FAMILY NAVIGATION: THE FINAL COMPREHENSIVE REPORT
THE MATERNAL AND CHILD HEALTH RESEARCH PROGRAM

I. Introduction
Nature of the research problem
Autism is a chronic condition with increasing prevalence over the last decade, as its defining criteria have evolved.(1) The understanding of effective treatments is also evolving. This diagnosis, which conveys lifelong disability in the areas of communication, social interaction and behavior, impacts not only the child but the entire family and the community.(2) In 2001, the National Research Council (NRC), one of the four agencies that make up the National Academies including the Institute of Medicine, published its landmark book, Educating Children with Autism, which placed the first benchmark around treatment for young children stating: "The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives.(3) Studies consistently report high levels of disparity in low-income communities in the timing of diagnosis of ASD and in the receipt of services.(4-8)

It often falls to the family to identify available services, follow through with application processes and coordinate care for their child. As a result, family members caring for a child diagnosed with an autism spectrum disorder often experience high levels of stress(9-15) and depression.(13, 16, 17) This in turn may impact the effectiveness of intervention.(3, 18) Low-income minority populations may experience additional challenges and barriers to accessing care due to a range of factors including linguistic and cultural barriers, financial constraints, transportation issues and limited social networks. Specific to autism there has been limited research about potential systems of care to support families around the time of diagnosis or at other points in the development of the child.

II. Review of the Literature
Despite intervention guidelines for children with ASD, low-income and minority children currently receive services that are of poorer quality and lower intensity than their peers and their caregivers are stressed and more likely to report dissatisfaction with services received. (4-8, 19, 20) Research has suggested that this may be due to a variety of barriers experienced by ethnically diverse and low-income families navigating this highly complex service-delivery system. These include economic and cultural barriers such as time and resources to access services, linguistic barriers, mistrust of healthcare providers, lack of communication, and differing views about what constitutes typical child development or social stigma surrounding an ASD diagnosis.(21-24)

III. Purpose, scope, and methods of the investigation
We adapted an evidenced-based Patient Navigator system to low-income families of children with ASD. The core concepts of patient navigation are: 1) Identification of those at risk; 2)Identification of individual barriers to care through a culturally competent approach; 3) Development and implementation of a care plan to overcome those barriers-with clinical team; and 4)Tracking problems to resolution.

Our adaptation, Family Navigation (FN), extended the basic navigator model to families dealing with the diagnosis of ASD, and added enhanced dimensions of culturally sensitive, family centered care, developmental and behavioral pediatric knowledge, and legal advocacy. Similar to oncology where the model revolves around a defined episode of care, in autism the analogous event is the period surrounding the receipt of the diagnosis, where the trajectory of a child may be decided. Families who successfully navigate this transition from diagnosis to services may subsequently have improved long-term outcomes.

IV. Study Design and Methods

A. Study design

Newly diagnosed children under the age of 8 years old with ASD were enrolled from a hospital-based developmental behavioral pediatrics clinic. Stratified blocked randomization, using the family as the unit of randomization, was used to allocate families to intervention (Family Navigation) or usual care immediately. We hypothesized that children less than three years old who are entering the Intervention (EI) system (which provides in-home family-centered care) would have quicker access to services than children over three years of age who will be entering the special education system (which is larger and often has potential barriers to care). Thus, to definitively eliminate age as a confounding variable, we randomized in age-defined strata with children less than 33 months old in one stratum and children greater than 33 months in the other. Randomization in blocks of four within each stratum ensured numerical balance between study arms.

Intervention Conditions

Family Navigation: The intervention group received six-months of Family Navigation, an adaptation of evidence-based Patient Navigation.(25) Family Navigators (FN) helped families overcome barriers to receiving care, functioning in a culturally competent manner to model effective advocacy within the systems families encounter.

Usual Care: The usual standard of care for children with autism nationally currently involves enhanced family support, typically in the form of a medical provider, resource support person, or legal advocate. This standard provided the basis for our study's control arm.

