). I have provided on-going technical assistance for the last twelve years to the statewide self-advocacy organization that is comprised of over 1,000 self-advocates. I spent

countless hours learning from, socializing with and advocating alongside strong adult leaders with developmental disabilities. This experience provided me a glimpse into the realities of growing up with a disability in the U.S. today.

As the director of the MODDRC, I have been responsible for enhancing and expanding the role of a statewide information and referral network, which includes the parent-to-parent service. The goal of this initiative is to provide the information and emotional support that self-advocates and families need to give them hope and help them achieve the lives they desire. This role exposes me to local, state and national opportunities for collaborating with families, disability professionals, researchers and policymakers.

Both of these initiatives provide opportunities for engaging with the Partners in Policymaking administrative organization and the Missouri Planning Council on Developmental Disabilities (MPC). The MPC is one of UMKC-IHD's network partners, as identified by the DD Act, which provides many opportunities for joint collaboration on initiatives and systems-change efforts. In addition, the MPC provides funding to support the work of the PFMO and of the MODDRC.

I also have frequent contact with many of the Partners in Policymaking graduates, since many of them become members of the MODDRC Leadership network or they are members of People First of Missouri. I believe that my personal and professional experience in the disability field not only serves as a tool for interpretation but also opens access to organizations and other families that might not be as readily available.

### **Participants**

Qualitative research uses purposeful sampling for gathering data to help the researcher understand the issue which is fundamentally different than the more readily

recognized practice and assumptions of quantitative sampling. Quantitative experimental designs attempt to randomly select participants so that each individual has the equal probability of being selected from the population, ensuring that the sample will be representative of the population (Keppel, 1991). 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.

Specifically with grounded theory, theoretical sampling is used. This type of sampling begins with data collected through interviews, as with this study, and then continues based on gathering more information about specific themes and categories. Interviews are driven by the need to delve further into topics as opposed to meeting a requirement for a certain number or type of sample. Once the researcher identifies the same categories and themes occurring consistently across the data collected, the category is considered saturated. According to Glaser & Strauss, categories are saturated when “no additional data are being found whereby the [analyst] can develop the properties of the category” (Glaser & Strauss, 1967, p. 61).

Participants for my study were recruited from the Missouri Partners in Policymaking program who graduated since the beginning of the program. The Missouri DD Council reports that 299 participants have graduated from Partners, since 1993. Table 9 provides an overview of each year of the class participants totaling 186 parents and 113 individuals with developmental disabilities.

Table 9

*Participants in the Partners in Policymaking Program in Missouri*

<b>Class Year</b>	<b>Total Participants</b>	<b>Self Advocates</b>	<b>Parents</b>
<b>1996</b>	26	8	18
<b>1997</b>	20	5	15
<b>1998</b>	14	2	12
<b>1999</b>	24	5	19
<b>2000</b>	17	6	11
<b>2001</b>	22	9	13
<b>2002</b>	20	11	9
<b>2003</b>	26	11	15
<b>2004</b>	25	12	13
<b>2005</b>	23	13	10
<b>2006</b>	14	5	9
<b>2007</b>	17	5	12
<b>2008</b>	25	9	16
<b>2009</b>	26	12	14
<b>Total Participants</b>	299	113	186

To participate in the Partners program, trainees are selected by the Missouri Developmental Disability Council from a pool of applicants who are a parent of a child with a developmental disability age eight or younger or who are an adult with a developmental disability. A developmental disability as defined by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-142) is a severe, chronic disability of a person five years of age or older which:

- (A) is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- (B) is manifested before the person attains age 22;
- (C) is likely to continue indefinitely;
- (D) results in substantial functional limitations in three or more of the following areas of major life activity:
  - self care,
  - receptive and expressive language,
  - learning,
  - mobility,
  - self-direction,
  - capacity for independent living, and

- economic self-sufficiency; and

(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated; except that such term when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental disability or specific congenital or acquired conditions with a high probability or resulting in developmental disabilities if services are not provided.

To be considered as a Partners graduate, trainees must attend eight two-day sessions between the months of February and September and complete homework assignments and a major project. The Partners program pays for lodging and meals and travel for all participants. Based on individual needs of the participants, the program can also reimburse for respite or attendant care. For purposes of this study, participants must have met the minimal graduation requirements.

