

Family well-being in a participant-directed autism waiver program: the role of relational coordination

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Abstract

Background Massachusetts is one of a very limited number of states exclusively employing participant-direction to deliver autism waiver services to children. A crucial element of this waiver program is the work conducted by the state's Department of Developmental Services (DDS) staff and state-approved providers with waiver families to facilitate the implementation of the participant-direction model. Our study investigates the effect of the collaboration between state providers and family caregivers on family well-being.

Methods We conducted a survey of 74 families who have been utilising waiver services for at least 6 months. Participants were asked to rate the coordination with providers as well as to report on parenting stress and impact of waiver services on family functioning. Data from in-home child and family assessments conducted by the state were also abstracted from program records.

Results After controlling for a host of variables hypothesised to affect the outcomes of interest, we found that the family's view of how well they coordinated with formal providers is significantly associated all of the outcomes. Families who reported greater coordination with state providers experienced lower parenting stress and reported a more positive impact on family functioning. Child exter-

nalising behavioural problems and caregiver's health rating also contributed to parenting stress and family functioning.

Conclusions Our findings highlight the importance of establishing a collaborative partnership with waiver families in promoting family well-being. These results suggest that training and/or resources that foster team building and communication can positively impact family functioning among families with young children with autism.

Keywords autism waiver program, parenting stress, participant direction, relational coordination

Introduction

In October 2007 the Federal Centers for Medicare and Medicaid Services (CMS) approved Massachusetts's request for a home and community-based services (HCBS) waiver to implement a participant-directed, in-home services program for children ages birth-8 with severe autism spectrum disorders (ASDs). About 250 children have been served under this waiver through 2012.

Families are eligible to participate in the HCBS waiver if their incomes are equal or below 150% of the federal poverty level (\$33 075 for a family of four in 2010). Under this program, families use an individually set budget of up to \$25 000 to select services and supports within an established number of options. Among the services made available to families are one-to-one behavioural, social and

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communication-based interventions through a service called expanded habilitation and education services. Although these are required services, families can choose from among different types of habilitation approaches such as applied behavioural analysis (ABA) and developmental and relational models (e.g. floor time and communication models). Of the total budget, up to \$7000 can be spent by families for services like community integration and respite and to purchase items to enhance their child's development such as home modification equipment, outdoor fencing and weight belts. The ultimate goal is to advance children's basic adaptive and verbal skills and further their development of appropriate interactive and play skills (Leutz *et al.* forthcoming).

According to the CMS website, Massachusetts is one of few states in the country with a waiver program specifically for children with autism¹. In addition to Massachusetts only 9 other states have adopted autism waivers for children. Though currently small, the number of states with autism waivers for children may soon be growing as a recent survey indicates many are planning to adopt them (Hall-Lande *et al.* 2011). Reasons for the expansion of this program range from increased demand, long waiting lists and scientific evidence showing that early intervention is critical (Hall-Lande *et al.* 2011).

Of these 10 states with autism waiver programs for children only four provide participant-direction (PD) opportunities. 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'.¹ This service delivery model is also referred to as self-directed or consumer-directed supports. In this paper these terms will be used interchangeably.

Massachusetts exclusively utilises participant-direction as its service delivery model. Under the program's PD model, parents worked closely with the staff to develop a support plan that outlined the goals and objectives for the child while also looking at the child's strengths and areas of concern. The plan was translated into a set of in-home services as

well as a budget that covered the costs of these services within the available \$25 000 annual allocation, including ancillary supports such as safety equipment (e.g. locks, alarms, fences, etc.), respite and community integration activities that could comprise up to \$7000 of the \$25 000. Family responsibilities under PD include choosing a therapeutic approach (e.g. ABA, Floortime, etc.), choosing and hiring providers, firing providers if they are unsatisfied, submitting time sheets so providers could be paid, and monitoring the budget.