B.   Population studied

Between May 2011 and September 2013, a total of 263 eligible parents were offered the study; 155 were assigned to a study arm. Participants were reflective of the low income and diverse population served by Boston Medical Center.

C.   Instruments used

Individualized Family Service Plan Assessment (IFSP): For children under the age of three, a copy of the IFSP and attendance records during the 6-month study period were obtained from EI and autism specialty providers. Children who received, based on actual attendance records, 25 hours/week of total intervention service in the last four weeks of the study were considered to have received "adequate" services. Change in services was calculated as the difference between hours received in the first two and last four weeks of the study. Time to ASD-specific IFSP was calculated as the number of weeks from ASD diagnosis to when ASD-specific services were added to the IFSP.

Individualized Education Program Assessment (IEP): For children three years of age and over, a copy of the Individualized Education Program and attendance records were obtained from the public school. An IEP that referenced ASD, either as a special education eligibility or as a rationale for services, was considered to be ASD-specific. Children with an IEP mandating 25 hours/week of service were considered to have received "adequate" services. The quality of the IEP was assessed using a tool that summed scores for the nine National Resource Council indicators for children with autism, and an additional indicator that addressed the extended school year (ESY).(26)

Psychological Functioning Measures

Parenting Stress – Short Form (PSI-SF) Version 3: A substantial body of published research links PSI scores to observed parent and child behaviors, specifically attachment style, social skills, and confidence. It has been used extensively to measure parenting stress in families with autism and in diverse populations.(27) A parent was considered to have clinically significant parenting stress if they scored above the 90th percentile; a score that signals a need for referral to treatment.(28)

Quick Inventory of Depressive Symptomatology (QIDS): The QIDS was selected to measure depression symptoms because of its sensitivity to change over time and in response to treatment. Using Item Response Theory, the QIDS, a 16-item measure has excellent correlation to other depression scales (29, 30) A parent was considered to have symptoms of depression if they scored an eleven or above, which is associated with moderate symptomatology.(31)

Client Satisfaction Questionnaire (CSQ-8): The CSQ-8 is a research-based quality assurance instrument measuring general satisfaction with health and human services.(32). In a variety of studies, the internal consistency of the CSQ-8, as measured by coefficient alpha, ranged from .83 to .93, with values of .86 and .87 in two of the largest samples.(33) The CSQ-8 was completed at the exit interview, and scores were summed to create an overall satisfaction score, with possible scores ranging from 8-32. Participants were considered to have responded positively if their answers fell into the 2 most positive rating categories for a given question.

Other Measures

Child Functioning: Adaptive Behavioral Assessment System (ABAS-2nd Edition): The Parent/Primary Caregiver Form of the ABAS II was used to assess child functioning at baseline. Children who's general adaptive composite score was ≤ 70 (2 standard deviations below the mean) were considered to have severe functional impairment in that domain.(34)

Patient Characteristics Questionnaire: At the baseline and six-month exit interview, patient characteristics were collected, including demographic data, current and historical receipt of services, and a query of family stress, including living in unstable housing.

D.   Statistical techniques employed
All analyses were performed with SAS version 9.3 (SAS Institute Inc., Research Triangle Park, NC).

Family Navigation feasibility and acceptability: Descriptive statistics were used to determine the type and quantity of Family Navigation services utilized, rates of attrition, and satisfaction with services received.

Parenting stress and depression at baseline: Separate models were run to determine variables associated with parenting stress and depression at the time the index child was diagnosed with ASD. A Chi-square test of independence was performed to compare the probability of depression/stress among the categorical variables. Variables that were associated with stress or depression in chi-square at p≤0.20 were eligible for entrance into the initial logistic regression model, with forward selection at p≤0.20 used to determine the final model.

Randomized Controlled Trial: Services received and psychometric properties: T-tests for continuous variables and chi-squared tests for categorical variables were used for the following analyses: 1) Difference in demographic and psychometric characteristics at baseline by study arm; 2) Differences in changes from baseline to study exit between study arms for parental stress, depression and unstable housing; 3) Differences in receipt of services on IFSPs (receipt of adequate services – defined as 25 hours/week, change in hours of services received from baseline to study exit and time to receipt of ASD-specific IFSP); and 4) Differences in receipt services on IEPs (receipt of ASD-specific IEP, receipt of adequate services – defined as 25hours/week, absenteeism, quality of IEP, and time to receipt of ASD-specific IEP). Kaplan Meyer survival curves were used to further explore time to receipt of IFSP/ IEP. Covariates in logistic regression models predicting parental stress, depression and unstable housing were selected using manual backwards selection.