### **Recruitment of Participants**

Upon approval from the university's institutional review board, I sent an email to the Coordinator of the Partners in Policymaking program that explained the study and its purpose. The coordinator then forwarded the email to all parent graduates of Missouri's program. Both the Coordinator and I determined that the use of email was the best process for recruitment since the main form of communication with Partners graduates is by email. I also believed that those who would be most willing to share their experience were probably active in on-going Partners communications, an important factor in qualitative selective sampling. Interested participants could contact me by phone, email or through a questionnaire and identify the best location and time for their interview.

I then contacted each interested participant to verify they were parent graduates of the Partners program, to answer any questions they might have about the study, and to verify

time and location for the interview. Twenty-three people contacted me with interest in participating in the study; however, one was a self-advocate and was therefore not able to be included in the sample. Based on both availability and saturation levels of the concepts, I interviewed 14 participants. Participants did not receive any compensation for participating in the study.

Fourteen parents participated in semi-structured interviews. Demographic information was gathered during the interview process. 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 having 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. Table 10 shows the representation of the different graduation classes.

Table 10

*Representation of the Study Participants by Graduation Year*

<b>Graduation Year</b>	<b>Number of Study Participants</b>
1995	1
1999	2
2001	1
2003	2
2005	2
2006	1
2007	2
2008	1
2009	1
2010	1

## **Ethical Considerations**

To ensure that the ethical and confidentiality standards were met, my study was submitted and approved by the UMKC-Social Science Institutional Review Board. All study participants were provided with a written and verbal explanation of the study along with a consent form. After verbally reviewing the materials before the interview, verbal consent was obtained from participants including permission to audiotape interviews. After the interviews, the audio-tapes were transcribed removing the name of the participant in the written document to ensure confidentiality. The audio-tapes are stored in a secure, pass code protected file.

## **Data Collection**

To inductively gain an understanding of the phenomenon studied, it is necessary to use methods of data generation that are both flexible and sensitive to the social context in which data are produced (Berg, 1995). To understand the impact of participation in Partners, I conducted in-depth interviews so parents were able to describe from their perspective how the training program impacted their lives.

According to Patton (2002), a qualitative interview should be open-ended, neutral, sensitive, and clear to the interviewee. For my study, a semi-structured interview guide provided direction to begin the interviews. Questions focused on information about the graduate, their family and their child with a disability, on their Partners training experience, and the impact of the training program. Questions were designed to examine the parent's understanding of disability before and after graduation as well as to discuss the distinguishing features of the program. I used the following questions to guide the interviews:

1. *Please tell me about yourself and your family.*
2. *Tell me specifically about your child with a disability?*
3. *Tell me how you found out about Partners and why you decided to participate?*
4. *What do you think has changed since you graduated in Partners?*
  - a. *What did you learn?*
  - b. *What do you do differently because of what you learned?*
  - c. *Have there been changes for your child with a disability? If so, what?*
5. *Before you graduated from Partners in Policymaking, what were your views of “disability?”*
  - a. *What did you believe life was like for individuals with disabilities?*
  - b. *Where did you think individuals with disabilities live, go to school, work and play?*
6. *Now that you have graduated, how have your views about disability changed or stayed the same? How do you think Partners influenced this?*
7. *Tell me what you liked about Partners?*
8. *Tell me what would have made your Partners experience better?*

All but one interview occurred over the telephone and that one occurred in person at the office of the interviewee. Prior to starting the interview, I confirmed verbal consent from the participant for participating in the study and for use of an audio tape recorder. Interviews lasted from 30 to 120 minutes. Interviews were conducted from July, 2010 to August, 2010. Interviews were audio taped and transcribed verbatim and then sent to each of the study participants to check for accuracy of transcription prior to analysis. Four study participants responded with minor grammatical changes.

### **Data Analysis**

Glaser and Strauss (1967) created a grounded theory framework which utilizes constant comparisons where the researcher moves back and forth among the data advancing from coding to conceptual categories and ending with theory development. According to Corbin and Strauss (1990), coding “represents the operations by which data are broken down, conceptualized, and put back together in new ways. It is the central process by which

theories are built from data” (p. 16). Moving through different stages defined by Strauss and Corbin (1998), I was able to use data to identify themes (open coding) and then begin to systematically compare information and form categories (axial coding) which I further compared and analyzed (selective coding) to move towards the formation of a theory. Table 11 provides a mapping model that illustrates the different stages of analytical process I used to reach the substantive theory of my study.

