

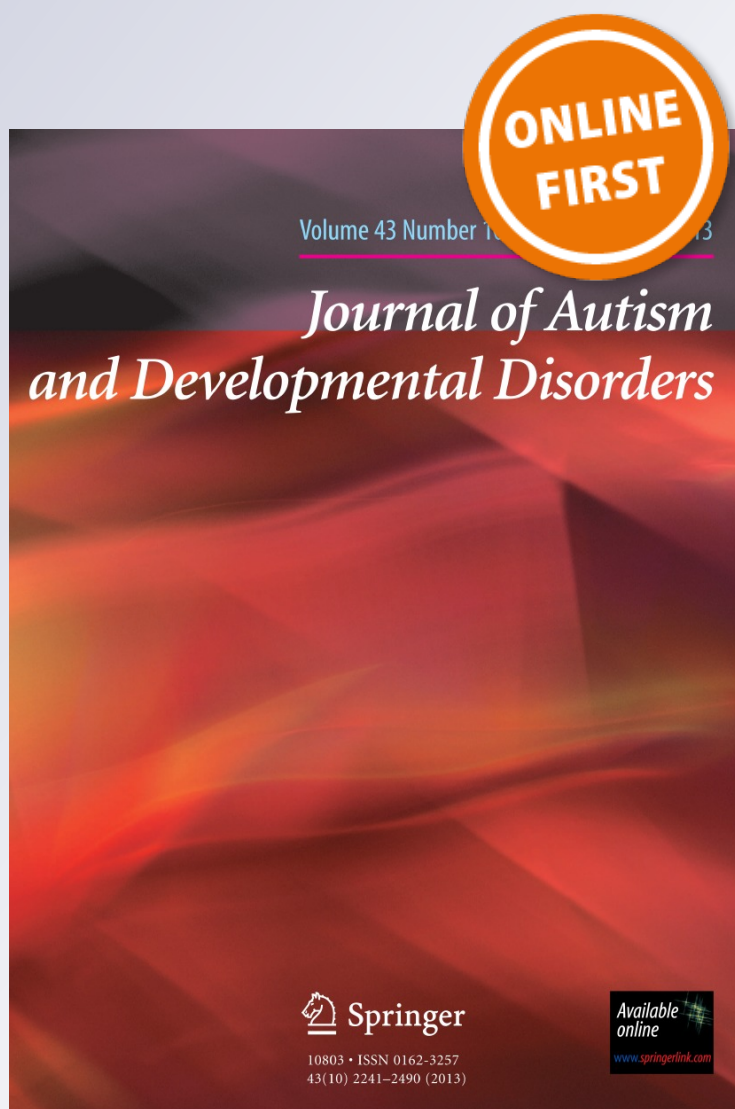
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Maria T. Timberlake, Walter N. Leutz, Marji Erickson Warfield & Giuseppina Chiri

Journal of Autism and Developmental Disorders

ISSN 0162-3257

J Autism Dev Disord
DOI 10.1007/s10803-013-1942-4



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“In the Driver’s Seat”: Parent Perceptions of Choice in a Participant-Directed Medicaid Waiver Program for Young Children with Autism

Maria T. Timberlake · Walter N. Leutz ·
Marji Erickson Warfield · Giuseppina Chiri

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Abstract This study investigated families’ experience of choice within a participant-directed Medicaid waiver program for young children with autism. Fourteen parents or grandparents participated in in-depth interviews about their experience of choosing personnel, directing in-home services, and managing the \$25,000 annual allocation. Key findings included families’ preference to hire providers with whom they have a prior relationship, parent empowerment and differences of opinion about parents as teachers. Professionals implementing participant directed service models could benefit from understanding the strong value parents’ placed on the personalities and interpersonal skills of providers. Parents’ descriptions of directing rather than merely accepting autism services revealed increased confidence in their ability to choose and manage the

multiple components of their children’s HCBS autism waiver program.

Keywords Participant direction · Choice · Medicaid home and community-based services · Autism waiver

Introduction

As the prevalence of autism spectrum disorders (ASD) has increased over the last decade, a number of states have created separate Medicaid Home and Community Based (HCBS) waivers specifically for children with autism (Centers for Disease Control and Prevention 2010; Centers for Medicare and Medicaid Services 2010). The Medicaid Home and Community Based (HCBS) waiver program is a federally-supported program that allows states to provide community-based services to assist individuals with developmental disabilities to live in the community and avoid institutionalization (42 U.S.C. §1915(b)(c)). The specific amount and type of benefits are shaped by the distributional policies in the states, but HCBS waivers allow states to “waive” traditional Medicaid eligibility requirements for individuals who would otherwise receive institutional care, and experiment with creative alternatives on a small scale (Thompson and Burke 2007). State children’s autism waivers represent such creative alternatives. Of the ten states with autism waivers for children, all share common requirements that participants have an ASD diagnosis and that their family is Medicaid eligible (Hall-Lande et al. 2011). A review of these waivers, however, revealed differences in the ages of children served, program duration, funds allotted per year, and services included. Further, Massachusetts is taking a unique approach

M. T. Timberlake · M. E. Warfield · G. Chiri
Starr Center for Intellectual and Developmental Disabilities,
Heller School for Social Policy and Management, Brandeis
University, 415 South Street MS 035, Waltham,
MA 02454, USA

Present Address:

M. T. Timberlake
Foundations and Social Advocacy Department, State University
of New York, College at Cortland, Cortland, NY 13045, USA

M. T. Timberlake (✉)
c/o Marji Erickson Warfield, Heller School for Social Policy and
Management, Brandeis University, 415 South Street MS 035,
Waltham, MA 02454, USA
e-mail: mew@brandeis.edu

W. N. Leutz
Schneider Institute for Health Policy, Heller School for Social
Policy and Management, Brandeis University, 415 South Street
MS 035, Waltham, MA 02454, USA

among states implementing autism waivers for children by using a participant-directed service model designed by the Department of Developmental Services and the Massachusetts legislature.