V. Detailed Findings

Description of sample studied
263 families were eligible, of which 155 consented. Baseline data were collected for 155 families. Participants self-reported their race/ethnicity as non-Hispanic White (29.7%), non-Hispanic Black (26.5%), Hispanic (31.0%) and Other (12.9%). 68.4% of caregivers received public insurance and 51.6% were born outside of the United States. 64.5% of families reported English as the primary language spoken in the home. 35.5% of families reported other languages, including Spanish, Haitian Creole, Somali, Chinese, Portuguese, and Vietnamese. Only 60.7% of parents reported being married or living with their partner, and 36.1% had a high school degree/GED or less. A fifth of the sample reported living in an unstable housing situation (20.0%). Over half of the parents met the threshold for being clinically stressed (56.7%) based on their PSI-SF score, and 29.7% of the parents had at least moderate depression symptomatology based on their QID score. Based on the ABAS score, the majority of the index children had severe functional impairment (79.2%).

Program Description
Family Navigators: The FN's were each hired at .5 FTE, and managed an average case load of 9 families at a given point in time and a total load of approximately 40 families per FTE over the course of the entire study. Approximately 40 percent of their time was spent in direct clinical care.

Allocation of FN Time: The number of contacts and time spent both at in direct clinical care and addressing specific barriers was not normally distributed. Therefore, medians and interquartile ranges (IQR) are presented. Overall, the FNs spent approximately 17 hours with a family over the course of the six-month intervention; travel time accounted for 6 of these hours. Families received six in-person visits (IQR 4-10), 17 phone contacts (IQR 13-25) and five email contacts (IQR 1-16). In-person visits accounted for 41% of the time a FN worked with a family, followed by travel time (32%), email (14%), and phone contacts (13%). In-person visits were predominately conducted at the family's home. In-person visits also included accompanying the family to meetings in the community, such as attending Individualized Family Service Plan or Individualized Education Program team meetings, going to the Social Security Administration office with the family to complete an application, or joining the family at outpatient medical visits when requested.

Barriers Addressed in Family Navigation: Treatment access was the most frequent barrier addressed, with a median of 5 hours per family (IQR 2-7 hours). This accounted for 35% of the FNs time. Social service program enrollment accounted for a median of 3 hours per family (IQR 1-6 hours) accounting for 30% of FNs time. FNs also spent a median of 5 hours working on other topics (including childcare, health insurance, housing and immigration), accounting for 29% of the FN's time, and <1 hour addressing family logistical issues, accounting for 5% of the FN's time.

Acceptability of the Family Navigator Intervention
One hundred percent (78/78) of the FN families completed the exit interview and were thus considered to have completed the study, regardless of how often they interacted with the FN. At the time of study exit, participants completed an 8 question Client Satisfaction Questionnaire. Overall 95.8% of all answers put the program in high regard (See table 1).

Parental Stress and Depression at Time of Diagnosis
Depressive symptomatology, the child's age at the time of diagnosis, and living in unstable housing were independently associated with the parent being clinically stressed at the time of diagnosis. Specifically, compared to parents who had no/mild symptoms of depression, those with at least moderate symptoms of depression had 5.6 times the odds of being clinically stressed (95% CI 2.40-13.12; p<.0001). Compared to parents of children 33 months of age or younger at the time of diagnosis, parents of children over 33 months had 2.9 times the odds of being clinically stressed

(95% CI 1.47-5.50; p=0.0019). We also found that those in unstable housing had 4.0 times the odds of being clinically stressed (95% CI 1.55-10.53; p=0.0043) than those in stable housing at baseline.