Participant direction

The philosophical orientation of participant-direction 'rests on the recognition that people with disabilities should not be forced to give up their basic civil rights in order to obtain support' (Moseley 2001). This principle has been translated into practice with the creation of programs or service options in which individuals with disabilities or their families actively and directly manage and design their supports (Caldwell & Taylor 2006; Hall-Lande *et al.* 2012). Fundamental elements of participant-direction include person-centred planning, individual budgeting and quality assurance and improvements (Smith *et al.* 2007; Walker *et al.* 2009).

Other critical components of the participant-direction infrastructure that Massachusetts has incorporated in its autism waiver are support brokerage and the presence of financial management services. These two components play an important role in ensuring that self-directed opportunities remain a viable option for waiver participants (Moseley 2004; Smith *et al.* 2007).

Research has shown there are tangible benefits to participant-direction. Foster and colleagues for instance found that Cash and Counseling² clients utilising the consumer-directed option had greater satisfaction with paid caregivers' reliability, schedule, and performance than a control group relying on agency services (Foster *et al.* 2003). Similarly, Beatty and colleagues reported that people who received consumer-directed personal assistance ser-

¹ See CMS website: <http://www.medicicaid.gov/Medicicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html>

² Cash & Counseling is a joint Robert Wood Johnson Foundation and US Department of Health and Human Services project that gives consumers individualised monthly budgets that can be used to hire home health workers of their choice.

vices exhibited more satisfaction with the services received relative to their non-consumer-directed counterparts (Beatty *et al.* 1998). A 2004 National Council on Disability review of the state of knowledge about consumer direction, found that the literature indicated a positive effect of consumer direction on consumer satisfaction, quality of life and perceived empowerment (National Council on Disability 2004). Evidence also suggests that consumer-directed family supports decrease the need for placement into institutions and nursing homes (Heller & Caldwell 2005; Caldwell 2007), expand community involvement for individuals with disabilities (Heller *et al.* 1999) and allow greater employment opportunities for the caregivers (Caldwell & Heller 2003; Caldwell 2007).

Support for directing services

Another key characteristic of the Massachusetts waiver program is the presence of a team of state Department of Developmental Services (DDS) staff and state-approved providers who work together with waiver participants to facilitate the implementation of the participant-direction model. The team includes 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 Senior Therapists to perform assessments and develop service plans and direct support workers to implement the plans in the home. The Senior Therapists and direct support workers can either work for agencies or work as independent providers, as long as they are approved by DDS.

Because Massachusetts' model requires a network of service providers to work together in a prompt, adaptable and coordinated manner, it is important to understand the nature of their interaction and its connection with family well-being. While collaboration may impose an organisational burden by requiring more frequent contact between team members and the family, the increased interaction among team members that demands added 'attention, training and cooperation from more people' (Leutz 1999), also has the potential to decisively improve both family outcomes and satisfaction with the program (Romer & Umbreit 1998). As current

systems of care are complex and families may have difficulties navigating them (Krauss *et al.* 2001), having access to a dedicated team of professionals can help families secure needed services (Freedman & Boyer 2000) while at the same time fostering independence and autonomy (Dunst & Trivette 1989).

There is a rich and vibrant literature on the role of service coordination³ in achieving valued outcomes for both clients and agencies. Several studies have reported positive outcomes from integrated service delivery such as more efficient access to services, more timely conveying of information to families, superior service quality, enhanced quality of life for caregivers and greater caregiver empowerment (Dunst & Bruder 2002). From the agency perspective, coordination can reduce costly duplicative efforts thereby freeing up resources that can be devoted for new or additional services (Sandfort 1999).

In this study we focus on the coordination efforts that occur at the client level. To examine the effects of the team organisational structure implemented in Massachusetts we employ one measure of service coordination known as relational coordination. In this paper we introduce the concept as it relates to the provision of services to families of children with autism.

We hypothesise that all other things being equal, greater relational coordination will generate lower parenting stress and greater family functioning.