Participant-direction in program design refers to individuals and/or family members determining the selection and distribution of their services and providers (Beach Center on Disability 2012; National Resource Center on Participant-directed Services 2010). Participant-direction in long-term care and disability supports for adults has included finding, interviewing and hiring in-home or personal care staff, managing a budget, and working with a team of therapists, a fiscal intermediary, and a support broker or case manager (Gross et al. 2012; Mahoney et al. 2007). Participant-direction has become widespread in long-term care supports for adults (Doty et al. 2012). Less is known about participant-directed program models for children. However, choice, empowerment, and participatory decision-making are recommended values in family centered models for early childhood services (Murray et al. 2007).

Massachusetts is the first state to require participant-direction for families of young children with autism seeking Medicaid HCBS waiver services. Under the program known as the Children's Autism Waiver Program, selected low-income families received intensive, in-home autism interventions and supports that were used to supplement special education services available from school systems. Parent priorities informed the development of communication, behavioral, and other goals that guided the intervention, and families' managed the relational tasks of hiring staff, as well as the administrative tasks of allocating the \$25,000 per year available for the child's autism interventions and supports. A comprehensive description of the children's autism waiver program in Massachusetts and its operation can be found elsewhere (Leutz et al., under review). The aim of this research was to understand how parents experienced participant-direction, particularly the responsibilities of choice, under the Massachusetts Children's Autism Waiver program. As family-centered approaches are now considered the ideal for medical and educational services and supports (Bellin et al. 2011; Turnbull et al. 2011), the participants in our research provide important lessons for clinicians, supervisors and researchers about how choice, respect and partnership is experienced by a sample of families.

Choice and Participant Direction

The National Resource Center for Participant-Directed Services calls choice the "hallmark of self-direction" (2010). A participant-directed philosophy maintains that the more choices an individual or family has, the more

empowered they become, but, there are challenges to creating a situation of real choice (Rabiee and Glendinning 2010). Our analysis of parent perceptions of participant-direction was informed by three key findings about the concept of choice. First, choice is unavoidable when parents have a child diagnosed with ASD, secondly, choice can be empowering, and third, informed choice can be costly and difficult to define, as families' desire for, and comprehension of information varied widely.

Choice is Unavoidable

Families of young children with ASD face an array of choices and decisions once a diagnosis is confirmed (National Autism Center 2009; Valentine 2010). Choices may include options related to early intervention, respite, diet, health care, adaptive equipment, and more (Rosenblatt and Carbone 2012). Prior research suggested families and individuals with disabilities appreciated choice but also found aspects of choice difficult, for example, the time required to locate and then decipher, relevant information (Freedman and Boyer 2000; Rabiee and Glendinning 2010). Even when the sense of control was enjoyable and empowering, choice, particularly after a child's diagnosis of autism, could be construed as an obligation and a parental responsibility that cannot be avoided (Altiere and Von Kluge 2009; Valentine 2010).

Choice as Power

The promise of choice for families of children with disabilities has been described as increased empowerment, autonomy, and a sense of control (Murray et al. 2007; Turnbull et al. 2001). The ability to choose program components within social service delivery is expected to result in increased satisfaction as well as greater program quality (Lent and Arend 2004). Caldwell and Heller's (2003) research supported this proposition as the families of individuals with developmental disabilities who described feeling more control over their choices of personal care and respite services, also felt more satisfied with their services than those who had less control over service options. In addition, informal and personal support has been more effective in supporting family choice than simply providing factual information (Nieboer et al. 2011). Parents who received personalized support when facing a choice of service providers for their child with a disability, evaluated more providers before deciding, and switched less often than parents who were provided with only descriptive information. Personalized supports included parent groups and individual counseling sessions, in addition to the written facts detailing the program components (Nieboer et al. 2011).

Prior research found adults' choice of treatment and lifestyle options were influenced by past habits and expectations, leading researchers to conclude that choice-making was not necessarily a rational act, based solely on a logical weighing of costs and benefits, but an emotional process as well (Arksey and Glendinning 2007; Jenkinson 1993; Lindbladh and Lyttkens 2002). Meaningful choices have been defined as situations where there are distinct options, all the options are potentially desirable, and the differences between them are understood (Arksey and Glendinning 2007; Storey 2005). Choice-making may also be a skill that increases with experience. Individuals and families may learn how to make better choices with regard to services and supports, as they learn more about the particulars of their child's disability and service systems (Rabiee and Glendinning 2010). Families' confidence in their ability to make choices may grow as ongoing decisions are made within a participant-directed model (Gross et al. 2012). Although families' skill and confidence may increase as a result of choice-making, there has been little research on how families' approach participant directed responsibilities and how families' prior exposure to autism interventions influences their confidence and skills. In addition, empowerment, defined as active family participation in decision-making, is not a static state, and can vary by circumstances and situations (Turnbull et al. 2001). As Murray et al. (2007) noted, families will be required to make choices across their child's lifespan, and support by early childhood professionals can lay the foundation for the building of decision-making skills. Prior empirical and theoretical work on choice suggests that opportunities to make decisions about their children's autism services will be beneficial for families. However, little is known about parents' experience of choice within participant directed services for children. Whether all choices are equally important, and factors that enhance or inhibit families' confidence and ability to choose autism services and providers is not clear.

