

Assessing a Participant Directed Service System for Low Income Children with Autism (R40MC15598): Final Report

I. Introduction

A. Nature of the research problem: The prevalence of autism spectrum disorders (ASD) among young children has grown in recent years, but low-income children and children from families of color are less likely to be diagnosed and to receive needed services. To help address these disparities, the Autism Division of the Massachusetts Department of Developmental Services (DDS) administers an Autism Waiver Program that is designed to help low-income children under age nine with autism from diverse cultural backgrounds gain access to therapeutic supports. Massachusetts is one of only 10 states to have adopted autism waivers for children and one of only four states to provide participant direction (PD) opportunities. Massachusetts exclusively utilizes PD as its service delivery model in the waiver program. Other key features are that families have a portion of the budget to purchase items that supplement the required habilitation services and that families are supported by a team of providers including DDS Clinical Managers and contracted Support Brokers from community-based Autism Support Centers, who help educate families on their options for appropriate expanded habilitation and supports. The Brokers help families choose and hire a Senior Therapist to perform assessments and develop service plans and a Direct Support worker to implement the plans in the home. A Fiscal Intermediary (FI) maintains financial records and pays providers. A recent survey indicates that more states are currently planning to adopt similar autism waiver programs (Hall-Lande, et al., 2011), making an evaluation of the Massachusetts experience timely and salient.

B. Purpose, scope, and methods of the investigation: The purpose of the project was to evaluate the Massachusetts Medicaid Autism Waiver Program in order to (1) assess how well the PD system was implemented and operated and what it cost (Aim I); and (2) understand the variation in implementation across individual families to identify policy relevant predictors of family well-being and child progress (Aim II). A mixed methods approach was utilized.

C. Nature of the Findings: The project generated four key sets of findings. (1) *Program Infrastructure and Operation:* Many factors contributed to successful operations, including educated/trained families, having skilled in-home therapists, clear communication with families and among staff, functioning information systems, and participation of families in "carry-over" of interventions. Families varied in their capacities and time to choose and manage services but staff adjusted their levels of assistance to compensate. (2) *Parents' Experience of Choice:* Five key findings emerged including (a) families' preference to hire providers with whom they had a prior relationship, (b) families' varying levels of readiness and ability to manage the personnel and managerial tasks, (c) the importance of interpersonal interactions to program satisfaction, (d) growth in parent empowerment and (e) parents' utilization of choice to both actively join in the educational interventions being provided by staff and/or to remain solely in the role of parent. (3) *Family Well-being:* Respondents who reported a higher level of relational coordination (i.e., a positive working relationship with program staff and chosen providers) reported lower levels of parenting stress. Greater relational coordination also increased the odds of respondents' reporting that the waiver services made a positive difference in the life of their family, improved their ability to care for their child, and helped their family cope better. (4) *Child Progress:* A measure for assessing child progress was developed and linked to service receipt and family wellbeing.

II. Review of the Literature

The importance of evaluating a Medicaid-funded and participant-directed (PD) support services program for children with ASD, and the outcomes of such programs for children and their families is supported by: (1) the growing prevalence of ASD and disparities in access to ASD services, (2) the effectiveness of current treatment and services, and (3) the fit between a Medicaid waiver approach using a PD model and child needs and family capabilities.

Prevalence of ASD and evidence of disparities in access related to ASD. The prevalence of ASD among children in the United States has risen rapidly in recent years (CDC, 2007a, 2007b). Although there is no consensus on the cause of this increase, the associated pattern of earlier identification and more proactive treatment has implications for systems that serve children with autism (Leslie & Martin, 2007). Surveys also show that prevalence is lower for minorities and for low-income groups, apparently reflecting differences in likelihood of diagnosis, which may reflect differential use of educational and health systems (Liptak, Benzoni et al. 2008; Grindle, Kovshoff et al. 2009). Compared to families with typically developing children, families with children with ASD have relatively more unmet service needs and more difficulties paying medical expenses (Chiri & Warfield, 2012; Kogan, Strickland et al., 2008).