Relational coordination

Developed by J.H. Gittell, the theory of relational coordination focuses on the interactive processes that occur among individuals in work settings. The theory emphasises the interpersonal nature of work and thus stresses the importance of 'understanding the relational dynamics of coordinating work' (Gittell 2011b). Gittell conceptualises relational coordination as the management of interdependent

³ Service coordination has also been variously called care coordination, service integration and case management. The definition is somewhat different depending on whether the term is employed in the health care, education, early intervention or human services field; however, it generally defines the efforts carried out by various agents to facilitate the identification of clients' needs and to act as a link between multiple participants.

tasks and those who perform those tasks ‘through a network of relational and communication ties’ (Gittell 2011a). More specifically, relational coordination is defined as a ‘mutually reinforcing process of interaction between communication and relationships carried out for the purpose of task integration’ (Gittell 2002b).

According to this theory, shared knowledge, shared goals and mutual respect are the three fundamental components sustaining and nourishing the process of coordination. Organisations where individuals habitually partake in high quality communication based on these three elements more easily realise their desired outcomes (Gittell 2002a, 2011b).

Originally developed as an explanation of the nature of interaction among employees of a domestic airline company and its positive impact on flight departure performance, the theory of relational coordination has also received scholarly attention in the fields of health care, early childhood education, early intervention and criminal justice. Several studies in these fields have demonstrated a significant association between relational coordination and positive outcomes.

In an evaluation of providers working in acute care hospitals, researchers found not only that as relational coordination increased the overall quality of patient care increased but also that key adverse events decreased (Havens *et al.* 2010). Similarly, an analysis of the working relationship between nurses, therapists, case managers and physicians who had shared patient responsibilities concluded that relational coordination significantly predicted reduced length of stay, cost per stay and readmission (Gittell *et al.* 2008b). Positive association between relational coordination and residents’ quality of life was also found when researching 15 nursing homes in Massachusetts (Gittell *et al.* 2008a). In the Netherlands, a survey of a national disease-management program revealed that relational coordination among professionals in the program was positively associated with the delivery of high-quality chronic illness care (Cramm & Nieboer 2012). A study of case management practices for high-intensity service users in Northern Ireland uncovered that the coordination of patient care was much more effective in those units where relational practices among providers were stronger (McEvoy *et al.* 2011). Finally, rela-

tional coordination was found to enhance informal caregivers’ competency in providing care to patients who had just undergone knee replacement surgery. Greater caregiver proficiency was in turn positively associated with patients’ functional status and mental health (Weinberg *et al.* 2007).

Outside of the health care field, Derrington & Erickson Warfield (2013) attributed increased access to and engagement with early intervention services for drug-exposed infants to the relational coordination taking place between early intervention agencies and staff at hospitals where drug-exposed infants had been delivered. Relational coordination theory has also been used to understand relationships among criminal justice agencies although its role in reducing recidivism rates has not been unequivocally determined (Bond & Gittell 2010). Lastly, relational coordination has also been associated with high-quality parent-teacher partnership as evidenced by a study of four early care and education programs operating in the United States (Douglass & Gittell 2012).

Method

Participants

All autism waiver participants who had been in the program for a minimum of six months between June 2010 and July 2011 were sent a letter by the Department of Developmental Services (DDS) informing them of the study. Letters were sent in English and in their primary language if it was not English. The letter told them that their DDS Clinical Manager would phone them to explain the study further, answer questions, and see if they wanted to participate. Of the 100 families contacted, 74 agreed to participate. The average length of time in the program at the time of contact was 19.6 months ($SD = 7.9$, range 7–33). Characteristics of the children and families are reported in Table 1. The vast majority of sample children was male (82.4%) and were 6.8 years of age on average ($SD = 1.2$, range 4–9) when the interview occurred. They represented four ethnic categories: 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. Slightly above one third