The Costs of Choice

Research in the health care arena has found that increasing patient choices created additional anxiety and worry, and required patients to invest additional time and resources in their care (Schwartz 2004). Choice-making may increase anxiety over making a wrong choice or wanting a service or support which conflicts with the philosophical views of the professionals (Murray et al. 2007). Families may want the "best" service or provider and prefer to rely on experts and professionals to decide what is "best" (Rabiee and Glendinning 2010; Valentine 2010). Finally, choice has the potential to increase inequality by enabling families with

information and resources to make stronger decisions than families who lack the resources and the social or professional networks to gather information and make sense of their options (Lent and Arend 2004). Because locating relevant and accessible information can take education, time, and energy, families may end up relying on habits or popular sources of information such as websites that may not be factually accurate (Baxter et al. 2008; Lindbladh and Lyttkens 2002; Schwartz 2004). Informed choice requires individuals to process potentially large amounts of information in order to sort out what is useful and helpful in their situation. This may be particularly challenging given the volume of popular information about autism. Families of young children with autism in particular, face the current professional recommendation for immediate, intensive and early intervention (Landa 2007). The time that individuals have to search for information is finite, and in general, individuals tend to search for information until an adequate decision may be made, and then stop looking (Baxter et al. 2008). Thus, the opportunity to choose services and supports for their children with autism is expected to require parents or caregivers to make informed choices between distinct and desirable options. The conditions that influence parents' experience of choice as empowering, and satisfying, as well as disappointing or anxiety-provoking, remain to be explored.

The Implementation of Choice

Our research explored the role of parent choice within the participant directed autism waiver program in Massachusetts and was part of a larger evaluation of the waiver program. How the promise of choice was realized for families of young children participating in the waiver program was hypothesized to depend on factors within the family as well as within the service system and among the providers. However, the voices of a small group of parents were expected to yield unique and important insights into the power and limitations of choice in the participant-directed model. At the policy level, choice is a significant component of the participant directed autism waiver program, but at the level of implementation, parents' experience of choosing autism supports is not well understood. Because choice is a complex and nuanced concept, it is imperative to understand more about how individuals' perceive and assert choice. The research questions of interest here were: (1) What characterizes parents' descriptions of choice (2) How do how parent perceptions of choice vary within the participant directed model and (3) What do parent perceptions of choice reveal about the participant-direction requirement of the children's waiver program?

Autism Waiver Overview

The Massachusetts Children's Autism Waiver program is administered by the Autism Division of the Department of Developmental Services (DDS) and served an average of 150 families over the course of the fiscal year who met the criteria for Medicaid income eligibility, a child's confirmed diagnosis of autism, and willingness to use the participant-directed model. With assistance from a support broker and oversight from a clinical manager, each family developed and directed a plan of supports and services within the limits of an individual budget, up to \$25,000 per year. Families received support in identifying and hiring qualified senior therapists to create educational interventions, and supervised staff who carried out the in-home instruction. Parents chose senior therapists and in-home staff from agencies, or selected "independent" providers, if these individuals met state qualifications. Children were unable to remain on the waiver if the parent(s) did not establish this in-home service component. Respite, community integration, and selected adaptive, sensory, safety and educational materials could also be purchased using waiver funds. All estimates for purchases, therapists' timesheets, and respite paperwork was signed by parents, approved by brokers, and submitted to a fiscal intermediary who issued payments to the appropriate parties. Children were able to remain on the waiver until their ninth birthday or until they received three years of services.

Methods

Participants

In-depth interviews were conducted with fourteen families receiving autism waiver services during the fall of 2011. The child's mother was the primary informant in ten cases, one interview was done with both parents, one interview was conducted with the father (the primary caregiver) and two interviews were conducted with the grandparents, who were the primary caregivers in both cases. Two of the children were female, while the other twelve were male, the average age of the children was seven years and all but one caregiver reported their child's health as excellent or good. Three of the families participating in the in-depth interviews considered Spanish their primary language but only two preferred that the interview be conducted via a Spanish language interpreter. Six families self-identified as White, one as African American, three as Hispanic and four indicated "other". The families represented a geographic cross section of the state: four families were from the southeastern region, four from the western, three from metro Boston, and three from central Massachusetts. All

Table 1 Characteristics of families participating in the MA autism waiver study

	Sample for in-depth interviews (n = 14)	Sample for larger waiver study (n = 74)
Child's gender- male	86 %	82 %
Average age of children	7	6.8
English as families' second language	21 %	20 %
Family headed by grandparents	14 %	7 %
Family identifies as white non Hispanic	43 %	38.4 %
Family identifies as Hispanic	21 %	21 %
Family identifies as black	7 %	16 %

participants were offered the choice of meeting at a community location (e.g. local coffee shop) the family home, or invited to choose a site where the interviewee felt comfortable. Twelve interviews were conducted in the families' homes, and two were conducted by telephone. The interviews lasted 50 min on average.

