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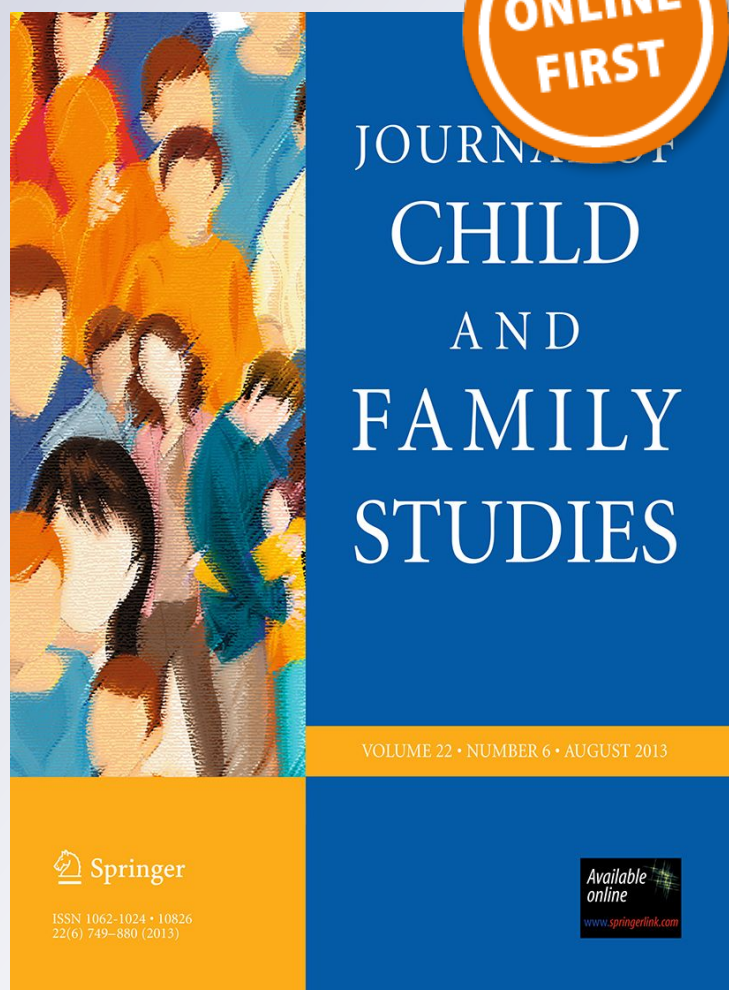# *Improving Family Functioning Following Diagnosis of ASD: A Randomized Trial of a Parent Mentorship Program*

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Improving Family Functioning Following Diagnosis of ASD: A Randomized Trial of a Parent Mentorship Program

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Abstract

Autism spectrum disorder (ASD) is known to impact family functioning and decrease family quality of life. Unfortunately, many parents of children with ASD are left to coordinate their child's care with little ongoing support or education. There is a growing interest in parent-to-parent (P2P) programs to provide family supports with the goal of improving family outcomes. This study investigates a P2P program for families of children newly diagnosed with ASD that combines (1) family-centered action planning, (2) education on accessing complex systems of care, and (3) ongoing mentorship by a trained Parent Mentor for six months. In a randomized controlled trial, the intervention was given to a group of parents ($N = 33$) and compared to a waitlist group ($N = 34$). The intervention consisted of development of an individualized action plan and training on navigating service systems immediately after entry into the program, followed by monthly check-ins by a trained parent mentor for six months. An intent-to-treat analysis examined the impact of CPM on family quality of life, family functioning, service utilization, and program acceptability and satisfaction. The intervention improved satisfaction with disability-related services and prevented rigidity in family functioning. Services used outside of school increased for both groups but did not meet the national recommendation. Participants described the program as highly acceptable and indicated that it improved their emotional wellbeing. The CPM program may be a useful tool for helping families cope with their child's ASD; although, additional research is needed to confirm these effects.

Keywords Quality of life · Satisfaction with care · Autism · Parent-to-parent mentorship · Systems of care

The prevalence of Autism Spectrum Disorder (ASD) has increased steadily in the last two decades and is now estimated to affect 1 in 59 children (Baio et al. 2018). Because there is currently no established standard of care for ASD (Autism Treatment Network (ATN) 2009), and systems of care are often very difficult to navigate, families are faced with many challenges creating, financing, and maintaining treatment plans. Indeed, the challenges of raising a child with ASD can negatively affect the whole family. For example, families of children with ASD have a compromised quality of life (Brown et al. 2006; Ezzat et al. 2017; Lee et al. 2008) and experience a number of stressors when trying to establish systems of support (Twoy et al. 2006; Vohra et al. 2014). There are high costs associated with care and often limited availability of services (Ganz 2007). Parents also worry about their child's wellbeing and future development (Lee et al. 2008) and are less able to engage with natural community supports (Russa et al. 2015; Twoy et al. 2006). These challenges may put family members at risk for increased mental health challenges (Benson 2010, 2012; Estes et al. 2009), decreased well-being (Singer 2006), impact family functioning (Jellett et al. 2015), and these risks appear to be greater for parents of children with ASD relative to children with other developmental disabilities (Estes et al. 2009; Hayes and Watson 2013).