Parents who were clinically stressed, self-identified as Hispanic, had some college education, or who were living in an unstable housing situation had significantly increased odds of being depressed. Specifically, compared to parents who were not clinically stressed, those who were clinically stressed had 5.6 times the odds of being depressed (95% CI 2.39-13.12; p≤.0001). Compared to White non-Hispanic parents, Hispanic parents had 6.13 times the odds of being depressed (95% CI 2.19-17.14; p=0.0005), and parents with only some college education had 2.4 times the odds of being depressed (95% CI 0.97-5.81; p=0.0585) when compared to parents who had graduated college or had an advanced degree. Female parents had 2.0 times the odds of being depressed (95% CI 0.84-4.76; p=0.1172) compared to male parents. We also found that parents in unstable housing had 4.75 times the odds of being depressed (95% CI 2. 07-10.87; p=0.0002) compared to those in stable housing at baseline.

Parents who self-identified as Hispanic, had some high school education, or who were living in an unstable housing situation had significantly increased odds of both being at least moderately depressed and having clinically-high stress levels. Specifically, compared to White non-Hispanic parents, Hispanic parents had 5.9 times the odds of being both stressed and depressed (95% CI 1.97-17.44; p=0.0015) and female parents had 2.2 times the odds of being both stressed and depressed (95% CI 0.85-5.77; p=0.1049) compared to male parents. We also found that parents in unstable housing had 7.5 times the odds of being both stressed and depressed (% CI 3.03 – 18.52; p<.0001) compared to those in stable housing at baseline.

RANDOMIZED CONTROLLED TRIAL

Randomization: There were no significant differences between parental age, gender, race, insurance, highest level of education, % US-born, English vs. other language spoke at home, employment outside the home, recent stressful events and housing stability in the two study arms at baseline (Table 2). However, participants in the control group scored higher on all psychometric measures: mean PSI scores (96.9 vs. 90.1; p=0.055); % with clinically significant parenting stress (63% vs. 51%; p=0.155); mean QIDS score (8.6 vs. 7.1; p=0.068); and % with moderate depressive symptomatology (37% vs. 23%; p=0.062). Control participants reported more close friends (7 vs. 5; p=0.083).

Education Services: Individualized Family Service Plan Assessment (IFSP)

Receipt of Adequate Services on IFSP: 68 children were eligible for an IFSP that specified autism-specific services for at least one day during the study period. Among these children, 3 children in the intervention and zero children in the control group received adequate services, defined as 25 hours/week. In the last 4 weeks of the study, services received averaged 10.5 hours/week (SD± 7.4 , range 0.6 – 30.8) for children in the intervention group and 13.1 hours/week (SD± 5.5, range 1.6 – 22.9) for children in the control group (p=0.11). Compared to hours received in the first two week, in the last four weeks children in the control group received an average of 9.7 additional hours (SD=9.6), compared to 6.8 additional hours (SD=5.8) amongst children in the intervention group (p= 0.06).

Time to Receipt of ASD-Specific IFSP: Time to receipt of an ASD-specific IFSP did not differ between study arms. Median time to IFSP was 8.1 weeks for navigated families (IQR 5.0-11.6) and 8.7 weeks (IQR 6.4-11.0) for control families (p=0.9372). (Figure 1)

Education Services: Individual Education Assessment Program (IEP)

Receipt of ASD-Specific IEP: Receipt of ASD-specific IEP: 81 children were eligible for an ASD-specific IEP for at least one day of the study. We received data for 72 of these subjects. Nine children already had ASD written into their IEP and were thus not eligible for this analysis, leaving 63 children who were eligible to receive a new ASD-specific IEP during the study period. Amongst this sample, 46 (73%) received an ASD-specific IEP, 15 (24%) had an IEP that was not ASD-specific, and 2 (3%) never received an IEP. There was no difference in the percentage of eligible children who received an ASD-specific IEP by study arm (73% vs. 73%; p=0.96).