The fourteen families were part of a larger study of waiver program recipients (Warfield, et al., under review). The larger study contacted all autism waiver families who had been in the program for a minimum of six months between June 2010 and July 2011 (n = 100) with an invitation to participate in the research. Structured in-home interviews were conducted with the 74 families who agreed to participate, and at the end of the initial contact, families were asked if they would consider participating in a second interview that would ask more in-depth questions about their experience organizing and overseeing their child's services. Families invited to participate in the second interview reported on here, were selected using a stratified random procedure so that relatively equal numbers of families received services through four of the five largest Autism Support Centers in the state with DDS contracts. The researchers contacted sixteen families (i.e., four from each center) and reviewed the purpose of the in-depth interview, explained the informed consent and reinforced the fact that participation in the interview was voluntary and would not affect the child's services or status in the waiver program. Fourteen families agreed to the second in-depth interview while two chose not to participate. The characteristics of the fourteen families are comparable to the participants in the larger autism waiver study as illustrated in Table 1.

Materials and Procedure

A semi-structured interview guide with questions pertaining to families' experience of participant-direction was created and approved by the authors' university

Table 2 Autism waiver parent interview questions

Interview questions	Optional probes
What services are you getting right now from the Autism Waiver Program?	
How is the Waiver Program working for you?	How about for your child (use name)? ... for the rest of the family? ...your other children? Are there things that are going particularly well? ...that could be going better?
How is it going with choosing and managing the services—the whole idea of participant direction?	Is it easy or hard to choose what services to use?
How did you choose what providers to use?	What information and help do you get to make these choices? What information and help do you get when you want to make a change in services?
How about the record keeping? What is that like?	Who does it? How much time does it take?
Are there other things you particularly like or don't like about participant-direction?	What would you change if you could?
Have you been able to get the services that you want?	At the times you prefer them? In the right language for you? Have there been any services you wanted but could not get?
Is it working well for (child's name) to get therapies (other services) at home?	What have been the barriers when there are problems? What strategies did you try to overcome these barriers? How have they worked?
How well would you say your team has been working together (that is, the Support Broker, the fiscal intermediary and the Clinical Manager)?	How does the team work with you? What have been the problems? (e.g., communication, time constraints, personalities, any issues about roles?) Do you have ideas about what could be done to make things better?
Do the team members (therapists, Brokers, Clinical Managers) know their jobs?	Do they seem to have knowledge and expertise about ASD? ...about how to work with families?
Do the different team members (FI, SP, CM) have enough time for you?	
How are the relationships between you and the staff?	Could you tell me more about that? What could be improved?
Do you know whom to contact to get help or answers? Do the contacts work well?	
Do you feel the quality of services high enough?	What can you tell me about the quality of your child's services?
Are there other things that would help us understand what makes the PD Waiver Program work for you?	If there was one thing you could change about the Waiver Program, what would it be? Knowing what you know now, would you choose to participate in the program again?

Institutional Review Board (IRB). Questions included the ease or difficulty of accessing desired interventions, locating and scheduling staff, team coordination and communication, perceptions of program quality, and suggestions for improvement. After making introductions and reviewing the informed consent, the questions shown in Table 2 were asked of all participants. The order of the questions varied when necessary to allow participants to expand or elaborate on a subject they were discussing or to move ahead when no further information was forthcoming.

Two-person teams conducted the in-home interviews, with one member asking questions and the other taking notes. A single researcher conducted the two telephone interviews. The only observable difference between the telephone and in-person interviews was that the

introductions and “warm up” conversation was shorter over the telephone. Both telephone interviews were with mothers and their responses to interview questions were similar in duration to the in-home sessions. All families were given a \$30 cash honorarium for their time.

Analysis

First, the research team engaged in “de-briefing” and reflection after each interview, team members shared observations about the interview process, particularly noteworthy quotes, general impressions, and ideas for additional probes or follow-up questions. Next, written notes taken during the interviews were transcribed and organized in Atlas ti, a qualitative data analysis software

Table 3 Key findings of parent choice in a participant-directed Autism Waiver

Research questions	Key themes	Key finding
#1 What characterizes parents' descriptions of choice?	Choosing what you know	Families often selected providers with whom they felt comfortable and had a prior relationship
#1	Interpersonal characteristics	Providers' personality and interpersonal style was strongly associated with parent satisfaction
#2 How do how parent perceptions of choice vary within the participant directed model	Degrees of readiness and participation	Amount of active choice varied across families, regardless of gender and geographic service area
#3 What do parent perceptions of choice reveal about the participant-direction requirement of the children's waiver program?	Advocacy and empowerment	Parent advocacy and empowerment was strengthened by making deliberate choices, and having those choices accepted by professionals
#3	Parents as teachers	Families differed in their desire and ability to carry over in-home services; the needs of siblings, schedules and other daily factors interfered with carryover

package. The primary purpose of the analysis was to discern parent experiences of participant-direction, therefore, a deductive approach to coding and subsequent examination of patterns among the codes and relationships to our key areas of interest, such as accessibility of services and managing staff was employed. A single researcher conducted the initial coding, and descriptors such as “respite” and “schedule” were assigned to segments of text representing concrete waiver activities. A codebook was developed to make coding systematic and provide transparency in the initial interpretation of parents' responses (Ritchie and Spencer 2002). A second round of coding focused on relational and administrative elements of participant direction such as managing the personnel and the financial paperwork. At this point, two additional members of the research team reviewed the codebook, confirmed the clarity of the definitions, and reviewed the written notes to help decrease the possibility of misinterpretation. The first researcher then returned to the data to label written sections of the notes with the emerging categories in order to judge the significance of each passage a second time as the nature of the themes (i.e. choosing what you know) became clear (Ritchie and Spencer 2002).