Treatments for ASD and the roles of and effects on families. There is a consensus in the field that treatments for ASD are most effective when they start when a child is younger, they are intensive and ongoing, and there is collaboration of systems, providers, and families. Swiezy and colleagues (2008) propose that the most effective approach is to have families who understand various strategies and participate as part of the care team in terms of coordinating services and sharing information across settings. However, research shows that providing and receiving ASD services in the home can pose issues. While there are advantages in the convenience and in the chance for learning by the family, there is also the chance for disruption of family routines and relationships (Grindle, Kovshoff, et al., 2009). Helping families overcome barriers to in-home support is important, since these interventions can be effective, particularly for high-risk families (Rickards, Walstab, et al., 2007).

Medicaid as a vehicle for addressing disparities in home-based ASD services. As the main vehicle for financing health care and long-term supportive services (LTSS) for low-income persons in the U.S., the Medicaid program has great potential to help these children and families. Massachusetts exclusively utilizes participant-direction (PD) as its service delivery model for the autism waiver program. The federal Centers for Medicare and Medicaid Services (CMS) defines a PD program as "a state Medicaid program that presents individuals with the option to control and direct Medicaid funds identified in an individual budget" (<http://www.cms.hhs.gov/IndependencePlus>). Although there is little research on the experiences of families of children with disabilities with PD in Medicaid LTSS systems, research from adult programs is instructive. First, even when public programs offer PD, there are limits in U.S. waiver programs on how much can be spent, what can be purchased, the availability and quality of covered services and supports, and the scope of what is controlled by the participant (Cummings, 2009). Second, few participants in PD programs fit the economic model of the fully informed buyer. They may be stressed, have little time for taking control, or may prefer not to take on PD responsibilities. Research, however, has found positive outcomes in PD programs, including better outcomes in satisfaction with care, worry, and physical and financial strain (Foster, Dale et al., 2007).

III. Study Design and Methods

A. Study design: A mixed methods approach was used. Data were gathered to understand the implementation and operation of the waiver program during its first two years of operation. Information on family experiences and well-being and child progress combined cross-sectional, in-home interview data and longitudinal data abstracted from program records.

B. Population studied: The autism waiver program serves children under age 9 with an ASD. To meet the eligibility requirements a child's family has to secure Medicaid eligibility. Each child must meet three clinical standards including a diagnosis of autism with functional deficits significant enough to qualify for DDS Children's services and a certain level of need based on two assessments of deficits in communication, socialization and activities of daily living.

C. Sample selection: All autism waiver participants who had been in the program for a minimum of six months between June 2010 and July 2011 were invited to participate in the study. Of the 100 families contacted, 74 agreed to participate. Most sample children were male (82.4%) and were 6.8 years of age on average when the interview occurred. Almost two-fifths (38.4%) were white, non-Hispanic, slightly more than one-fifth (21.6%) were Hispanic and fewer (16.4%) were black. Almost one-quarter (23.3%) were mixed race, Asian, or American Indian. More than two-fifths (43.2%) had another diagnosed disability in addition to autism. The primary caregivers were almost all parents (93.2%). The vast majority (79.7%) spoke English as their primary language, and almost two-fifths (37.8%) reported having more than one child in the household with a disability. Less than one-fifth (16.2%) considered themselves to be in fair or poor health.

D. Instruments used:

- (1) **Focus group:** A focus group was conducted to identify and weight program components. Participants included State Coordinators, Clinical Managers, Support Brokers, and representatives from the financial management service.
- (2) **Web-based survey:** Results of the focus group were used to develop a waiver program implementation scale. This scale composed a web-based survey that was administered to the Clinical Managers, Support Brokers, and representatives from the financial management service.
- (3) **Program cost:** DDS administrators provided one calendar year of state data on the costs of administration and service utilization for 107 children enrolled in the Program in CY 2009.
- (4) **Qualitative provider and family interviews in selected sites:** Twenty-six interviews were conducted with the Clinical Managers, Support Brokers and their supervisors, financial management representatives, Senior Therapists, and Direct Support workers. Similar interviews with 14 randomly selected families from across the four sites were conducted.
- (5) **Structured family interviews:** Interviews gathered data on how 74 families utilize the program's services and included standardized self-report measures of relational coordination (Gittell, 2006), parenting stress (Abidin, 1990), and parental efficacy (Frank, et al., 1986).
- (6) **Program data:** Utilization data and therapists progress notes were abstracted from the DDS program records for 71 of the 74 families who participated in the structured family interviews.

E. Statistical techniques employed: Thematic analyses (Boyatzis, 1998) of the qualitative data were conducted. Quantitative data were analyzed using a series of multiple and logistic regression models to test hypotheses regarding both predictors of utilization and family PD experiences and the influence of the PD experience on family wellbeing and child progress.