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While research firmly establishes that having a child with ASD can negatively impact family quality of life and functioning, these constructs are variable and it is unclear how different domains change over the first year post-diagnosis (Benson 2010; Ekas et al. 2010; Emerson 2003; Hastings and Brown 2002). Investigation of a variety of protective factors repeatedly found that social support was one of the best predictors of maternal mental health outcomes (Benson 2012; Weiss 2002; Zaidman-Zait et al. 2017), increased sense of competency (Benson 2012; Ekas et al. 2010; Weiss et al. 2016) and service utilization (McIntyre and Brown 2018). Unfortunately, there is little systematic support available to families (Vohra et al. 2014). Despite recommendations for ongoing treatment and assessment in the first year following an ASD diagnosis (Filipek et al. 1999), clinicians are rarely available to support families in acting on these recommendations (Banach et al. 2010). Long waitlists for assessment and treatment and a lack of funding for family support often leave the family to coordinate care on their own (Banach et al. 2010). Consequently, many have requested programming focused on increasing family support and assistance in navigating services (Department of Health and Human Services 2010; Interagency Autism Coordinating Commitee (IACC) 2011; Ozturk et al. 2014; The Johnson Foundation at Wingspread 2011).

As a result of the challenges facing families of children with ASD and the calls for family support programs, the Colorado Parent Mentoring Program (CPM) was developed. The goal of CPM is to teach parents how to navigate systems of care in ways that are most meaningful for their family based on current recommendations, while creating ongoing support through parent-to-parent mentorship. This program was designed to be cost effective by leveraging natural supports rather than relying on more expensive and scarce professional guidance. We hypothesized that this form of family support would lead to improved family quality of life and functioning, an increase in service use, and high acceptability among recipients. We tested these hypotheses in a randomized controlled trial (RCT) as described below.

Method

Participants

Participants were parents of children between the ages of two and eight years diagnosed with ASD within the last three months ($n = 67$). To be included in the study, the child had to be the first in the family diagnosed with ASD and the participating parent had to speak English. The parent also had to be willing to travel to the study site to participate in
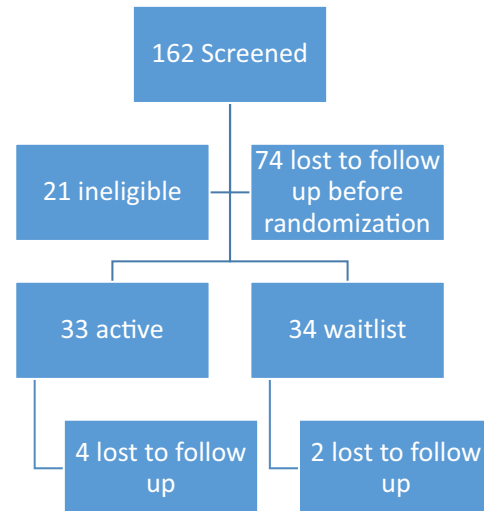

Fig. 1 CONSORT 2010 Flow Diagram

meetings, have regular contact with her or his assigned mentor if assigned to the active condition, complete assessments, and participate in an exit interview. There were no limitations regarding the child's functioning level, verbal ability or co-morbid conditions. All study procedures were approved by the Institutional Review Board of the institution and all participants were treated in accordance with the American Psychological Associations code of conduct (American Psychological Association 2017).

Participants were recruited through listservs, parent support groups, and word-of-mouth from three local clinics in university, hospital and community-based settings. The intent-to-treat (ITT) analysis included 33 parents in the Active Group who received the CPM program while they sought services on their own and 34 in the Waitlist Group who received no additional family support while searching for services on their own (see Fig. 1 for Consort Diagram and Table 1 for demographics). Overall, the sample was predominantly comprised of white women who were fairly well educated. Based on feedback from our Parent Advisory Committee we did not inquire about family income in an effort to minimize any participant sense of discomfort related to their economic means. However, other demographic data suggests this was a largely middleclass sample. Eighty six percent of mothers had at least some college education and 70% of fathers had a similar level of education. Further, of the mothers who worked outside the home, 73% held some sort of professional position (e.g., medical professional, business owner, manger, director, legal professional, etc.).

There were also 26 parents who participated in this research as Mentors who delivered parent-to-parent emotional support to Mentees. Parent Mentors were recruited in a similar manner to Mentee participants but had a child with