	<i>n</i>	%	Mean (SD)	Range
Child				
Gender (male)	61	82.4		
Age in years			6.8 (1.2)	4–9
Ethnicity [†]				
White, non-Hispanic	28	38.4		
Black	12	16.4		
Hispanic	16	21.6		
Other	17	23.3		
Has other diagnosed disability	26	35.1		
Communication disorder	16	21.6		
Intellectual disability (ID)	8	10.8		
Other ID/DD	6	8.1		
Seizure disorder	5	6.8		
Physical disability	3	4.1		
Externalising behaviour problems	69		13.2 (8.5)	0–36
Primary caregiver				
Relationship to child				
Parent	69	93.2		
Grandparent	5	6.8		
English is primary language	59	79.7		
More than 1 child in HH with disability	28	37.8		
Caregiver capacity	68		6.1 (1.9)	1–8
Health rating				
Excellent/good	62	83.8		
Fair/poor health	12	16.2		

Table 1 Characteristics of sample participants (*n* = 74)

[†] One case was missing information on ethnicity. The other group included 12 cases where two or more ethnic categories were selected, four Asians and one American Indian. DD, developmental disability; HH, household.

(35.1%) had another diagnosed disability in addition to autism, the most commonly reported being communication disorder (21.6%).

The primary caregivers were almost all parents (93.2%), grandparents were the primary caregivers in 6.8% of the cases. The vast majority of respondents (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 of the caregivers (16.2%) considered themselves to be in fair or poor health.

Procedures

Our study was approved by the Institutional Review Board of our institution and by the review board at DDS. The data were gathered from two sources. First, as part of the eligibility procedures for the waiver program, each child had to meet a certain

level of need as determined by an in-home assessment that captured each child's current level of deficits in the areas of communication, socialisation and activities of daily living as well as an understanding of the capacities and stressors of the parent/caregiver. Data from these assessments were abstracted from program records. Second, structured, in-home interviews were conducted by trained interviewers to collect information on child and family characteristics, receipt of services beyond the waiver services, relational coordination, parenting stress, and the impact of the waiver services on aspects of family functioning.

Measures

Dependent variables

Parenting stress. Parenting stress was measured using the Parenting Stress Index Short Form

(Abidin 1990), a 36-item self-report measure of parenting stress. The measure includes three sub-scales of 12 items each, plus a total stress score. The Parental Distress sub-scale was selected as it focuses on the distress experienced by parents as it relates to the parenting role including feelings of not being a skilled parent, limitations associated with parenting a small child, absence of social supports and depression. Recent research has found it useful for assessing the severity of distress among parents of children with ASD (Zaidman-Zait *et al.* 2010). Examples of questions from this sub-scale include: 'I often feel that I cannot handle things very well', 'I feel alone and without friends', 'Having a child has caused more problems than I expected in my relationship with my spouse', 'I feel trapped by my responsibilities as a parent'. Higher scores indicate greater distress. The reliability coefficient (Cronbach's alpha) for the sub-scale was 0.83.

Impact on family functioning. Caregiver perspectives of the impact of waiver services on family functioning were measured by asking each caregiver to report whether they believed the waiver services (1) made a positive difference in the life of their family, (2) improved their ability to care for their child, and (3) helped their family cope better. Answer choices for each item were coded as (0) sometimes or no and (1) yes.

Independent variables

Our choice of independent variables was based on the literature on parental adaptation to caring for a child with developmental disabilities and other special health care needs. This work has identified selected child, family and system characteristics that influence family well-being. Child behaviour problems are related to a range of indicators of well-being including stress and depression (Bailey *et al.* 2007; Rezendes & Scarpa 2011). Caregiver health and other assets such as coping skills and supports have also been shown to be related to greater well-being (Raina *et al.* 2005; Lyons *et al.* 2010). Greater service utilisation has also been shown to reduce stress among parents of young children with disabilities (Cowen & Reed 2002). Moreover, the formal services families receive are an important factor in defining the caregiving context (Seltzer & Heller 1997).