IV. Detailed Findings

Aim 1 - To assess the extent to which and manner in which participant-directed service systems are implemented in the communities served by the Medicaid autism waiver program.

Ia. Components of Participant Direction: The staff focus group identified the following factors that were important to the success of waiver program operations and their average weights: educated/trained families (18%), staff skills (16%), communications (15%), information systems (9%), pool of providers (9%), leadership (8%), working through other service issues (7%), clear but flexible rules (7%), adequacy of level of effort (6%), and policies and procedures of Brokers' home agencies vs. the Waiver Program (4%). Participants commented that the relative weighting reflected where the Program was at that point in time and also that the relative weight of components varied from family to family. They also reported that the results of the exercise showed that "people are basically on the same page" with respect to the overall understanding of the Program and what was important to its functioning. These findings were supported by the results of the web-based survey which found no differences across the sites in perceptions of program operations. The consistency of program operations is likely related to the fact that the program is small (approximately 100 families are served at any one point in time) and the two state Clinical Managers oversee multiple sites.

Ib. Factors that facilitate and impede implementation and operations: The qualitative interviews with providers and families yielded both similar and different views on implementation and operation of the Massachusetts autism waiver program.

Providers: Although consensus emerged around ten factors that were considered essential to program success, three factors were considered most important. First, Brokers and Clinical Managers agreed that the most important factor related to families' success with the PD model was their knowledge of autism and autism treatments and their capacity to manage the requirements of a PD model. The consensus of both the Senior Therapists and the Direct Support providers was that some families were ready from the start, others could be brought along with help, and others were just not capable - even with help. The most knowledgeable families had previous experience with early intervention or school systems, and the treatment approach and even the providers they chose were generally a continuation of approaches from these settings. Families without these experiences were more challenged around making choices.

Second, given the range of family situations and capabilities, respondents said that staff skills were important to the success of the program. The specific aspects of staff skills that were discussed in the focus group and interviews related to having the "right relationship" with clients, strong clinical and management skills, and the ability to work within the PD system. The discussion of "right relationship" issues included understanding the scope of the relationship with participants ("boundary issues") and how not to get pulled outside of that scope. Trust was said to be important but without becoming too enmeshed. At the same time, the "trick is not to become too paternalistic" and instead to use an empowerment model. Brokers needed to help families develop a clear understanding of the program, what it was and wasn't, with clear expectations. Skills were discussed in the context of people knowing their jobs, and staff judgments were nearly unanimous that people in the other staff categories did know their jobs. For example, there was general agreement that the Brokers had confidence in the skills and

qualifications of the Clinical Managers, and vice versa, that “weaker” providers have been “weeded out,” that Clinical Managers knew about ASD and family support, and that other staff groups were responsive to inquiries and requests. Overall, the Brokers were the hub of the wheel that connected the Clinical Managers, Senior Therapists, Direct Support Workers and FI.

Third, the focus group identified the importance of clear communication among the Broker, the Clinical Manager, the FI, and the family. The interview respondents pointed out that all needed to understand their roles in the process. Open communication between state coordinators and Program staff led to flexibility and the ability of the Program to adapt and respond to individual child and family situations.

Providers also identified areas of greater uncertainty about operations. These areas of uncertainty included (1) hours of therapy needed and the distribution of make-up hours; (2) setting boundaries around where provider jobs started and stopped (e.g., when families were in crisis); and (3) whether family participation in therapy and carrying over therapy was expected or not.

Finally, logistical problems created barriers to smooth program operation. These included (a) the cumbersome steps and procedures for purchasing goods and equipment so that families would not have to pay upfront, resulted in delayed acquisition of these items and (b) service options that could not be as utilized as families wanted, such as having respite services provided outside of their home (the original waiver only offered respite in the family’s home). The purchase of goods and services in a waiver program that is self-directed is inherently difficult around the country because participants are poor by definition and cannot have much in the way of assets. This means that programs have to develop ways to make purchases for participants while maintaining the appropriate paper trail so that expenditures can be submitted for claiming. Additionally, it is impermissible to give cash to a participant.