Table 1 Participant demographic and baseline characteristics

Characteristic	Active ($N = 33$)	Waitlist ($N = 34$)	Test statistic	p-value
Participating parent gender			Fisher exact	1
Female	30 (91.0%)	30 (88.2%)		
Male	3 (9.1%)	4 (11.8%)		
Child gender			Fisher exact	0.75
Female	6 (18.2%)	5 (14.7%)		
Male	27 (81.8%)	29 (85.3%)		
Parent ethnicity			Fisher exact	0.42
Hispanic	2 (6.7%)	5 (15.6%)		
Non-hispanic	28 (93.3%)	27 (84.4%)		
Child ethnicity			Fisher exact	0.32
Hispanic	3 (11.5%)	7 (22.6%)		
Non-hispanic	23 (88.5%)	24 (77.4%)		
Parent race			$\chi^2 = 0.06$, df $= 1$	0.80
White	27 (81.8%)	27 (79.4%)		
Other	6 (18.2%)	7 (20.6%)		
Child race			$X^2 = 2.72$, df $= 1$	0.10
White	28 (84.8%)	23 (67.6%)		
Other	5 (15.2%)	11 (67.6%)		
Mothers education			Fisher exact	0.26
High school	6 (19.4%)	4 (12.5%)		
Some college	14 (45.2%)	21 (65.6%)		
Some post graduate	11 (35.5%)	7 (21.9%)		
Fathers education			Fisher exact	0.61
High school	10 (30.3%)	9 (45.2%)		
Some college	18 (54.5%)	14 (45.2%)		
Some post graduate	5 (15.2%)	8 (25.8%)		
Mothers age mean (SD)	35.3 (5.3)	33.0 (6.1)	t value -2.25	0.03
Fathers age mean (SD)	36.3 (6.4)	34.7 (6.2)	t value -1.40	0.17
SRS total	78.1 (10.0)	74.1 (10.2)	t value -2.25	0.03
SRS awareness	75.6 (7.8)	68.7 (9.2)	t value -4.57	<0.001
SRS cognition	74.5 (10.6)	70.2 (10.2)	t value -2.33	0.02
SRS communication	75.6 (9.5)	73.4 (10.2)	t value -1.25	0.21
SRS motivation	72.5 (11.3)	70.2 (12.5)	t value -1.09	0.28

ASD at least two years post-diagnosis. Each parent Mentor was asked to mentor up to four people over the 12- month period and was given $100 per month to compensate them for their time. Decisions regarding the number of Mentees assigned to a given Mentor was based on Mentor availability as well as on matching family characteristics when possible. Mentors were 85% female, 90% white, and 85% non-Hispanic.

Procedure

Using a randomized controlled trial (RCT) design, the CPM program was evaluated on four main Mentee outcomes: (1) family quality of life, (2) family functioning, (3) service use, and (4) program acceptability. Following consent, participants were randomized into the Active or Waitlist groups and completed baseline measures. Active participants were then paired with a Parent Mentor and began the CPM program. Waitlist participants continued with assessment and treatment as usual which varied by recruitment clinic and their own ability to find and access care. Both groups were free to find and access care as they wished over the six-month study period, with a short questionnaire distributed monthly to Active participants to assess their interaction with their Mentor. After six months all participants (Active and Waitlist) completed follow-up measures, and Waitlist participants were offered the full intervention to ensure that no potential benefits were withheld. All assessments were administered online using the REDCap system (Harris et al. 2009). A project coordinator sent

weekly reminder emails for six weeks following the original request. If participants did not complete an assessment after the sixth follow-up email, they were considered lost to follow-up.

Colorado parent mentoring (CPM) program

The CPM program was designed for parents of children newly diagnosed with ASD to provide them with the tools to make informed decisions regarding their child's care and to facilitate engagement with their local autism community. The specific goal of the program was to provide parents with emotional and information support soon after their child's diagnosis so that they would be able to find services that meet their family needs and to improve their emotional wellbeing in the first year following a diagnosis of autism.

The CPM curriculum was created through a partnership between the JFK Partners, at the University Colorado Anschutz Medical Campus, Autism Society of Colorado, Family Voices Colorado and The Living Spectrum, a support group formed and run by parents of children with ASD with over 400 members. The materials were created through an iterative, three-phase process, based on Community-Based Participatory Research (CBPR; Israel et al. 2008) principles, with each phase adding additional refinement to ensure accurate portrayal of the content based on expert feedback. This process resulted in the three intervention steps: (1) an Action Planning meeting, (2) Navigation Training, and (3) Parent-to-Parent Mentorship, as well as a two-day mentor training. Additional program details, including training materials can be attained from the corresponding author (EM). The first two study components were delivered in the first month of entry into the program and the third was provided on an ongoing basis by another parent for the six months of intervention. Each intervention component is described below.

Action planning

This was a three-hour in-person process facilitated by study staff to provide family-centered assistance in thinking critically about intervention, support, and access to care. Study staff were trained to deliver a semi-structured protocol individualized to meet each parent's needs. Study staff reviewed the child's clinical recommendations, parent concerns, desires, and available resources. From this review, staff helped distill treatment needs from the diagnostic recommendations and the parent's concerns, creating actionable steps for accessing care both in and out of the school setting. This process resulted in an individualized Action Plan based on the national standards (National Research Council 2001) to help parents identify the treatment components that are most effective, regardless of

intervention model. The family's emotional wellbeing was also addressed, including determining respite care needs, existing social supports, overall family functioning, and counseling needs. Mentors were included in this meeting to facilitate introductions and ensure that the process was family-centered. Mentees left the meeting with a list of current goals, resources and next steps based on this parent-centered process. The study team kept a copy of the plan but did not monitor the parent's use of the plan. That is, parents were free to use and modify the plan as they wished, and in conjunction with their mentor.