Receipt of Adequate Services: Of those with an ASD-specific IEP, 7 (29%) of intervention children and 7 (29%) of control children had adequate services listed on their IEP (p=0.85). Absenteeism did not differ by study arm. Children with navigation had an average of 6.7 absences (SD=7.6) vs. 4.8 absences (SD=4.4) in the control group (p=0.85). IEP quality, as measured by a tool assessing compliance with the NRC did not differ by study arm. Mean score for intervention families was 10.9 (SD=3.7), compared to 10.5 (SD=4.0) for control families (p=0.85). There was no difference in the percentage of children who received social objectives (25% intervention vs. 21% control, p=0.69), nor the percentage of children who received ESY (63% intervention vs. 66% control, p=0.81),

Time to Receipt of ASD-Specific IEP: Time to receipt of an ASD-specific IEP did not differ between study arms. Median time to IEP was 13.9 weeks for navigated families (IQR 7.0-Not Reached) and 17.7 weeks (IQR 8.6-Not Reached) for control families (p=0.7250). (Figure 2)

Family Psychological Functioning
Parenting Stress and Depressive Symptomatology: 153 parents had complete data for parenting stress and 154 parents had complete data for depressive symptomatology at baseline and at study completion. At study completion, 57% of control parents experienced clinically significant parenting stress, compared to 54% of intervention families. After adjusting for baseline parenting stress, this was not a significant difference (difference in differences=8 percentage points; p=0.366). (Table 3). There was also not a significant difference in the mean change in parenting stress score by study arm, (difference in differences= 4.74; p=0.067). Similarly, at study completion 28% of control parents presented with at least moderate depressive symptomatology, compared to 17% of intervention families. After adjusting for baseline depressive symptomatology there was not a significant difference in end-of-study symptomatology by study arm (difference in differences= 3 percentage points; p=0.682). Similarly, there was not a significant different in the mean change in QIDS score by study arm (difference in differences=0.16; p=0.818). This lack of significant differences remained after stratifying by age at diagnosis, housing stability, and by parental place of birth. (Table 3).

Using logistic regression with manual backwards selection we found the following 1) clinically significant stress at baseline predicted stress at study exit 2) depressive symptomatology at baseline (as well as not working outside the home, speaking a language other than English in the home, and an older child) predicted depressive symptomatology at study exit and 3) unstable housing at baseline predicted unstable housing at study close. Having a family navigator was not associated with clinically significant levels of parenting stress (AOR 1.03, 95%CI0.49-2.16; p=0.93), depressive symptomatology (AOR 0.56, 95%CI=0.19-1.60, p=0.27) nor unstable housing (AOR=0.63, 95%CI=0.22-1.83; p=0.40) at study exit. (Table 4)

Client Satisfaction: 150 parents completed the client satisfaction questionnaire at study completion. Navigated families reported a mean score of 29.2 (SD=3.5), compared to 26.1 points (SD=4.7) for control families (p<.0001).

VI. Discussion and Interpretation of Findings

This study was ambitious and innovative in its approach and scope of expected impact. While we learned valuable information in several areas, overall we did not have the impact on the factors we hypothesized namely parental stress and depression and time to receipt of services and we will discuss below why we think this was so. But nonetheless we did learn important information on several levels.

The first valuable lesson from this study was knowledge about who are the inner city families with children diagnosed less than 8 years of age with autism spectrum disorder. In general they are a very diverse group with approximately a third non-Hispanic White (29.7%), a third non-Hispanic Black (26.5%), and almost a third Hispanic (31.0%). This is reflective of CDC data showing a rise in the proportion of black and Hispanic families with children newly diagnosed.(35)
Almost two thirds of our sample (68.4%) received public insurance and over half (51.6%) were born outside of the United States. From an advocacy perspective, it is important to recognize that over a third of our sample (35.5%) reported speaking other languages, including Spanish, Haitian Creole, Somali, Chinese, Portuguese, and Vietnamese. From a support vantage it is critically important to acknowledge that a fifth of the sample reported living in an unstable housing situation (20.0%).