Families: The interviews with families sought to understand how parents experienced PD, particularly the responsibilities of choice, under the autism waiver program. Family choice included both relational tasks such as hiring and overseeing a Senior Therapist and in-home support staff, and administrative tasks, like paperwork and managing the budget. Five prominent themes emerged in relation to families’ experience directing the multiple components of their child’s autism waiver program, including (1) choosing what you know, (2) varying degrees of readiness and ability to participate, (3) the importance of interpersonal characteristics, (4) parent advocacy and empowerment, and (5) the role of parent as teacher.

First, when families agreed to be part of the participant-directed service model, they accepted responsibility for choices in areas like autism interventions and hiring staff, where they often had little or no experience. Many families described going with what they know, and choosing to hire their child’s teacher or early intervention provider under the waiver. Choice, for these families, was associated with familiarity, comfort, and consistency. Despite the opportunity to select from a field of new people, some families used their power of choice to retain someone they already knew and trusted.

Second, 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. Other parents, however, expressed a less confident view of choice and control. While agreeing that they appreciated PD, these individuals were less assertive about overseeing the activities and personnel. There were other occasional references to the size of the information packet received upon program entry and comments that the timesheets were overwhelming at first. Several families found both the Clinical Manager and Support Broker's assistance with managing the budget to be essential.

Third, questions about PD mostly elicited responses about therapist and support broker's interpersonal skills, personalities, and observed interactions with the child. 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. Parents appeared to evaluate provider qualifications based on observed interactions with their child. Although parents may not have had expertise in the specific intervention, many were astute at observing the relationship and interactions, and having a sense of when the person was a good fit. The evaluative observations also included positive affirmations that reflected intuitive reactions to the child-provider interactions in the same way. Although these low-income parents and caregivers were admittedly not well informed about the professional training and techniques of the providers who came to their homes, they were clearly close observers of their interpersonal skills, particularly with their children. They trusted their own 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.

Fourth, 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. The increased feelings of empowerment these parents reported are an encouraging outcome of PD.

Finally, while our findings are consistent with the view of choicemaking in a PD model as one where families rather than professionals, make decisions about services, it was not anticipated that parents would also exercise choice by either making the decision to actively join in the educational interventions being provided by staff in the home, or to remain solely in the role of parent. Our analyses reveal two recurring, yet different, responses: (1) some 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. The number of siblings and interference with the home routine were additional factors responsible for complicating parent participation in direct services.

Ic. Program cost: Of the \$3 million spent on the program in calendar year 2009, 82% was spent on goods and services and 18% on administration, led by the costs of Brokers (9% of total budgeted costs). The funds supported 12 Broker 0.5 FTEs, or about 9 children per Broker on average at a cost of approximately \$24,000 per Broker. State staff reported that caseloads later increased substantially. The Central Office staff budget included two Clinical Managers, the Program administrator and a portion of the Program director's time. Also in this figure are residual infrastructure costs for the development tasks associated with the new program.

Approximately 85% of the children in the program had individual budgets of over \$22,000 worth of services and supports per year, and another 13% had services and supports budgets between \$16,000 and \$22,000. There were 8 participants with budgets under \$16,000, and for the majority of these participants it was because they were almost age nine and they had prorated budgets to reflect their short time in the program.

A review of expenditure data from the Fiscal Intermediary from calendar year 2009 showed that the actual spending per individual participant averaged about \$16,000 a year, which is lower than the anticipated \$20,000 available to the average individual participant in his/her budget. This lower expenditure rate is common in waiver programs with capped budgets (Leutz, Sadowsky et al. 1992; Leutz, Nonnenkamp et al. 2005), and program staff noted that start-up of in-home services takes time for a variety of reasons, including the need for family training and finding in-home staffing. Issues with staffing and services also arise once providers are in the home, including staff turnover and occasional family decisions to exercise their power to replace unsatisfactory providers.

Aim II: To understand the variation in the implementation of participant directed services across families and assess which aspects of this service delivery model predict family well-being and child progress.

Hypothesis 1. Use of PD services will be predicted by predisposing and need factors. Specifically, children closer to aging out (i.e., age 9), from smaller families, and with more mental health needs, will have higher PD utilization.

Two measures of service use were developed to capture the use of required habilitation services and utilization of ancillary services that families could choose as part of their individualized plan. Habilitation services are delivered in fifteen-minute units. Since individual children and families varied in terms of the number of months they were in the program (mean = 19.61, SD = 7.9, range=7-33), we created an annualized total number of habilitation service units received to measure utilization (mean=1,185.7, SD=553.8). Child age, family size, and mental health needs were not significant predictors of annualized habilitation utilization. This suggests that the waiver was successful in providing a similar intensity of expanded habilitation to all children.