Navigating systems of care

This was an in-person group training on accessing systems of care in Colorado for insurance, Medicaid, and school services. This training followed the Action Planning meeting so that parents could apply their Action Plans to the systems information and receive specific guidance. The training was conducted in person, by an expert in navigating service systems and was based on a standard parent training used by Family Voices Colorado. This training ranged from 2–3 h, depending on the number of participants. Mentees were free to focus on whatever area of navigation needs they had at the time, but information that would likely be relevant later in life was also made available. For example, a family with a young child being served by an Individual Family Support Plan would still be given information on the Individual Education Plan process and other relevant future systems of support.

Mentorship

A Parent Mentor was assigned to each Mentee. Mentors were all parents of a child with ASD at least two years post-diagnosis, trained and certified by our staff. The Mentors were trained over two consecutive days. The first day consisted of a variety of information including a discussion of the program, information about ASD, ways to determine effectiveness of interventions, confidentiality, funding mechanisms (e.g., insurance, Medicaid), and natural supports. The curriculum for the second day focused on how to be an effective mentor, including listening techniques, role-play and examples, and active and reflective listening techniques. This training prepared Mentors to be able to provide unbiased emotional support to their mentees based on their own experiences without being directive. Mentors were also extensively trained on how to identify potentially beneficial interventions based on the National Research Council's recommendations (National Research Council 2001).

The Mentors were matched with Mentees on a range of characteristics, including demographics, child characteristics, geographic location, socio-economic status, religion, military

status, parenting style, and employment status. Mentors participated in the action planning meetings so study staff could facilitate introductions and to ensure that the action planning process was family-centered. The Mentor then provided ongoing emotional support during monthly meetings over six months. Mentors were asked to contact their Mentee at least monthly, by whatever means were mutually agreeable to them (i.e., phone, in person, etc.). Mentors asked mentees how they were doing, whether there were any new challenges, and offered any support possible. Study staff remained available to monitor the mentor assignment and manage difficulties if they arose. Difficulties included not being able to provide guidance on a particular challenge, uncertainty about available resources for ASD, and any difficulties with the Mentor/Mentee match.

Fidelity of delivery

Several efforts were used to ensure that participants received the program as intended. First, All Action Planning meetings were conducted by study staff who received in-depth training. These trained staff then used a standardized format to conduct the meetings, with accompanying documentation to ensure challenges, goals and resources were discussed for the child and family. Second, navigation trainings were conducted by a single trainer, using a standardized curriculum. This trainer used a curriculum developed by one of our community partners (Family Voices Colorado) who provides the same training as part of their standard programmatic activities. Finally, monthly support was provided through the trained Mentors. Short questionnaires were sent to all Mentors and Mentees monthly to determine if meetings had taken place and to assess their overall rating of the meeting.

Measures

All instruments were collected at baseline (Pre) and after 6 months (Post), unless otherwise noted. Mean subscale scores were calculated for all instruments to accommodate missing items, except for the Family Adaptability and Cohesion Evaluation Scale-IV and the Social Responsiveness Scale, which employ standardized scoring algorithms.

Family Quality of Life Scale

(FQOL, Zuna et al. 2009). This questionnaire assesses both the *importance* of and *satisfaction* with serveral domains of quality of life (range 1 = a little important to 5 = critically important): (1) *Emotional wellbeing*—emotional well-being of the family; (2) *Family wellbeing* —quality of overall family functioning; (3) *Parenting wellbeing* —degree to which the whole family helps the child with the disability;

(4) *Physical/Material wellbeing* —degree of access to needed care (medical, dental, etc.) and ways to pay for it, and (5) *Disability-related wellbeing*— level of supports specifically related to disabilities. Higher scores reflect greater importance or satisfaction on separate subscales. The FQOL has good validity and reliability (Hoffman et al. 2006) and observed Cronbach's alpha was 0.91.

Family Adaptability and Cohesion Evaluation Scale-IV

(FACES-IV, Olson 2011). This instrument measures the continuum of family cohesion and flexibility based on the Circumplex Model of Marital and Family Systems (Olson 2000). This model suggests that families with balanced levels of cohesion and flexibility have better family functioning (Olson 2000). This scale produces two *balanced* scales, which measure healthy levels of cohesion and flexibility: (1) *Balanced cohesion*—degree to which the family operates as a cohesive unit (range 16–85), and (2) *Balanced Flexibility*—degree to which the family can flexibly cope with issues (range 16–85). Higher scores on these subscales indicate better family functioning. The extreme ends of each of these continua (i.e., Family Cohesion and Flexibility) are associated with poorer family functioning. This instrument uses four separate subscales to measure these extremes, called *unbalanced* scales. These include: (1) *Disengaged*—extreme lack of family cohesion (range 10-99), (2) *Enmeshed*—extreme levels of family over-cohesion or enmeshment (range 10–99). (3) *Rigidity*—extreme lack of family flexibility (range 10–99), *Chaotic*—extreme over-flexibility leading to chaos (range 10–99). Higher scores represent poorer family functioning in these domains. All subscale scores can be converted to descriptive ordinal scales to aid interpretation (e.g., Low, Moderate, High). This instrument has good reliability and validity (Olson 2011) and observed Cronbach's alpha was 0.83.