This fact alone- unstable housing- linked with the child severity rating of almost 80% of our sample having severe functional impairment, may be more intimately linked to our findings around mental health both pre and post intervention than the fact of the diagnosis alone. Over half of the parents met the threshold for being clinically stressed (56.7%) based on their PSI-SF score, and almost a third (29.7%) of the parents had at least moderate depression symptomatology based on their QID score. Thus no single intervention lasting a short six months might have been able to significantly impact this level of intrinsic stress.

What we were able to accomplish with this study is nonetheless significant if not statistically. We were able to define a new profession as part of the health care team to support families with a child diagnosed on the autism spectrum. We found that several pieces are critical to successful family navigation as based on feedback from families as well as our data: 1) **Targeted FN training:** FNs should receive at least 40 hours of disability-specific training with an additional 40 hours of training on advocacy, logistics, cultural competence and principles of motivational interviewing; 2) **In-person contacts**: Although there was significant variability, over half of the contact time (excluding travel time) in our cohort was "in person" and this appeared critical to relationship building; and 3) **A flexible family-centered focus**: Barriers are unique to each family and navigation must be tailored to individuals and communities The success of this approach was reflected in our patient satisfaction scores: among those who received the intervention 95.8% of all satisfaction questions were answered positively, with the percentage of positive responses ranging from 93.5%-98.7% depending on the specific question.

We identified that the barriers they most needed help with post diagnosis were treatment access, with a median of 5 hours per family (IQR 2-7 hours), and social service program enrollment, accounting for a median of 3 hours per family (IQR 1-6 hour). Other topics addressed included childcare, health insurance, housing and immigration with <1 hour per family addressing family logistical issues.

Perhaps the most significant take-home from this study is that as a state, we still have along way to go in providing autism specific services to children. Despite a median of 5 hours per family of assistance accessing treatment, only 22% of all children received an ASD-specific IEP within 9 weeks. Rather, median time to IEP was 13.9 weeks for intervention families and 17.7 weeks for control families (p=0.725). We also found that IEPs were less than recommended by the NRC with only 64% receiving ESY and only 23% having a social goal, which is the hallmark of the disability. Similar data occurred in EI with 68 children eligible for an autism specific IFSP yet only 3 children in the intervention and zero children in the control group received adequate services, defined as 25 hours/week. In the last 4 weeks that the child was eligible for the study, services received

averaged 10.5 hours/week (SD± 7.4 , range 0.6 – 30.8) for children in the intervention group and 13.1 hours/week (SD± 5.5, range 1.6 – 22.9) for children in the control group (p=0.11). Thus across the board children were not receiving the treatment intensity recommended.

B. Explanation of study limitations

Our primary outcomes were determined a priori, and were specifically chosen to reflect a variety of clinical outcomes (time to receipt of an ASD-specific IEP or IFSP, adequacy of services etc.) and patient-centered outcomes (psychometric measures such as depression and stress). While intervention families expressed high satisfaction with the program, it is possible that the outcome measures do not capture the benefit of Family Navigation. Though it may not be captured in the numbers, we learned a significant amount from our families about what the first weeks after diagnosis entail by "walking the walk" with them through navigation. Having a child diagnosed with a lifelong disability such as autism spectrum disorder, the first six months may be more reflective of the typical stages of grief parents experience that is denial, anger, bargaining, depression, acceptance.(36) Our 6 month intervention results may be reflective of parents at all of these stages thus no significant impact can be seen or expected with such a small cohort.

C. Comparison with findings of other studies

We are not aware of other research studies that use Family Navigation in this population.

D. Possible application of findings to actual MCH health care delivery situations

Given the unique needs of families in obtaining care for children with special health care needs like ASD, we identified the following three components as critical for a family navigation program: 1) **Targeted FN training:** FNs should receive at least 40 hours of disability-specific training 2) **In-person contacts**: this appeared critical to relationship building; and 3) **A flexible family-centered focus**: Barriers are unique to each family and navigation must be tailored to individuals and communities.

E. Policy implications

Massachusetts is doing a solid job of diagnosing children in a timely manner,(37) but in particular challenged communities such as ours, we still have a long way to go in addressing both the quality of treatment and more importantly the mental health and support to families.