Ancillary services include a variety of services that families can choose to receive under the waiver program. These include community integration and ADL skills services, respite and family training services, and homemaker services. The number of ancillary services accessed by families varied with one-fifth (22.5%) not receiving any ancillary services, two-fifths (40.8%) receiving one ancillary service, and two-fifths receiving two or more ancillary services (36.6%).

There was a significant difference in the number of months in the program by the number of ancillary services received with more services being associated with longer program duration [$F=7.27$ (2, 68), $p < .01$]. Logistic regression analyses also indicated that families with older children (8 years versus younger) were more likely to access ancillary services ($OR=1.33$, $p < .0$), controlling for family size and mental health needs.

Hypothesis 2. Controlling for differences in the use of existing services, family PD participation will be influenced by enabling factors. Specifically, families with more support and greater coping skills will be more active participants.

Family PD participation was measured using items modified from the National Core Indicators (NCI) project that were asked during the in-home family interviews. Caregivers indicated the extent to which, as part of the waiver program, they were involved in gathering information and planning services, they were able to gain access to and delivery of the services they desired, and they were able to exercise choice and control over waiver services. Family support and coping skills were assessed when the family entered the program by program staff. Regression analyses on the family PD participation outcomes revealed a significant relationship between a family's social resources and their access to the services they desired ($b=-1.22$, $p < .10$). Having fewer social resources predicted greater access to and delivery of desired services. Although this was opposite to what was predicted, it suggests that perhaps the waiver program was able to address some previous disparities in service provision.

Hypothesis 3. Families in service areas with greater PD implementation and better coordination among providers will be more active participants.

The web-based survey found no differences across the sites in perceptions of program operations so the analysis of Hypothesis 3 focused on the relation between measures of relational coordination and family PD participation across all sites. The table below shows the consistent, positive, and significant correlations between the three measures of family PD participation and high levels of the seven facets of relational coordination. Thus, the involvement of the family in the waiver program was associated with the quality of the relationship between each family and the waiver program staff and providers with whom they interacted.

Correlations between Family PD Participation and Relational Coordination

PD	Frequent Comm	Timely Comm.	Accurate Comm.	Problem Solving	Shared Knowledge	Mutual Respect	Shared Goals
Information and Planning	.40*	.26*	.18*	.39*	.47*	.65*	.60*
Access and Delivery	.38*	.41*	.29*	.37*	.30*	.36*	.29*
Choice and Control	.32*	.41*	.31*	.49*	.33*	.50*	.54*

* $p < .05$

Hypothesis 4. Controlling for predisposing and need factors, greater service use will predict greater child progress.

The process of developing a measure to capture child progress under the MA Children's Autism waiver involved three steps (1) identifying the skill areas to be measured (2) determining the number of scoring codes for each skill area and (3) generating the type of scoring codes to best indicate progress. The measure was designed to gather the most relevant and accurate data from existing progress reports. These reports were primarily narrative summaries written by therapists utilizing different therapeutic approaches and reporting formats.

A review of the therapists' progress notes for a sample of children was undertaken to discern the amount and type of data available in terms of the skill areas mentioned and the number of time intervals reported on. Initially, twelve discrete skill areas were identified but further analysis revealed that the reports varied too widely to be able to code progress at that level of detail. Combining categories resulted in four final skill areas most representative of the skills targeted: Communication, Interpersonal, Independence, and Problem Behavior. The number of time intervals reported on also varied widely as well as the type of information recorded about progress. Three ratings were developed and used to code the information provided about each of the four skills at each time interval: PQ, NQ or SP. PQ was used to indicate positive qualitative statements (i.e., the child "is demonstrating increased self-regulation"). NQ was used to indicate negative qualitative statements such as skill regression or an increase in difficult behavior. The code SP represented general statements about programming without evidence of progress (i.e., the child "continues to work on toothbrushing"). A continuous process for testing and improving the measure was instituted. Two researchers from the project team independently rated one child's report with the initial progress measure, compared scores, and revised the progress measure. The revised measure was used for three new reports with improved inter-rater agreements of 33% on the first and 46% and 66% on the second and third files. The same process was continued through twelve additional children's reports. The last two files produced 91% agreement, resulting in an overall inter-rater agreement of 75% after 15 child files.