Service utilization (internally generated)

This measure is a five item, open-ended, self-report measure of services used within the previous month. Responses were coded for the total number of hours of all services delivered per week in three settings: (1) to the child *in a school setting*, (2) to the child *out-of-school* ,and (3) services to the *family*. All service types (behavioral, speech, occupational therapy, etc.) were summed, and reported for each participant at baseline and following six months of intervention.

Program acceptability and satisfaction (internally generated)

This is an 11-item questionnaire (total range 8–40) that was colecteSPEe program. Higher scores reflect greater

satisfaction with the intervention. Observed Cronbach's alpha was 0.83.

Fidelity of intervention delivery

Fidelity of the intervention delivery was assessed by computing the proportion of participants who completed each of the study components. This includes the proportion of parents who participated in Action Planning meetings, the proportion of parents who received the Navigation Training and the proportion of participants who completed the expected number of mentorship meetings (six meetings).

Post participation interview

Qualitative interviews were collected from each participant following their six months of study participation. These semi-structured telephone interviews were conducted by a trained qualitative researcher. Participants in the Active group were interviewed following the 6-month intervention and those in the Waitlist group following the six months wait when they were offered, but had not yet begun, the CPM program. For both groups, post intervention interviews lasted approximately one hour and covered topics such as motivation for participating in the study, satisfaction with the program and their Mentor, how the parent felt before and after their child's diagnosis, how participation in the program or interventions impacted family functioning and quality of life, and how well they were engaging with service systems, the ASD community, and other parents. The interviews were recorded and transcribed prior to coding. For the present analysis, these interviews were used to help illuminate quantitative findings. The full results of the qualitative analysis will be reported in more detail elsewhere.

Two additional measures were administered as part of this research, the Parenting Sense of Competence Scale (Johnston and Mash 1989) and Family Impact Questionnaire (Donenberg and Baker 1993). There were no significant group differences or interactions from our sample. Therefore, these measures are not discussed further.

Demographics

This is a short questionnaire that measured key demographics about the respondent and family, including parent/child gender, parent/child race/ethnicity, child primary and secondary diagnosis, and parent marital status, occupation, and education.

Social Responsiveness Scale

(SRS, Constantino 2002). This is a 60-item instrument that measured the degree of social impairment due to ASD. It produces a total impairment score and five subdomains: (1) social awareness, (2) social cognition, (3) social communication, (4) social motivation, and (5) restricted interests and repetitive behaviors. This instrument has good validity and reliability (Constantino et al. 2003) and observed Cronbach's alpha was 0.89.

Data Analysis

Participants were randomly assigned into groups by a random number generator after determining eligibility and before starting any research activities. Differences between groups at baseline were tested with chi-square, Fisher Exact or t-tests as appropriate. Fidelity of the intervention delivery was assessed as described above; however, as this is an ITT analysis, all randomized participants were included regardless of how many intervention steps or how much mentorship they received. Then, a series of linear mixed models were fit for all primary outcomes. Mixed modeling is a modern statistical procedure that allows for both fixed and random effects, and accounts for repeated measures (Zuur et al. 2009). This is analogous to a repeated measures ANOVA or a generalized linear model with a compound symmetry error structure.

We used a baseline as covariate longitudinal approach to test whether the CPM program led to changes in our four primary outcomes. This strategy uses a two-level categorical variable representing the period (Pre vs. Post) and directly tests differences of the outcome between the periods. This strategy controls for any baseline characteristics that may differ at baseline by chance. That is, variables that differed at baseline were added to the models as fixed effects to adjust for potential confounding. However, the test of interest in the baseline as covariate approach is the interaction term of study group (Active vs. Waitlist) by time period (Pre vs. Post). This formally tests if the changes in both groups are different from one another over time. In the case of a significant interaction term separate analyses were run for each group (i.e., stratified analyses) for ease of interpretation. Fixed effects were evaluated overall if the interaction term was not significant. To conform to convention, we set alpha at .05 as an indicator of significance. However, given the American Statistical Association's statement on the use of p-values in research (Wasserstein and Lazar 2016), we are cautious not to use a specific p-value threshold as a justification of any specific scientific claim. Therefore, we also report on p-values between .05 and .10 as non-significant marginal trends that may be worthy of future exploration.

Continuous fixed effects were mean centered to facilitate interpretability when appropriate. Covariate fixed effects were added in a forward selection procedure and were retained if they met a significance threshold of less than 0.10. Akaike Information Criteria (AIC) and residual diagnostics supported the use of linear mixed models and

AIC was used as a guide to arrive at parsimonious models (Akaike 1974). Also, there was no correction for alpha to permit greater clarity of our findings (Feise 2002). Mean scores of assessment subscales were used as the primary outcomes.