The analysis then shifted to a more inductive approach in order to gain insight specifically into the concept of choice within the larger context of participant direction. In vivo codes of parents' own words such as “it's a little bit hard” referring to challenges understanding the administrative requirements, and “in the driver's seat” describing control of waiver services, were utilized to maintain integrity to participants' experience (Charmaz 2006). A member of the research team engaged in content analysis to gain a deeper understanding of how the concept of choice was enacted by first compiling the patterns found in parent quotes about myriad decisions, examples of

control, and statements suggesting empowerment. Next, memos exploring the possible implications of the patterns were written, and finally, a visual matrix of the patterns leading to the themes was created (Bernard and Ryan 2010; Charmaz 2006). The themes derived both deductively and inductively were then combined and reviewed by the team to answer our research questions regarding how families perceived choice and the variations within family's experiences of choosing and managing autism waiver services. Trustworthiness was enhanced through triangulation between members of the research team, and by comparing the themes with findings from two additional data sources that were part of the larger waiver study (Patton 2002). These data sources included a focus group conducted by the research team and individual interviews with a sample of support brokers, clinical managers, senior therapists, in home support staff, state Children's Autism Waiver staff, and representatives from the fiscal intermediary. The focus group was designed to discover what made the waiver program work well (or not). After listing the components and processes of the waiver program, participants ranked the relative importance of each. Based on the findings from the focus group, individual staff were interviewed to gather additional data about the nature and importance of the items. Staff rated the education and training of families to be the most important component of program success. Detailed information about the staff participants and findings can be found in Leutz et al. (under review). Parent responses were compared with findings from staff responses for similarities and inconsistencies in descriptions of family choice. The other data sources supported parent perceptions of the benefits and challenges of directing their child's autism waiver program, while the parents' words added depth and nuance to the concept of choice.

Results

Our findings revealed that families overwhelmingly reported positive perceptions and an appreciation of choice, but exercised their choice-making authority in different ways with different levels of confidence and assertiveness. Five prominent themes emerged in relation to families' experience of choice within the components of the autism waiver program. The key findings associated with each theme, and their relationship to our research questions are illustrated in Table 3 and explained in detail below. The first two themes, choosing what you know, and the importance of interpersonal characteristics, contributed to answering the first research question concerning specific descriptions of choice. The next theme, varying degrees of readiness and ability to participate, informed the second research question, how parent perceptions of choice varied. The remaining themes, parent advocacy and empowerment, and parent as teacher, provided insight into the third research question concerning choice as a valued component of participant-direction.

Choosing What You Know

Six of the families described going with what they know, and chose to hire their child's teacher or early intervention specialist to provide waiver services. One parent asked the therapists at her son's school to be her providers; another hired her son's preschool teachers because they already had a good relationship. She explained, "I offered it [direct support position] to the ladies from the preschool...I trust them because they know the boys...it made me feel more like a mom versus services from the school where they dictate." A third parent reportedly scrutinized autism blogs on the web and after studying posts from unhappy parents, explained, "it spurred me to go with people who were known, versus an agency". Choice, for these families, was associated with familiarity, comfort, and consistency. These families used their power of choice to retain a provider they already knew and trusted despite the opportunity to select from a field of new people. One explanation for the frequency of choosing someone known to the family was revealed by a grandparent who expressed concern about the invasion of her privacy and about being judged by the professionals coming into her home. The fear of being judged by unknown outsiders was also articulated by a mother when asked how she felt about directing her son's autism waiver services, "It was scary at first, I was afraid they were going to come in and take [son] away because of his behavior." Choosing a familiar provider may reduce that anxiety as well as the uncertainty parents face when presented with the prospect of introducing new people into their home and family.

The Importance of Interpersonal Interactions

Parents and caregivers were particularly influenced by perceptions of the providers' personality and interpersonal interactions. One parent was very happy with her senior therapist and selected her over all the potential providers she interviewed, because "she was the most upbeat". Another explained her choice of therapist, "She [provider] was very relaxed. The prior one was a drill sergeant! But [new provider] still did routines like dinner...then shower, then teeth. She had a routine but she was laid back." A third parent was impressed that the senior therapist "is really good with people"... and the in-home support workers are "flexible and good at talking things out....", while a fourth parent affectionately described the direct support provider as "part of the family", adding "the boys love [provider] and wish he'd never leave." A mother, referring to the team of staff including support brokers and therapists pronounced, "They don't have an attitude that says they know and you don't". Finally, one parent explained her discomfort with a provider as "it was her attitude; she was a "snob". The value of personal characteristics may be magnified by the fact that services must be provided in the home, making the situation more personal than a center-based or school-based program. The importance of interpersonal characteristics was not restricted to those families who reported choosing a provider they already knew. Personality traits and attitude were qualities most parents looked for when interviewing all providers and observing them in the home.