Child externalising behaviour problems

The in-home assessment conducted by trained state staff included ten items that evaluated the child's severity and frequency of behavioural problems. Each item was assessed in terms of the severity of the behaviour on a three-point scale and in terms of the frequency of the behaviour also on a three-point scale. These severity and frequency ratings were multiplied to yield a total number of points for each item. Item values ranged from 0 to 9, such that higher scores represented greater behaviour problems. The 10 items described both externalising behaviours (e.g. attempts to destroy or break property) and internalising problems (e.g. presence of perseverative behaviours that interfere with child's ability to participate in activities).

In order to test the viability of combining the items into a single measure we conducted an exploratory factor analysis. The factor analysis with varimax rotation identified one key factor. The four survey items forming the factor are: attempts to destroy or break property, has tantrums that significantly interfere with his/her own or family's social activities outside of the home, exhibits physically hurtful behaviours toward others, and exhibits self-injurious behaviours. After rotation, the factor loadings for the 4 items ranged from 0.67 to 0.74 and the proportion of variance explained by the factor was 0.56. We then added together the scores from each of the four items to create a composite measure. This measure has a reliability coefficient (Cronbach's alpha) of 0.81. We chose a composite score over the individual items because the small sample at our disposal necessitated us to be as parsimonious as possible in the number of independent variables employed in the models.

In our sample the average score for this measure was 13.2 (SD = 8.2, range 0–36).

Primary caregiver health and capacity

The primary caregiver's health was assessed with a 4-point self-report rating of health as excellent, good, fair or poor. We elected to collapse the two lower and two upper categories together as the fair and poor categories had low cell frequency.

The caregiver capacity variable is a composite measure we created from the ratings of each

caregiver's skills and capacities in the domains of physical health, mental health, substance use, safety, knowledge, involvement, supervision, organisation, social resources, and housing stability made during the in-home assessment conducted by the trained state worker. All items were scored using a 4-point scale, with higher scores indicating the caregiver is able to care for the child and needs no or only minimal assistance and lower scores signalling the caregiver has substantial difficulties requiring immediate and intense support.

We performed a factor analysis with varimax rotation on all 10 items. One key factor was identified. The survey items forming the factor are: caregiver knowledge of the child's needs, caregiver involvement as an advocate for their child, caregiver monitoring skills, and caregiver ability to organise and maintain the household. We named this factor 'caregiver capacity'. After rotation, the factor loadings for the 4 items ranged from 0.51 to 0.75 and the proportion of variance explained by the caregiver capacity factor was 0.64. Finally, the scores from each of the four items were summed to create a composite measure. The reliability coefficient (Cronbach's alpha) for the scale is 0.77.

In our sample the average score for this measure was 6.1 (SD = 1.9, range 1–8).

Service environment

Two measures of the service environment were assessed. First, the time a family participated in the program was calculated as the number of months between the date of the in-home assessment and the date of the interview. Second, as part of the in-home assessment, caregivers were asked if their child received any other services (e.g. from personal care attendants (PCAs), visiting nurses, home health aides, early intervention programs, ancillary support services, etc.) outside of the waiver program. The most commonly received service was PCAs ($n = 16$ or 21.6%) followed by ancillary support services ($n = 12$ or 16.2%). Families were identified as either receiving additional services or not. We chose to bundle individual items into a composite score because of the small sample size and because most families received only one outside service.

Relational coordination

Coordination between formal and informal providers was evaluated using Gittell's relational coordination measure (Gittell 2006, 2011b). This measure has been shown to possess solid psychometric properties such as high inter-rater agreement, inter-rater reliability and internal consistency (Gittell 2002a; Gittell *et al.* 2010; Valentine *et al.* 2012); furthermore the structural validity of the instrument was confirmed via factor analysis (Gittell 2002a, 2011b).

Caregivers were asked to rate their interactions with the clinical manager, support broker, senior therapist and direct support worker on seven dimensions which included four communication dimensions (frequency, timeliness, accuracy and problem-solving communication), and three relationship dimensions (respect and understanding of parental role, and extent to which goals were shared). Questions asked included the following: 'How frequently did you communicate with each of these providers about your child?', 'When problems arose about your child, did these providers work with you to solve the problem?', 'How much did these providers share your goals for your child?'