Qualitative data were analyzed using a thematic analysis approach (Braun and Clarke 2006) to allow for discovery of recurrent patterns of responses by the participants. Interviews were collected from each participant after completing the CPM program. This interview focused on the participants' experiences while in the program, their emotional responses and perceived impact of the program, whether positive or negative. Each interview was transcribed and verified by a research assistant and then coded by two coders independently. Coders read each transcript and coded major themes, then revisited, re-coded and collapsed themes to arrive at their final themes. These themes were then presented to the whole team to arrive at consensus.

Results

Quantitative Findings

Table 1 presents the baseline characteristics of the sample. The sample is predominantly non-Hispanic and white, college educated, and in their 30's. Fidelity of the intervention delivery was generally good. Of the 33 participants, all 33 completed the Action Planning meeting; 29 of the 33 (88%) attended the navigation training; 29 of the 33 (88%) completed all expected mentorship meetings. Additionally, there was one participant who completed half of the meetings, one Mentee who completed one meeting and 2 Mentees who reported attending no meetings. Each of those who did not complete all steps was considered lost to follow up. See Fig. 1 for attrition and study step completion.

Baseline differences between groups were only apparent with SRS scores and mother's age where the Active group had a significantly higher SRS score and mothers were older. Therefore, these were explored as fixed effects in the models to control for confounding.

Quality of life

Differences were found in the FQOL and in the FACES-IV and are presented in Tables 2 and 3. Table 2 presents results from the Disability Related Satisfaction Score from the FQOL. The interaction term of intervention by time-period was significant ($p = 0.03$) suggesting differences over time between groups. Additionally, a 3-way interaction of intervention by period by SRS scores was a non-significant marginal trend ($p = 0.06$, not shown) suggesting a complex relationship over time of the intervention and SRS scores on

Table 2 Mixed model parameter estimates: family quality of life scale (FQOL)

	Beta	SE	*p*-value
Disability related supports satisfaction			
Intercept	3.56	0.12	<0.001
Study group (active)	−0.29	0.17	0.098
Period (follow up)	0.10	0.12	0.383
SRS total score	−0.02	0.007	0.030*
Intervention*period	0.37	0.17	0.034*
Stratified by study group (active)			
Intercept	3.26	0.11	<0.001
Period (follow up)	0.46	0.15	0.005*
SRS total score	−0.007	0.009	0.398
Stratified by study group (waitlist)			
Intercept	5.54	0.12	<0.001
Period (follow up)	0.10	0.10	0.300
SRS total score	−0.02	0.01	0.041*

Note: *indicates *p* values that are less than 0.05

Table 3 Mixed model parameter estimates: family adaptability and cohesion evaluation scale – IV (FACES-IV)

Rigidity	Beta	SE	*p*-value
Intercept	40.03	2.64	<0.001
Study group	−0.38	3.78	0.919
Period (follow up)	7.59	2.55	0.004*
Intervention*period	−7.68	3.66	0.044*
Stratified by study group (active)	Beta	SE	*p*-value
Intercept	39.6	2.70	<0.001
Period (follow up)	0.00	1.78	0.999
Stratified by study group (waitlist)	Beta	SE	*p*-value
Intercept	40.03	2.59	<0.001
Period (follow up)	7.93	3.14	0.018*

Note: *indicates *p* values that are less than 0.05

disability satisfaction. Despite differences at baseline, SRS scores did not confound these associations. Stratified results suggest that those in the intervention reported increased satisfaction of 0.46 points by the follow up assessment ($SE = 0.15$, $t(29) = 3.10$, $p = 0.005$) and were not affected by SRS score. Those in the Waitlist condition did not report an increase over time but were affected by the SRS score where for each point increase in SRS score satisfaction decreased on average 0.02 points ($SE = 0.01$, $t(30) = −2.13$, $p = 0.04$).

Family Functioning

The interaction between time and group for Family Interaction Importance subscale of the FQOL analysis also yielded non-significant marginal effects, $p = 0.08$. Over

Table 4 Means, standard deviations and confidence intervals of hours of services received by group and time

	Active M/SD	Active CI	Waitlist M/SD	Waitlist CI
Pre				
In school	2.78 (4.49)	1.16–4.40	3.27 (6.97)	0.80–5.74
Out of school	1.20 (1.39)	0.70–1.69	0.89 (1.01)	0.53–1.24
Family supports	0.08 (0.18)	0.01–0.14	0.06 (.11)	0.02–0.10
Post				
In school	2.08 (3.56)	0.80–3.37	4.82 (7.72)	2.08–7.56
Out of school	2.73 (5.07)	0.93–4.54	3.23 (7.33)	0.63–5.83
Family supports	3.23 (17.52)	−3.09–9.54	0.38 (1.82)	−0.27–1.02

time, however, neither trended substantially differently from the baseline measure. The waitlist group may have reported slightly more family interaction importance (0.12 points, $SE = 0.07$, t [30] = 1.7, $p = 0.11$).