Our Governor, Deval Patrick, recently signed the Autism Omnibus Bill in August 2014 which makes as a requirement that MassHealth cover medically necessary treatments for children with ASD who are under 21 years old – including ABA therapies as well as dedicated and non-dedicated Augmentative and Alternative Communication devices. In addition it created an Autism Endorsement for special education teachers to enable them to voluntarily gain in-depth knowledge about the complexities of educating students with ASD. These two pieces of the bill should vastly improve the quality and quantity of treatment families receive.

E. Suggestions for further research

We are already in the midst of our next study. With the support of NIMH we have begun an RO1 study to take Family Navigation to two other sites- Yale and Children's Hospital of Philadelphia- and more importantly to tweak the model so that families are identified and supported at the time they fail an autism screen and followed for 100 days after the diagnostic evaluation to better address time to diagnosis and treatment as well as supporting families in the critical early days post diagnosis. We anxiously await the recruitment of the first patients for this study at all three sites.

VII. List of products

Conference Presentations

Autism Consortium, Boston, MA
- 2012 Family Navigation: Overcoming Barriers to Care in Diverse Families Impacted by ASD
- 2013 The Family Navigator: Newest Team Member in the Care of the Child on the Autism Spectrum

Combating Autism Act Initiative (CAAI), Washington, DC
- 2012: Families from low income and diverse backgrounds & ASD: Clinician perspective.
- 2013: Family Navigation: Overcoming Barriers to Care in Diverse Families Impacted by ASD

Manuscripts – published

1) Where Do We Start? Using Family Navigation to Help Underserved Families
Authors: Stephanie Blenner, Ivys Fernandez, Adriana Giron, Xena Grossman, Marilyn Augustyn
Publication: *Zero to Three.* July 2014. Volume 34, No.6

Manuscripts – submitted

1) Making Family Navigation Work: Addressing disparities in care for the child with Autism Spectrum Disorder
Authors: Xena Grossman, Stephanie Blenner, Emily Feinberg, Eleanor Cooper, Marilyn Augustyn
Submitted to: Journal of Developmental and Behavioral Pediatrics

Manuscripts – in progress (information is tentative)

1) Stress and Depression in a low-income and diverse population of parents with a child newly diagnosed with Autism Spectrum Disorder
Authors: TBD

2) Use of Family Navigation in low-income and diverse families with a child newly diagnosed with Autism Spectrum Disorder: The results of a randomized controlled trial.
Authors: TBD

3) What does an Autism Spectrum Disorder diagnosis mean to me? Qualitative data from US and non-US born families of children newly diagnosed with an Autism Spectrum Disorder
Authors: TBD

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Table 1: Client Satisfaction Questionnaire Scores Given By Navigated Patients to Family Navigation Program

Client Satisfaction Questionnaire Scores Given By Navigated Patients to Family Navigation Program				
	Low Regard		High Regard	
Question	N	%	N	%
1 Quality of Service	1	1.3%	76	98.7%
2 Receive Desired Services	3	3.9%	74	96.1%
3 Met Needs	4	5.2%	73	94.8%
4 Would Recommend	2	2.6%	75	97.4%
5 Satisfied With Help Amount	4	5.2%	73	94.8%
6 Services Help Deal With Problems Effectively	5	6.5%	72	93.5%
7 Overall Satisfaction	5	6.5%	72	93.5%
8 Likelihood Would Comeback	2	2.6%	75	97.4%
All Questions		**4.2%**		**95.8%**

Note:
1. Patients score the Family Navigation program on a scale of 1-4. Scores of 1 or 2 are counted as 'low regard.' Scores of 3 or 4 are counted as 'high regard.'