Table 11

*Analytical Mapping Model for Development of Substantive Theory*

<b>Substantive Theory</b>	<b><i>Parents “ready” to participate in the Partners in Policymaking program in Missouri experienced a transformation in their perception about the future for their child with a disability.</i></b>		
<b>Themes</b>	<i>Sense of being “ready” to participate  A training program built on respect  A change in perception about disability  A sense of membership within the disability community  Understanding possibilities  Ability to navigate for a future  Decreased intimidation for advocating</i>		
<b>Categories</b>	Past Understanding of Disability	Respect	Perception of Disability
		Inclusion of Self-Advocates	Advocating for Child
	Needs of Parents	Group Learning Dynamics	Options and Services
	Emotional Impact of Parenting Child with Disability	National Speakers	Network of Support
	Timing of Partners	After Partners Activities	Legislative and Policy Activities
<b>Open Codes</b>	<i>Based on initial interviews</i>		

Using the methodology described by Strauss & Corbin (1998), interviews were analyzed beginning with open coding. Strauss (1987) explains open coding as “scrutinizing the field note, interview, or other document very closely; line by line, or even word by word. The aim is to produce concepts that seem to fit the data (p. 28).” Codes were tracked in the margins of the interview document. During open coding, I identified over 150 conceptual labels or quotes, as listed in Table 12.

Table 12

*Codes Identified During Open Coding Analysis*

<b>Open Codes</b>		
Ability to let go	Help to stop thinking of people as different	Saw that people with disabilities dream, live on their own
Advocate better	Idea for employment options	See possibilities
Assumptions	Information about services and supports	Self-advocacy look beyond stereotypes
Band advocacy together	Information to help let go	Self-advocates as classmates
Being a part of the disability community	Interests	Share dreams and fears with each others
Beyond own child	It was time to attend	Show how parents need to let child take risks
Camaraderie	Jobs	Skill set for policy advocacy
Can open closed doors	Learn about people with disabilities	Speakers live the experience
Change life forever	Lessened fear of legislator	Stereotype before partners
Child had to be okay left at home	Lifelong connection	Take chances
Civic Action after Partners	Living in the community	Tips for inclusion in schools
Commitment of program staff	Living options	Transformation of husband
Commonalities with others	Made community better	Try new things
Community involvement	Major change in family	View of possibilities for people with disability
Confidence	Need to take chance	Work with school
Connect to other parents outside of MO	New view of the world	Want to do more
Decreased isolation	Not to give up	Widen viewpoint
Develop future for child	Others saw people with disabilities in a different light	
Don't make assumptions about self-advocates	Parent expectation of child with disability	
Experiential, interactive learning	Parent to parent connection	
Eyes and ears for own child	Parent work hard for inclusion	
Focus off own child and help others	Partner with professionals	
Future options for child	Reluctance to attend	
Gave parents a different perspective	Reopen closed doors	
Group dynamics	Respect	
	Right time of life	

The next step was to group the codes according to conceptual categories referred by Corbin and Strauss (2008) as axial coding which “consists of intense analysis done around one category at a time in terms of the paradigm items” (Strauss, 1987: 32). Comparing the open codes with the interview documents and my field notes and memos, I was able to form distinct categories. Then the final step in the analysis was selective coding, that is, the process of refining and grouping categories around a theme (Corbin & Strauss, 1990), which is described in Table 13. By using memos, I was able to conceptualize the data in narrative form analyzing and organizing the data to formulate the reality of the participants (Lempert, 2007). Table 13 highlights the open codes into categories

Table 13

*Themes Identified During Selective Coding Analysis*

<b>Categories</b>	<b>Open Coding</b>
Timing	Right time of life Reluctance to attend Child had to be okay left at home
Internal Changes	Take chances Want to do more Try new things Not to give up Ability to let go Confidence New view of the world
Information and Tools	Future options for child Tips for inclusion in schools Idea for employment options Living options Information about services and supports
Self-advocates	Stereotypes Assumptions Interests

Categories	Open Coding
	Show how parents need to let child take risks Gave parents a different perspective View of possibilities for people with disability Help to stop thinking of people as different Saw that people with dream, live on their own
Advocacy skills	Partner with professionals Advocate better Reopen closed doors Band together with others to make change Lessened fear with legislators Civic Action after Partners Focus off own child and help others Skill set for policy advocacy
Aspects of Partners	Self-advocates as classmates Speakers live the experience Camaraderie Being a part of the disability community Share dreams and fears with each others Respect Commitment of program staff Group dynamics Experiential, interactive learning Decreased isolation