Each of the seven dimensions was scored on a five-point Likert-type scale. The scales ranged from 1 (never/nothing/not at all) to 5 (constantly/always/everything/completely). Each respondent rated the relationship with each individual provider separately; these individual scores were then averaged across all providers to form a single index reflecting total relational coordination. Higher scores indicate the respondents felt the team of providers engaged in timely, accurate and problem-solving communication and to be knowledgeable, respectful of their role as parents and in agreement with their goals for their child. For example, families with strong relational coordination scores would know which member of the team to call to discuss specific issues, would get a quick response from that team member, and would be supported by the team in making decisions such as terminating a provider and choosing one better suited for their child.

The reliability coefficient (Cronbach's alpha) for the scale was 0.85. In our sample the average score for this measure was 4.4 (SD = 0.5, range 2.8–5).

Data analysis

Depending on the measure, only between 5% and 8% of the sample had missing data. We replaced these missing values with median substitution so that all analyses were conducted on the sample of 74 families. This choice is methodologically appropriate given that with small amounts of missing data single imputation performs almost equally as well as other more sophisticated imputation techniques (Shrive *et al.* 2006; Peyre *et al.* 2011).

Basic descriptive statistics and bivariate tests were conducted on the analysis variables followed by hierarchical ordinary least squares (OLS) regression and nested logistic regression to assess the influence of relational coordination on parenting stress and family functioning, controlling for child, family, and service characteristics. All analyses were conducted using Stata statistical software (StataCorp 2011).

Results

Descriptive analyses of the outcome variables revealed a mean parenting stress score of 32.3 (SD = 7.9) and a range from 16 to 52. Slightly more than one-quarter (27.0%) of the respondents had parent domain stress scores in the high risk range of 36 or greater (Abidin 1990). Although the vast majority of respondents indicated that the waiver services had a positive impact on family functioning, the level of support varied somewhat across the three measures. Almost three quarters (71.6%) stated that the services helped their family cope better and 81.1% indicated that the waiver services improved their ability to care for their child. Additionally, 84.8% indicated that the services made a positive difference in the life of their family.

Bivariate tests (e.g. *t*-tests, chi-square and correlations) were conducted to identify any significant associations between child (e.g. age, additional diagnoses, ethnicity) and family (e.g. primary language spoken at home, relationship to the child) demographic characteristics and each outcome variable. None were found so these characteristics were not included in the final regression models.

A hierarchical OLS regression model for parenting stress and three nested logistic regression models for the impact on family functioning out-

comes were conducted. In each equation, the independent variables were entered in the following steps (1) child externalising behaviour problems; (2) caregiver health and caregiver capacity; (3) number of months in the waiver program and receipt of any other non-waiver services; and (4) relational coordination. The variables order of entry in the regression models was chosen to assess both the extent to which different aspects of the family and service environment influence parenting stress and impact on family functioning and the extent to which relational coordination added significant unique variance in predicting parenting stress and impact on family functioning above and beyond these other environmental characteristics (Pedhazur 1997).

Overall, all four models were statistically significant and relational coordination contributed significantly to all four outcomes.

OLS regression results

In the OLS model, respondents who reported a higher level of relational coordination reported significantly lower levels of parenting stress (see Table 2). The OLS regression further showed that excellent or good caregiver health, as compared with fair or poor health, was significantly related to lower parenting stress.

Logistic regression results

Table 3 shows that caregivers were significantly more likely to feel that the waiver program made a positive difference in the life of their family, improved their ability to care for their child, and helped their family cope better, when relational coordination was high.

In addition, child behaviour problems and caregiver health also influenced some measures of family functioning. Waiver services were less effective in helping the family cope when their child had more externalised behaviour problems. Also, caregivers in good or excellent health were more likely to report that the waiver improved their ability to care for their child and helped their family cope better than caregivers who reported their health as poor or fair.