Three progress variables were created for each skill area counting the number of each code type and dividing by the total number of reports. Thus, recorded for each skill area and each child was the proportion of reports with positive progress, proportion of reports with negative progress, and proportion of reports with statements about programming without an indication of progress. The mean percent of positive statements varied by skill area: communication ($M=.50$, $SD=.27$), interpersonal ($M=.37$, $SD=.18$), independence ($M=.17$, $SD=.25$), and behavior ($M=.17$, $SD=.22$).

Regression analyses revealed that, controlling for child age and caregiver capacity, greater utilization of habilitation services predicted a higher rate of positive progress on independence skills ($b=.01$, $p < .10$). Service use did not predict progress in any of the other skill areas.

Hypothesis 5. Controlling for PD implementation at the service system level, better family relations with providers will yield greater parental efficacy, lower parenting stress, and increased satisfaction.

Caregivers were asked to rate their interactions with the Clinical Manager, Support Broker, Senior Therapist and Direct Support worker on seven dimensions of relational coordination, which included frequency, timeliness, and accuracy of communication, willingness to solve problems together, providers respect and understanding of parental role, and the extent to which goals were shared. Scores were then averaged for all providers to form a single index reflecting total relational coordination (Cronbach alpha = .85). Controlling for child behavior problems, caregiver health and capacity, number of months in the waiver program, and receipt of non-waiver services, greater relational coordination predicted lower levels of parenting stress ($b=-4.1$, $p<.05$). Similarly, a series of logistic regressions found that greater relational coordination predicted a greater likelihood of reporting that the waiver services made a positive difference in the life of the family ($OR=9.74$, $p<.01$), improved the caregiver's ability to care for their child with ASD ($OR=6.75$, $p<.01$), and helped the family cope better ($OR=6.26$, $p<.01$).

Hypothesis 6. Children in more positive family environments will make more progress.

Correlations were analyzed between measures of the family environment including the three subscales of the parenting stress index (i.e., stress related to parenting, to parent-child interaction, and to child difficulty), and parental efficacy, and the child progress measures in communication, interpersonal skills, independence, and behavior. Significant associations were found between measures of stress and progress in independence and interpersonal skills. Specifically, significant associations were found between lower parenting stress and greater progress in independence ($r=-.27$, $p<.05$), less stress around the parent-child interaction and more progress in independence ($r=-.24$, $p<.05$), and interpersonal skills ($r=-.27$, $p<.05$), and less stress emanating from the child's behavior and more progress in independence ($r=-.24$, $p<.05$) and interpersonal skills ($r=-.26$, $p<.05$).

V. Discussion and Interpretation of Findings

A. Conclusions to be drawn from findings. Three conclusions can be drawn from the study's findings. First, participant direction can be a viable service delivery model for low income families who are parenting young children with ASD. Success depends on having skilled staff, good communication mechanisms, and a willingness to allow for flexibility in how families with different capacities and interests play the role of director. Second, families thrive when there is comfort with and trust of the program staff and providers whom families work with, accurate and timely sharing of information between team members, and problem solving in an atmosphere of mutual respect and shared goals. Benefits of this type of team work include greater PD among families, lower parenting stress and more positive family functioning. Third, preliminary analyses suggest some association between child progress and both greater utilization of expanded habilitation services and a positive family environment. Further development and utilization of a standardized tool aimed at monitoring child progress in a more systematic way can pay dividends in furthering waiver program development and better explicating the role of families in both direct service provision and indirect provision through carryover.

B. Explanation of study limitations. The study's limitations include its small sample size which lowers the statistical power needed to identify significant relations if they exist. Second, the data gathered from families was cross-sectional and we were only able to interview 74% of the

eligible families we contacted. Finally, three of the interviewed families refused to give us access to their DDS program files so their program service data and intake assessment data are missing.

C. Comparison with findings from other studies. Similar to waiver programs for adults that offer PD (Cummings, 2009), there are limits in the autism waiver program in terms of the services that can be chosen (i.e., each child must receive expanded habilitation services but can choose from among different ancillary services) and what can be spent. Our finding that the actual spending per individual participant was lower than the amount available is a common finding in waiver programs with capped budgets (Leutz, Nonnekamp, et al., 2005).