Assessing the quality and rigor of qualitative research has been debated by many from within and outside the field of qualitative methods. Early standards were defined using the quantitative criteria of internal validity, external validity, reliability, and objectivity. However, these standards could not be addressed in naturalistic research. As a result many different researchers and theoreticians recast the four criteria to meet varying needs that exist (Lincoln, 2001). According to Creswell & Miller (2000), terms abound in the qualitative literature that addresses different criteria such as trustworthiness, authenticity and credibility. Other terms have also been used such as rigor, quality, transparency and integrity. The lack of agreement or terms is due in part to the fact that “there is not one single way to analyze

qualitative data—it is an eclectic process in which you try to make sense of the information. Thus, the approaches to data analysis espoused by qualitative writers will vary considerably (Creswell, 2002, p. 258).”

My study utilized the broad categories of qualitative reliability and qualitative validity as defined by Creswell (2009) to assess the trustworthiness and dependability of the data and the overall findings. Gibbs (2007) defines qualitative reliability as the use of an approach consistently across different researchers and different projects. Grounded theory, by nature, provides a systematic approach that provides the researcher with a constant comparison method for analysis which is a recognized approach in the field.

To further enhance the reliability of the study, several strategies of transparency were used throughout the collection, analysis and reporting stages. Transparency allows the reader to assess the intellectual strengths and weaknesses of the researcher (Soklaridis, 2009). This is accomplished by maintaining and documenting careful records of what occurred at each stage of data collection and analysis. After the interviews were transcribed, completed transcriptions were sent to each of the study participants for review. This enabled the participant to change or clarify any portion of the interview. In addition, field notes and memos were kept throughout the process to guide and check for assumptions during all phases of the research. This was further enhanced by presenting a code map that enables the reader to see the different stages of comparison and how the theory emerged from the different codes and categories. This criteria of disclosing methods and detailing the research adds to the credibility of the research and to quantitative methods in general (Anfara, Brown & Mangione, 2002)

Creswell (2009) also provides a definition and recommendations for achieving qualitative validity in a study. He believes a researcher is able to achieve qualitative validity by using one or more of 8 defined strategies to check for accuracy of the findings; (1) triangulation, (2) member checking of findings, (3) using thick description to convey findings, (4) clarifying the bias of the researcher, (5) presenting negative information that runs counter to themes, (6) spending prolonged time in the field, (7) using peer debriefing to enhance accuracy of information and (8) using an external auditor.

Following Creswell's recommendations, I used several validity strategies to ensure accuracy of this study. The first strategy was triangulation which brings together different but complementary data to support a claim. Triangulation was achieved in this study by comparing memos and findings to the results with past studies and evaluation reports from around the country. Data was further triangulated with my personal and professional experience. Secondly, participants reviewed their transcripts as well as the results for accuracy and for reflection on the identified categories and theme. Four participants returned transcripts with minimal grammar changes and three participants provided feedback on the results section. The third strategy was the utilization of thick descriptions in the results section provided by participants that conveys their understanding of participation. This was captured by italicizing for the reader the direct phrases from participants.

In addition, I identified and clarified my personal bias and experiences to increase the readers understanding of my position as the researcher. I believe that my prolonged involvement with the Partners in Policymaking program and its participants added greater knowledge beyond the data collected during interviews. My experience of living as a family

member of a person with a disability as well as working as a professional in the field of disability also added to validation of results.

To further validate the results, several professionals in the disability field reviewed the findings. Specifically, the past and current program coordinators for the Missouri Partners in Policymaking program, a Partner in Policymaking graduate who did not participate in the study and a current participant in the program reviewed and responded on the results section. In addition, two coordinators from other states were debriefed to ensure for accuracy. Table 14 highlights the strategies I used to ensure accuracy of the data.