The skill level of providers was referred to less often, and parents reported more instances of evaluating provider qualifications based on observed interactions with the child. Although parents may not have had expertise in the specific intervention, many sounded astute at observing the relationship and interactions, and having a sense of when the person was a good fit. For example, one parent perceived a provider as unable to handle her child, and elaborated by explaining, "He never brought materials and always asked to leave early." Another parent used her observation of professional behavior to explain her decision to replace a provider, "She didn't do anything, just sat there and wrote notes". A third parent explained what she looked for in providers, "You have to be able to bend and move with [son]...he can't write his name but he can change a tire on a car. They need to be flexible with him but they are locked into certain things, she [therapist] is too distant, too clinical... she forgets [son] is a person." A similar observation came from a parent who reported, "He [provider] just came in and made our son sit at the table for two hours...he [son] would see him coming and be miserable."

The evaluative observations also included positive affirmations that reflected intuitive reactions to the child-provider interactions in the same way. One parent called the senior level therapist “an angel” and “a miracle worker” while another dubbed her senior therapist “a whiz”. When probed for details, parents explained the therapist handled the child’s behavioral incidents in a calm and reassuring manner. Another parent termed the providers’ skills “excellent” and explained his view as a contrast, “I know it’s excellent because we’ve gotten poor services in other places.” The senior therapist is “right on the money.... She knows exactly what to do” reported another caregiver. Further conversation revealed this perception was based on the observation that the child complied with directions from the therapists more readily than from the parents and demonstrated skills with her that didn’t necessarily carry over when the parents were with her alone. Finally, two different families valued the way the provider paid attention to their child. One parent who had requested a new provider explained why the new situation was working “[provider name] is better...he listens...he pays attention to our son”, while another family shared “The people who come in [to the home] do very good work...he [son] enjoys the things they do together...they [provider] are always interested in his experiences and how he’s getting along”. Although these low-income parents and caregivers were generally admittedly not well informed about the professional training and techniques of the providers, they revealed themselves to be close observers of the providers’ interpersonal skills, particularly with their children. They trusted their judgments in this area and they acted on them by retaining and praising providers who knew how to connect with and help their children, and by replacing those who did not.

Varying Degrees of Participation

Despite a unanimous affirmative response to general questions of participant direction, (e.g. “I like it,” “it’s great” and “I like being in charge,”) deeper analysis of response data revealed that parents desired very different levels of control. At one end were those who embraced the full range of participant-directed responsibilities, and provided support for the theory of choice as positive and empowering. One parent enthusiastically declared “you can be the CEO or the SOB!” as he described embracing an active role directing the waiver program in his home. He had interviewed several potential providers and questioned their qualifications and experiences. He explained “he [candidate for in-home support position] is getting an online degree, I want to know more about that, what that’s all about.” At one point he had to slow the team (support broker, therapists) down when he felt the process was

proceeding without his leadership. “In the beginning they stressed that I decide, I interviewed therapists, I talked to them...then they got a little lax... things started moving fast. They just showed up at the house with a person”. He added “I understand they were rushing because [child] is already eight years old and they wanted to get things started quickly. But I redirected this and they were understanding of my viewpoint. I understand they have to get things done, but I need to talk to people about their credentials and background before they start.” This family member was happy to be in the drivers’ seat and was determined to be in charge of the waiver services. It was not clear how much he weighed the providers’ interpersonal skills as part of his evaluation but he was unique among this sample of families in discussing the credentials instead of the personality of the providers. His experience illustrated not only his active role as driver of participant direction, but also the willingness of the providers to support his desire to lead.

A mother living in a different part of the state, working with different providers also employed a high level of control over implementation of her waiver responsibilities. She utilized her support broker to organize her child’s services and was pleasantly surprised to find, “I can go to her with any problem and she sets up a meeting right away. They actually listen!” Her child hadn’t “been himself” for a few months and was having difficulty with communication and behavior. She reported “He throws a tantrum without notice... they’re [therapist] into social stories, but it doesn’t work with him, it doesn’t stop the tantrum...and I don’t have the time to sit with him before the tantrum comes and do a story. So I went to [broker] and we all got together and they’re doing a new plan.” The broker reportedly provided a list of agencies and this parent took charge, “I called the supervisors and set up interviews. I chose who would work well with [child]. If I’m uncomfortable with a provider and if I want to change, I give them two weeks notice and start the interviews again.” This parent made active choices not only about the personnel, but also about the nature of the activities and interventions for her child, demonstrating a high desire for control and a willingness to assert her desires.

Other parents, however, expressed a less confident view of choice and control. While three of the fourteen participants agreed that they appreciated participant-direction, these individuals were less assertive about overseeing the activities and personnel. One parent relied on the support broker to manage the budgeting and paperwork, and the recruiting of service providers. The support broker found an appropriate senior level therapist and brought her to the house for an interview with the parent. He explained “I chose but [broker] brought them for the interview”, adding “I like that [broker] takes care of it, it’s overwhelming to

me...stressful situations get me upset, I couldn't do it [waiver program] without help." Another parent who appeared less active in taking charge of her child's waiver services felt that she had fewer choices, explaining, "I chose ABA because that 's what the doctor said." When asked about choosing providers, she replied that she goes with whoever the broker tells her although she acknowledged, "If I don't like the therapist, they'll change, but I don't choose." She was unique among this sample of parents in her comfort with the paperwork instead of the people. She reported little control over the services or the therapists, but when asked about the managerial tasks, she replied in more detail. She brought out a thick binder, with records and reports accumulated over two years. While showing the researchers the timesheets and budgets, she explained, "I like to do these things. It's a lot but I can do it." She had created a type of spreadsheet with the days and times that forms needed to be sent to the fiscal intermediary for the therapist to be paid. She reported that she went to a local store and faxed the time sheets every other week and didn't mind this responsibility.