Parental choice is an important element of the waiver program and one that families in general embraced. Other studies have noted, however, that the array of choices and decisions that need to be made by any family once a child's ASD diagnosis is confirmed can be immense (National Autism Center, 2010; Valentine, 2010). Prior research suggests families and individuals with disabilities appreciate choice but also find aspects of choice difficult, for example, the time required to locate and then decipher, relevant information (Freedman & Boyer, 2000; Rabiee & Glendinning, 2010). Even when the sense of control is enjoyable and empowering, choice, particularly after a child's diagnosis of autism, may be construed as an obligation and a parental responsibility that cannot be avoided (Altiere & Von Kluge, 2009; Valentine, 2010).

Our findings on the relation between positive collaboration among families, program staff, and providers and increased family well-being as well as the challenges of in-home service provision are supported by similar studies. There is a consensus in the field that treatments for ASD are most effective when they are intensive and ongoing, and when there is collaboration of systems, providers, and families. For example, Swiezy and colleagues (2008) propose that the most effective approach is to have families be "knowledgeable about different strategies" and be "integral members of the care team responsible for coordinating services and disseminating information across settings." However, research shows that providing and receiving ASD services in the home poses issues: on the one hand the advantages of the convenience and the chance for learning by the family, and on the other the chance for disruption of family routines and relationships (Grindle, Kovshoff, et al., 2009). Helping families to overcome barriers to in-home support is important, since interventions there can be effective, particularly for high-risk families (Rickards, Walstab, et al., 2007).

D. Possible application of findings to actual MCH health care delivery situations. PD is a promising service delivery approach that could be extended to other MCH populations including vulnerable children and families served by home visiting and early intervention programs, since choice, empowerment, and participatory decision making are also recommended values in family centered models for early childhood services (Murray, et al., 2007). Training for providers in how to build relationships with families and encourage their service direction could enhance the number of providers skilled at delivering this type of care and thereby support program expansion. The ability to educate families about different types of autism care and therapies was found to be an important factor to program success. Opening up a space to allow families to request a change of providers or care managers is also suggested. Developing educational materials for families could help in this regard.

E. Policy implications – Nationally, the documentation of the implementation, operation, and organization of the Massachusetts autism waiver program provides useful data for other states. A recent survey indicates that more states are currently planning to adopt similar autism waiver programs (Hall-Lande, et al., 2011). In Massachusetts, state officials are examining ways to implement training around relationship building so providers can utilize these skills to foster improved family well-being early in their work with waiver families.

F. Suggestions for further research. Future projects being considered include (1) conducting a longitudinal study of waiver participants to examine how family and staff approaches to PD evolve over time and how families and providers negotiate roles regarding in-home therapy; and (2) training providers to document child progress using a standardized data collection tool in order to better assess the impact of waiver services on child outcomes.

VI. List of Products

A. Papers Submitted to Academic Journals. Three papers have been submitted:

- (1) Leutz, W., Timberlake, M., Warfield, M.E., & Chiri, G. The infrastructure of participant direction for Medicaid-funded in-home autism services for children in Massachusetts (*Journal of Policy and Practice in Intellectual Disabilities*)
- (2) Timberlake, M., Leutz, W., Warfield, M.E., & Chiri, G. In the driver’s seat: Parent perceptions of choice in a participant-directed Medicaid waiver program for young children with autism (*Journal of Disability Policy Studies*)
- (3) Warfield, M.E., Chiri, G., Leutz, W., & Timberlake, M. Family Well-Being in a Participant Directed Autism Waiver Program: The Role of Relational Coordination. (*Journal of Intellectual Disability Research*)

B. Conference Presentations

- (1) Warfield, M.E. “Assessing a participant directed service system for low income children with autism.” Plenary Speaker at the Combating Autism Act Initiatives (CAAI) Conference (January). Washington, DC.
- (2) Leutz, W. “Implementing participant direction for services for low income children with autism.” Roundtable Discussion at the Combating Autism Act Initiatives (CAAI) Conference (January). Washington, DC.

C. Manuscripts in Progress

- (1) Developing a Reliable and Valid Measure of Child Progress from Data Gathered via an Autism Waiver Program; Planning on submitting this to *Health Services Research*
- (2) Understanding Patterns of HCBS Service Utilization among Children with Autism in Massachusetts: Implications for Policy; Planning on submitting this to *Journal of Autism and Developmental Disorders*

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