Table 14

*Strategies for Checking Accuracy of Findings (Creswell, 2009)*

<b>Recommended Strategy</b>	<b>Strategy Applied to Study</b>
Triangulation	Compare findings with past studies and evaluation reports
Member checking	Transcripts sent to participants for editing and feedback of results
Thick description	Description and quotes in results section
Clarifying bias	Provided in methods
Presenting Negative information that runs counter to themes	Provided in results
Spending prolonged time in the field	Sibling and professional in field
Peer debriefing to enhance accuracy	Shared with current and past coordinator and other states
External auditor	Results reviewed by Partners participants not interviewed

## CHAPTER 5

### 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.

This chapter describes the key elements of this life-changing transformation for 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 they would be exposed to 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.

### **Summary**

The design of the Partners in Policymaking program made life-changing transformation possible for parent graduates. The themes of readiness, respect, changed perceptions, newfound membership, possibilities, skills for navigating a future, and decreased intimidation for advocacy are central to these changes. Partners in Policymaking exposed parents to information and experiences that transformed their assumptions and stereotypes about individuals with disabilities into a positive realization that individuals with disabilities can lead fulfilling and productive lives.

## CHAPTER 6

### CONCLUSION

#### **Discussion**

Parents and families of children with disabilities have become increasingly involved in developing programs and policy related to disability services over the past half century. Training programs have been created to foster the knowledge and skills necessary for parents and families to advocate for their child and to participate in the larger political process. One of these programs, Partners in Policymaking, was conceived in 1996 to mobilize parents of children with developmental disabilities and adults with disabilities to participate in policies which support inclusion, independence, integration, self-determination, and productivity of individuals with developmental disabilities as set forth in the federal Developmental Disabilities Act.

The present research focuses on parents who participated in the Partners in Policymaking program hosted in Missouri over the past sixteen years. Fourteen parents participated in semi-structured interviews until reaching saturation of themes. Using grounded theory this study delves into the specific impact of the Partners program on the participants and how features of the program impact the outcomes. The result of this study is a substantive theory that concludes that *parents “ready” to participate in the Partners in Policymaking program in Missouri experience a transformation in their perception about the future for their child with a disability.*

This substantive theory builds on previous positive research findings from the Partners in Policymaking program by describing the meaning of participation from the perspective of the parents. These studies recognize graduates satisfaction with the program

and demonstrate that participation enhances self-advocacy skills, knowledge of and ability to obtain services, and ability to contact policy offices (Wieck & Skarnulis, 1987; Zirpoli, Hancox, Wieck, & Skarnulis, 1989; Zirpoli, Wieck, Hancox, & Skarnulis, 1994; Conconan-Lahr & Brotherson, M.J., 1996; Balcazar et al., 1996).

The Partners in Policymaking program, by design, provides concrete information and skills about the disability field, however this study identifies that it also provides much more than that. It changes parents' perception of individuals with disabilities and ultimately their own perception of their child's possibilities. It provides membership into community that helps to increase their confidence in parenting, navigating and advocating for what they believe and want. Moreover, it ultimately gives parents a sense of hope, opportunity to dream and ability to create a vision for the future. This transformation is possible because parents come "ready" to hear about a new reality and because the Partners in Policymaking program created a respectful and inclusive environment that allows for growth and change.

This study also supports the need to implement the program with very specific features, as set forth by its founders of the Partners in Policymaking program. Built upon the principles of respect and dignity, programs must include experiential learning, national speakers, self-advocates, and diversity if they are to replicate it (Barenok & Wieck, 1998). From the perspective of the participants, these features served as the causal agent of their transformation.

### **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.

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## VITA

Michelle Christine Reynolds (Sheli) was born on October 24, 1973. Her elementary education was in the local public school district of Francis Howell School located in St. Charles, MO. She graduated from high school from St. Joseph's Academy in Frontenac, MO. in 1992. She attended Meramec Community College on an academic and athletic scholarship and later transferred to Rockhurst University to complete her Bachelor of Arts degree in 1996 and continue her athletic career. She continued her higher education experience at Rockhurst University where she completed her Masters in Occupational Therapy in 1999.

In 1997, while attending Rockhurst University, she began her career as a research assistant at the University of Missouri-Kansas City, Institute for Human Development working in the disability field. Since 2001, she has served there in the role as Director of Individual Advocacy and Family Support. She began her work toward her Interdisciplinary Ph.D. in Public Administration and Sociology at the University of Missouri-Kansas City in the Fall of 2001. Upon completion of her degree requirements, Ms. Reynolds plans to continue her career in the developmental disability field and to pursue her research interests focusing on families and individuals with developmental disabilities.