There were other occasional references to the size of the information packet and comments that the timesheets were overwhelming at first. Three families found both the clinical manager and support broker's assistance with managing the budget essential. For instance, "Understanding the money was hard at first, [clinical manager] came over and explained where all the money was going." Two other parents used the same language "it's a little bit hard at first" when asked about managing the budget and finances.

Parent Advocacy and Empowerment

Parents reported that their knowledge and confidence in choosing and managing services grew over the course of their time on the waiver. Experiencing positive results of their choices was empowering, and provided some parents with reassurance of their skills and abilities. While three families reported an increase in their confidence in understanding autism and their child's communication, the majority of these participants reported that the increased confidence was in their own behavior. Nine parents reported feeling good about their ability to manage specific waiver requirements. These requirements included signing the providers' timesheets and submitting them to the fiscal intermediary, and talking with and evaluating potential therapists. When asked about what she had learned as a result of directing her child's autism waiver services, one parent replied, "I'm capable. I said in the beginning, I can't do this, how will I hire people? How will I set the right goals? How will I be able to do everything the way they expect it to be done? I'm glad I didn't chicken out in the beginning!" Another reported similar growth: "I surprised

myself as a parent." If somebody told me I'd be taking care of a little girl with ASD 10 years ago I'd have said I couldn't do it. I'm proud that [child]'s doing well. I think I'm a very good parent, I'm not patting myself on the back, but I bathe her, get her toys, and take care of her, "I'm stronger than I ever thought I was." The increased feelings of empowerment these parents reported are an encouraging outcome of participant direction.

Parent as Teacher

One unanticipated finding was that parents' exercised choice over their own participation and not just the managerial components of the waiver. Two parents said they actively joined in the educational interventions being provided by staff in the home, four chose to carry on with other activities while the child received services, and the remaining eight families described a fluid hybrid of observing their child, monitoring the provider, occasionally participating, while at the same time, attending to siblings and household routines. Our analyses reveal two recurring responses: (1) caregivers found their own participation in therapy or teaching sessions challenging because their child did not "do as well" when they participated compared to when the provider worked alone, and (2) parents received mixed messages from providers regarding their participation. Some senior level and direct support providers reportedly expected to be left alone to do their work, while other staff expected active parent engagement. Different parents illustrate this contrast in expectations. One mother explained, "I'd rather watch and learn" as she shared how the senior therapist taught her specific skills by taking her hands and physically demonstrating how a motor movement should feel. The therapist was impressed and told her "some parents go and drink coffee or read while the kids get services". A second parent however, "does her own stuff" while the therapist works with her child. "[Provider] doesn't like me to interfere with the program...he'll tell me to ignore an outburst and go do my own thing". She was not unhappy with this arrangement and valued the opportunity to have a few minutes to herself. Seven of the fourteen parents said they preferred to let the therapists work directly with their child because they had the necessary skills. As another parent explained, "I don't have the experience, I didn't go to school to learn how to deal with behavioral stuff, it's difficult. I have learned a lot [on the waiver] but there's different behavioral issues that come up every week."

The number of siblings and interference with the home routine were factors described as responsible for complicating parent participation in direct services. One strained parent described the dilemma created by the requirement for active participation, "They want you to be there and be

hands on which is OK if I had one kid. I have four. I can't be spending hours with [child and therapist]". She expressed the difficulty of finding a balance between participating in one child's therapy while supporting homework and after school activities for the other siblings.

Limitations

Although the study has several strengths, there are important limitations as well. Our findings cannot be generalized to all families of young children with autism, as the Massachusetts waiver is specifically for low-income families of children with autism from birth through age nine who meet the clinical level of care required for a CMS waiver program. The in-depth interviews were conducted with parent volunteers and potentially reflect the views of more interested and/or confident parents. Although the researchers and the MA Department of Developmental Services reassured potential participants that participation would not impact their eligibility for services, it is possible that the families who declined to be interviewed perceived participation as a risk. The families interviewed represent ten percent of families currently served by the autism waiver across the largest sites. The findings also cannot be generalized to autism waiver services in general, as the MA autism waiver is designed as a participant-directed service model only, and participant direction required full directing of all components, including personnel, educational interventions, and administrative paperwork.

This specific participant-directed autism waiver model, where families are able to choose the type of autism intervention, as well as the personnel to provide the service for their child, is the only one of its kind in the nation at this time. Despite the limited scope of the sample, the voices of these parents and caregivers of young children add valuable insights to the knowledge generated by prior studies of participant-directed programs for adults with developmental and intellectual disabilities.