Block no		Parenting stress				Total R ²
		B	Beta	SE	ΔR^2	
1	Behavioural problems	0.10	0.10	0.11	–	0.01
2	Good/excellent health	–7.15***	–0.34	2.40	0.11	0.12
	Caregiver capacity	0.06	0.01	0.51		
3	Non-DDS services	0.26	0.02	1.92	0.01	0.13
	Months in the program	–0.07	–0.07	0.11		
4	Relational coordination	–4.10**	–0.27	1.70	0.07	0.20

Table 2 Hierarchical ordinary least squares

* $P < 0.10$, ** $P < 0.05$, *** $P < 0.01$.

Coefficients and SEs reported are those for the final model with all variables. Coefficients are marked with an asterisk if they are significant in the final model.

DDS, Department of Developmental Services.

Discussion

Two large-scale movements have influenced the way services and supports are provided to individuals with intellectual and developmental disabilities. First, since the introduction of the Olmstead mandate in 1999 to find alternatives to institutional treatment, more and more care is being provided in the home of the person with a disability. Concomitantly, the advent of the self-direction movement has shifted key responsibilities regarding service provision from state administrators to families and individuals with disabilities (Breihan 2007). Yet, despite the societal impetus for greater individual involvement in making ordinary life decisions, the participant-direction model can only truly work if service recipients are given professional guidance and counselling on an ongoing basis (Scala & Nerney 2000). Thus establishing and maintaining a collaborative working relationship among providers and between providers and service recipients is the bedrock of this service philosophy.

Our study investigated such collaboration by exploring the influence of provider and caregiver coordination on family well-being among a sample of low-income families caring for a young child with ASD involved in a participant-directed program. Overall we found that, after controlling for a host of variables known from previous research to affect the outcomes of interest, relational coordination was significantly associated with lower parenting stress and a more positive impact on family functioning. These results add further empirical support to both

the extant body of research calling attention to the benefits that ensue from effective service coordination and to the growing literature that views relational coordination in particular as a critical element in the provision of care.

We interpret these findings around the teamwork construct in several ways. First, we view them from the larger context of helping families create a positive environment in which to foster child development. Families are a critical part of the child's environment and perform an essential function in enhancing their developmental outcomes (Altiere & von Kluge 2009). Caring for a child with ASD and other developmental disabilities, however, is a demanding task that can cause strain and disruption in family routines (Seltzer & Heller 1997; Hutton & Caron 2005; Kersh *et al.* 2006; Plant & Sanders 2007; Eskow *et al.* 2011). In addition to experiencing rates of depression and anxiety higher than those of parents of 'typically' developing children, parents of children with ASD also experience lower well-being (Blacher & McIntyre 2006) and have more difficulties in carrying out daily tasks (Quintero & McIntyre 2010). The stress associated with caring for a child with autism can impact negatively the child, the parent and more generally the entire family (Hutton & Caron 2005). Developmental models of determinants of parenting as well as family system models of functioning, place the psychological well-being of primary caregivers, conceptualised as low levels of stress and depressive symptoms, as central to their functioning as competent parents (Mitchell & Hauser-Cram 2008). Thus

Table 3 Nested logistic regression (LR)