A similar interaction term was identified in the FACES-IV Balanced Flexibility analysis (not shown) where groups were different from each other at the post timepoint ($p = 0.03$) but did not change markedly from their baseline scores. A drop of 4.6 points in the Active group from Pre to Post assessment was also a non-significant marginal trend ($p = 0.07$). Likewise, an interaction term suggested that groups were different at post for Parenting Importance ($p = 0.04$); however, neither group changed substantially from their baseline condition. Finally, the interaction term in the FACES-IV Rigidity scale suggests different effects between groups over time ($p = 0.04$; see Table 3). The Active group reported no change over time; however, the control group reported increased rigidity at the Post time point (7.9 points, $SE = 3.1$, $t(3.1) = 2.5$, $p = 0.02$). Interestingly, the Active group remained in the Low Rigidity range across time; however, the Waitlist group started in the Low Rigidity range before the study began and moved to the Moderate Rigidity range following 6 months of treatment as usual.

Service utilization

Utilization was generally low in both groups but increased over time. That is, there was a main effect of time for out-of-school services ($F[1,59.7] = 5.65$, $p = 0.02$) with both groups reporting on average 1.97 more hours of services after six months. No other main effects or interactions were found. See Table 4 for means and standard deviations by group, and time. Also, one sample t-tests revealed that neither of the groups at either time point received the 25 hours of behavioral services that are often recommended

for newly diagnosed children with autism (Stansberry-Brusnahan and Collet-Klingenberg 2010). All p-values for each group and time point were <0.0001.

Acceptability and satisfaction

On average, participants reported high levels of satisfaction with this program ($M = 32.73$, $SD = 4.51$, 95% CI [31.36, 34.10]). A visual scan of the distribution for this measure revealed a slightly positive skew and one outlier. The outlier reported that the mentor was not engaged and that she had several unique circumstances that were not addressed by any of the program components.

Qualitative Findings

All post participation interviews were transcribed and read by three separate coders. This was not a full qualitative analysis. Rather, interviews were read to search for comments that could help us interpret the quantitative results. In particular, participants commented on how the support they received from their Mentors improved their quality of life, family relationships, and reduced feelings of isolation and stress. For instance, one Active participant, stated:

> I found [CPM] very supportive, and I felt like it put me in a position to advocate more for my family just to have my Mentor and talk about our husbands and have the same experience and know that my husband's not the only idiot. Just kidding. You know what I'm saying, men deal with these things differently and it was nice to hear that it wasn't just having a difficult relationship that this is kind of how it affects your relationship but it's definitely helped make us a stronger family…I think it's made [our life] better because I don't have the stress or this burden and kind of not knowing if I'm doing things right. My Mentor in the navigation meeting kind of helped me make sure I have everything covered so now I can go home and be with my kids and not worry about that stuff.

For this participant, connecting with another mother who had a child with autism who could help her navigate the first few months of post-diagnosis stress helped her relieve potential stress at home, thereby improving her family's quality of life. When asked how participating in the program affected her family's quality of life, another mother replied, "I think it definitely helped us be more at ease, which made us happier, like, I don't, it doesn't stress me out as much I guess." A third mother, when asked how participation influenced her relationship with her husband, said, "…it just mostly in the aspect that we had two different

approaches to my son. That's kind of been resolved. So, we're more on the same page. And that usually creates less tension between…". Each of these comments highlight that the program reduced stress at home and made parents feel less isolated. Their relationships with spouses were improved as they were able to get support and assistance from people outside of the family unit.

Discussion

These results suggest that the CPM program was generally acceptable to participants and impacted several areas of family quality of life and family functioning, regardless of the amount of formal services the family received elsewhere. First, parents in the Active group reported increased satisfaction with their child's disability related supports relative to the Waitlist group. This finding suggests that the CPM intervention helped parents find services that were appropriate to their child and family situation. Interestingly, stratified analyses found that the child's level of autism symptoms as measured by the SRS influenced the level of satisfaction in the Waitlist group, but not in the Active group. Specifically, satisfaction went down as symptoms increased for the waitlist group. This suggests that increased autism severity may decrease satisfaction, but when we intervene, we mitigate this relationship. That is, families seem to be more satisfied with their care regardless of autism severity in the Active group. This finding suggests that social support is a protective factor against adverse mental health outcomes regardless of the child's severity symptoms, and is consistent with previous research (Pottie and Ingram 2008).

We also found differences between the groups in family functioning. Parents in the Waitlist group reported more rigidity over time, whereas the Active group remained relatively unchanged (FACES-IV: Rigidity). This sub-scale measures the degree to which the family has explicit expectations for their family's behavior (Olson 2011) and is considered an unbalanced dimension of family functioning. That is, higher scores represent poorer family functioning. The score for the Waitlist group became moderately problematic after six months. This could mean that the CPM program prevented rigidity in this sample. That is, it may be that without community support, parents are forced to find services on their own and become more rigid in their demands on family members. Likewise, we found suggestive, but statistically non-significant differences in the importance parents place on their level of overall family involvement (FQOL: Family Interaction Importance). For the Active group, it became *less* important that their family interact well together. The Waitlist group reported that how their family interacted with each other became *more* important with time. However, neither of these results were

significantly different from zero, so these results should be interpreted cautiously. Larger samples could help clarify these findings.