Discussion

The purpose of this research was to discover how parents perceived being 'in the driver's seat' when it came to directing their child's autism waiver program. Our study uncovered details about what makes choice satisfying or stressful for families with young children with autism in a participant directed waiver program. Our findings align with prior studies that showed individuals generally appreciated and embraced choice, but that choice was a nuanced concept experienced differently by different families (Freedman and Boyer 2000; Gross et al. 2012; Rabiee and Glendinning 2010). Although the waiver

required significant paperwork responsibilities, it is noteworthy that parents spoke most often of the people. This finding is important to share with supervisors, clinicians and those providing professional development because it empirically supports the essential role of interpersonal qualities and skills when supporting children and families. The importance of personal characteristics was consistent with prior research by Gross et al. (2012) who despite studying participant direction in supports for adults with intellectual and developmental disabilities instead of young children with autism, also documented the importance of provider relationships to families. The opportunity to choose who came into the home, as well as to hire and fire staff were the most frequently cited benefits to participant-direction. In the waiver program, parents frequently exercised their authority by choosing providers with whom they felt comfortable and confident, evidence that the ability to select familiar providers is a positive component of a participant-directed policy. However, our analysis also revealed why familiarity was important to participants, because it appeared to counteract the perceived risk of exposing siblings and other household members to unwanted scrutiny and expedited the process of setting up teaching situations in the home. The experiences of directing their child's autism waiver services described by these families provides a glimpse into their emotional and logical reasoning and supports prior theoretical conceptualizations of choice as power (Arksey and Glendinning 2007; Turnbull et al. 2001).

Two families reported anxiety about making "good" choices about personnel and interventions, consistent with prior research on the potential costs of choice (Rabiee and Glendinning 2010; Valentine 2010). Families occasionally asked their brokers and clinical managers, "what do you think?" and "what do you recommend?" and staff reportedly responded with flexibility as needed. In order for families to be in charge, professionals must understand what parents need, as well as encourage and enable family leadership. There was an intuitive aspect to the way staff supported families, suggesting that professionals must know individual families well enough to gauge the appropriate level of support. Although waiver programs must have consistent rules for eligibility and equity of service provision, the costs of choice can be minimized when staff have the flexibility to spend more time with less experienced and/or less confident parents. Parents and grandparents (as primary caregivers) were supported to take control but staff provided an individualized level of reassurance and support for those not ready to assert themselves or unable to fully understand the administrative details. Support brokers in particular, played a pivotal role for many families, by reportedly offering to assist less confident parents when they wanted to hire or replace staff.

Implications for Research and Policy

The first implication is for all personnel involved with autism waiver services to understand the great value these parents' placed on attitude and interpersonal skills. Beyond a few references to the initial frustration of figuring out the paperwork, questions about participant direction elicited responses about providers' and support brokers' interpersonal skills, personalities, and observed interactions with the child. Families responded positively to respect, acceptance and a lack of judgment from staff at all levels.

Second, informed choice has been theorized as potentially helpful in equalizing family's knowledge base and compensating for preexisting disadvantages in time, energy, and resources (Baxter et al. 2008). Therefore, providing new waiver families with some autism '101' materials may be helpful. Doing so could minimize the time and costs of researching interventions and ensure that families are getting accurate and relevant information from reputable sources.

Third, waiver staff might investigate whether experienced parents or waiver program "alumni" may be willing to mentor or otherwise support new parents. Four parents expressed surprise and satisfaction at themselves and their ability to cope, providing support for the premise that choice is a skill that develops with practice. Satisfaction with their choices may reflect a difference that occurs when actually directing rather than merely accepting autism services. Thus, sharing the voice of experience could potentially decrease the anxiety of families new to an autism diagnosis, and strengthen the promise of choice. Children may be accepted into the MA Autism waiver program from age 3 to age 8, resulting in potentially different levels of family exposure to autism services and personnel.

The first area for further research is the implications of parent choice about their own level of participation in carrying out the autism interventions, and the implications of expecting parents to interact with their child as a therapist or teacher during family activities and household routines. The diversity of viewpoints concerning the level of active parent involvement expected (and desired) in therapy services warrants further study, particularly within a program for low income parents raising children with multiple behavioral and communication challenges. Although parent training was expected to increase the child's progress on targeted skills, the benefits of parent empowerment and advocacy even without significant teaching time, may prove beneficial to the child in the long term. The fact that many parents proved to be good observers and recognized positive teaching scenarios suggested parents were actively monitoring their child's services even when they were not directly carrying out the interventions.

The second area for further research is the opportunities and costs of choice when selecting particular communication, social and behavioral interventions. Our findings revealed details about how these parents chose providers, but it was less clear how parents made choices between particular autism interventions. The dimensions of choice when applied to selecting interventions will be important to discover.

Conclusion

To the best of our knowledge, this is the first study of parent perceptions of participant-direction in a state waiver program for young children with autism. Choice is a complex construct involving information, experience, emotion, risk, confidence, and relationship with others. The voices of these families suggest the participant-directed autism waiver policy in Massachusetts is having a positive impact on parent empowerment and satisfaction. Future research should continue to deepen our understanding of the power and costs of informed choice in order to fulfill the promise of program quality and family capacity in participant-directed policies for children with autism as well as other disabilities and support needs.

Acknowledgments Preparation of this manuscript was supported with a grant from the Maternal and Child Health Bureau, HRSA, grant number R40MC15598.

Conflict of interest The authors declare that they have no conflict of interest.

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