Blockno.	Autism services made a positive difference in the life of my family				Autism services improved my ability to care for my child				Autism services helped my family cope better			
	ORs	95% CI	LR chi2 (d.f.)	Prob > chi2	ORs	95% CI	LR chi2 (d.f.)	Prob > chi2	ORs	95% CI	LR chi2 (d.f.)	Prob > chi2
1	0.93	0.8–1.0	0.69 (1)	0.41	0.97	0.9–1.1	0.16 (1)	0.69	0.92**	0.8–1.0	2.89 (1)	0.09
2	3.69	0.5–0.27.1	1.63 (2)	0.44	6.70**	1.3–35.2	4.15 (2)	0.13	4.11*	0.9–18.6	3.20 (2)	0.20
	0.95	0.6–1.5			0.87	0.6–1.3			0.91	0.6–1.3		
3	1.44	0.2–9.5	1.44 (2)	0.49	1.47	0.3–6.6	1.37 (2)	0.50	0.93	0.3–3.4	0.26 (2)	0.88
	1.02	0.9–1.1			1.01	0.9–1.1			1.01	0.9–1.1		
4	9.74***	2.0–47.9	9.77 (1)	0.002	6.75***	1.8–24.8	9.73 (1)	0.002	6.26***	1.9–21.0	10.28 (1)	0.001

* $P < 0.10$, ** $P < 0.05$, *** $P < 0.01$.

ORs and CIs reported are those for the final model with all variables. ORs are marked with an asterisk if they are significant in the final model. An OR greater than 1 indicates that the odds of positively answering each of the outcomes of interest increases with each one-unit increase in the independent variable. Conversely, ORs smaller than 1 indicate a decreased chance of positively answering each of the outcomes of interest.

OR, odds ratio; CI, confidence interval.

the finding that higher relational coordination is associated with lower stress and more favourable self-reported family functioning is important given how essential parental well-being is for parenting competence.

Second, an alternative explanation for our findings is that families with lower stress and particularly positive views of family functioning may be more inclined to engage in relational coordination. This is also an important consideration because it implies that whenever possible individuals responsible for service coordination should endeavour to assess the level of stress and other family well-being indicators prior to implementing any specific type of service coordination efforts. Our findings of significant relations between selected outcomes and both caregiver health and child externalising behaviour problems also suggests that relational coordination needs to fit with the individual family context.

Third, we note the implications from a policy and practice standpoint of having a workable measure to assess the quality of family–professional relationships. In a climate of shrinking resources and increased pressure to document service outcomes and employ evidence-based research to develop policies, we concur with those who recommend including the quality of family–professional relationships as an evaluation outcome or as one of the requirements for facilitating family goals (Blue-Banning *et al.* 2004; Keen 2007).

Last but not least, from a broader systems perspective, our study suggests that it is possible to build positive partnerships between professionals and the families they serve in a participant-directed program. States considering the development and implementation of waiver services for children with ASD and their families may benefit from seeking ways to train providers around the importance of relational coordination and ways to build cooperative team relationships. Tools for this type of training have been developed and used by nurses. For example, the Agency for Healthcare Research and Quality (2006) has developed an evidence-based teamwork program – TeamSTEPPS – to improve teamwork and communication skills. Within the waiver program, training might focus on team building and communications, care planning guidelines, and developing and following shared goals. Training might

also focus on respecting families' preferences and capacities in service direction. In Massachusetts, the provision of training to promote relational coordination is currently under consideration.

The main limitations of this study are its small sample size and its cross-sectional nature. The cross-sectional design limited our ability to disentangle the causal ordering of the variables, whereas the small sample size did not allow us to conduct a more nuanced analysis of whether different relational coordination dimensions were more relevant to each of the outcomes. Future studies should investigate the directionality of the association between relational coordination and various measures of family well-being and assess these relations over time. It is important to understand how parent stress levels upon entry into the waiver program influence how the assembled team operates initially and how these two constructs interact over time as parents gain experience with self-direction and as the team members become more familiar with one another.

A third potential limitation is self-selection bias, although we feel that the high response rate we achieved (about 75%) helps to protect us against that risk as does the fact that all families eligible for the waiver program share the characteristics of having a child with a diagnosis of autism and low income.

Despite some limitations we believe our paper advances the literature on family well-being by providing a deeper understanding of the role service coordination can play in achieving valued outcomes for families, over and above other child, family, and service environment characteristics. More specifically, this paper represents an original contribution to the empirical work on relational coordination in that it adds to the limited research on relational coordination between formal and informal caregivers.

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