Our qualitative data provide some context for these results. Many parents in the Active group found the social support provided by other parents of a child with ASD empowering and often more beneficial than support they received from spouses or family members. Given the known struggles parents face following a child's ASD diagnosis (Gau et al. 2012; Lee et al. 2008), it is possible this intervention helped parents with the challenges of raising a child with ASD through connecting them with other parents, and as a result, participants were able to place less importance on their whole family's involvement. If true, it would make sense that parents in the Active group placed less importance on how their family interacts given that they are able to access support that is more meaningful to them in their own community. Conversely, if the primary source of support for the Waitlist group is their family, they may have become more rigid over time, which may have led to increased importance on how their family interacts with their child with ASD. Although the exact nature of the relationships between these domains is unclear, it is possible that this intervention helped align the parent's expectations for family involvement and what kind of services to expect for their child. Future research is needed to clarify these findings.

Interestingly, we found these effects despite there being no difference in the overall amount of services received between the two groups. Even though out-of-school services were found to increase over time regardless of group, groups did not differ from each other. This may be because all participants received the diagnosis within 3 months of entry into the study, which likely allowed access to services not available previously (e.g., insurance, Medicaid). School services, on the other hand, are linked to educational objectives and not as impacted by a medical diagnosis. Family services may be less available in general to this sample. Regardless, the increase in out-of-school services did not approach the typical recommendation of 25 hours a week (Stansberry-Brusnahan and Collet-Klingenberg 2010). This is a commonly used standard in two of our recruitment sites and the discrepancy between this recommendation and actual services used is substantial. However, that we found improved satisfaction with disability-related supports in the Active group despite this shortage of services suggests that family functioning and satisfaction may be independent of actual service delivery.

Limitations and Future Directions

Several limitations to this study are worth noting. First, this program has multiple components that were studied

simultaneously for a relatively short period of time. Due to this design, we are unable to address several questions. We have a high degree of certainty that participants received the Action-Planning and Navigation Trainings to fidelity; however, not all mentorship meetings took place as planned. We, therefore, cannot attribute the observed effects to any one intervention component or amount of mentorship received. Further, there was no control on how the Mentor and Mentee conducted their interactions. This flexibility was implemented to increase the acceptability of the intervention and to increase the ecological validity of the program. Regardless, it is difficult to understand which of the three program components has led to these effects. Future research should investigate the unique contribution of each element to better tailor the program for each family's circumstances. Additionally, due to the funding mechanism, we were only able to study a fairly short implementation period. Indeed, we did not find that this program improved parents' ability to access care, which is not surprising. Additional data points would help identify *when* improvements were realized, and a longer implementation period could find longer-term impacts on ability to access to care. More generally, this program is similar to a growing body of literature on family navigators (e.g., Broder-Fingert et al. 2018). For all of these programs, including ours, it will be important to fully explore the relative impact of each program component, and their impact on a range of outcomes such as service utilization, time to accessing services, family and child wellbeing, developmental trajectory, and improvement of core symptoms of autism.

Also, Mentor matching was difficult, in some cases, due to a small mentor pool. Many Mentees requested to be paired with other parents who shared many of their family circumstances. Geographic proximity was the most common request, but other family characteristics were important. For example, military service, gender, religion/faith, parenting practice, and beliefs about the causes of autism were all mentioned by Mentees as important. With larger implementation, these requests could be more easily accommodated. Also, future implementation could benefit from using a support group model that allows Mentors and Mentees to naturally select each other rather than relying on a centralized process. For instance, a large pool of trained parent Mentors could be made available to all Mentees through a support program in which Mentees could find other parents who they connect with naturally. Partnerships with robust parent support groups would likely be necessary for such a model to be effective.

Finally, this was a fairly homogeneous sample which could limit the generalizability of these findings. Future implementations in more diverse populations may find that adaptations are needed to make this a feasible program. For instance, there are known association between Socio-Economic Status (SES) factors and parenting related stress that are compounded when the child has autism (Trentacosta et al. 2018). Any implementation of this program should carefully consider the demographics of the target population and adapt as appropriate. For example, the use of this program in rural areas that have limited availability of services may need to consider alternative means of engaging families or providing service recommendations to them (Singh et al. 2018). Further, this program is similar to the *Promatora model* which is often used in Latino communities (Koskan et al. 2013; Magana et al. 2017). CPM could be highly acceptable to Latino communities but would need to be adapted to be culturally appropriate and linguistically accessible.

Family functioning and quality of life following the diagnosis of a child's ASD are complex constructs with many subdomains to consider. While some areas of functioning improve with time, this model of family support helps maintain low levels of family rigidity and improve satisfaction with disability-related services. These effects were achieved despite low levels of services received over six months. The program is highly acceptable to participants and may reduce demand for involvement from other family members. The gains in parent satisfaction are in line with the Affordable Care Act's focus on patient-centered care and improved patient-satisfaction ("Protection, Patient and, Affordable Care Act," 2010). Parent-to-parent mentoring combined with parent education could provide families with a viable source of social and informational support. Family support programs, such as this, are an important tool in helping families cope with the challenges of raising a child with ASD.

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Compliance with Ethical Standards

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

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the University of Colorado and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The Colorado Multiple Institutional Review Board provided oversight of this research.

Informed Consent Informed consent was obtained from all individual participants included in this study.

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