Table 2: Test of Randomization

Family characteristics

	Controls (N = 77)	Navigator families (N = 78)	P-value
Age, mean	33.00	35.00	0.1651
Female, %	77%	71%	0.4623
Race, %			
White	32%	27%	0.4500
Hispanic	29%	33%	0.5215
Black	31%	22%	0.1859
Asian	8%	18%	0.0593
Education, %			
Some high school	19%	12%	0.1717
High school / GED	18%	23%	0.4516
Some college	29%	29%	0.9001
College	34%	36%	0.7807
US born, %	48%	49%	0.9339
Language most commonly spoken in the home, %			
English	65%	64%	0.9138
Spanish	19%	14%	0.3703
Chinese	3%	3%	1.0000
Hatian Creole	6%	4%	0.4947
Vietnamese	0%	1%	1.0000
Marital status, %			
Married	49%	54%	0.5755
Divorced	5%	8%	0.7456
Single	34%	29%	0.5667
Work outside the home, %	45%	47%	0.8047
Insurance, %			
N/A	1%	3%	1.0000
Private insurance	29%	33%	0.5215
Public insurance	70%	64%	0.4246
Recently experienced, %			
Ilness	13%	13%	0.9753
Death	10%	18%	0.1776
Divorce	6%	4%	0.4947
Thrown out	8%	5%	0.5337
Unstable housing	22%	18%	0.5205

Notes:

1. P-values have been assessed using t-tests for continuous variables and chi-squared tests for categorical variables.

2. Due to incomplete data, female share of Navigator families was calculated among 77 families.

Table 3: Improvement from baseline to exit: difference in differences

Table 3g
Assessment of psychological conditions
Difference in difference summary table

Condition	Overall Difference in Difference	P-value	Under 33 Months Difference in Difference	P-value	At Least 33 Months Difference in Difference	P-value	Foreign Born Difference in Difference	P-value	US Born Difference in Difference	P-value	Unstable Housing Difference in Difference	P-value
Parenting stress												
Total PSI score, mean	4.74	0.0668	5.50	0.1092	3.47	0.3703	6.10	0.1114	3.31	0.3471	0.65	0.9175
Clinically significant parental stress, %[3]	0.08	0.3657	0.12	0.3083	0.02	0.8938	0.18	0.1670	-0.02	0.8425	-0.10	0.4832
Perceived stress												
PSS total score, mean	0.04	0.6470	0.08	0.5531	0.00	0.9837	0.13	0.3596	-0.05	0.6079	0.07	0.7024
Depressive symptoms												
Total QIDS score, mean	0.16	0.8179	0.76	0.4598	-0.32	0.7242	-1.10	0.2833	1.48	0.0937	-0.96	0.5825
Severity of depressive symptoms, %												
None	-0.04	0.6043	-0.03	0.8137	-0.07	0.5075	-0.08	0.4690	0.00	0.9770	-0.16	0.3941
Mild	0.01	0.8815	-0.02	0.8845	0.05	0.7276	0.15	0.2259	-0.13	0.3636	0.13	0.5770
Moderate	0.10	0.1790	0.10	0.3430	0.14	0.2286	0.08	0.4848	0.13	0.2293	0.38	0.0963
Severe	-0.06	0.1722	-0.05	0.3455	-0.08	0.2743	-0.15	0.0343 *	0.03	0.6464	-0.34	0.0413 *
Very Severe	-0.01	0.3204	0.00	1.0000	-0.03	0.3240	0.00	1.0000	-0.03	0.3238	0.00	1.0000
Social support measures, mean												
Number of close friends, mean	1.40	0.0623	1.63	0.1021	1.25	0.2844	1.31	0.1643	1.50	0.2105	-1.01	0.5241
Total MOS-SS score, mean	-0.02	0.8681	-0.06	0.7016	0.04	0.8519	-0.11	0.5463	0.07	0.6453	0.32	0.2878

* p-value<0.05, ** p-value<0.01
Notes:
1. Analysis was limited to those families with available data at baseline and at study completion, by condition.
2. P-values were assess using t-tests for continuous variables and chi-squared tests for categorical variables.
3. Clinically significant parental stress is defined as a total PSI score above 90.
4. Clinically significant depression is defined as a QIDS score of at least 11.

Table 4: **Analysis of stress, depression, and housing status outcomes for parents at study exit**

Analysis of stress, depression, and housing status outcomes for parents at study exit

Family characteristics[1]	Clinically significant parental stress Odds Ratio (95% CI)[2,3]		P-value	Clinically significant depressive symptoms Odds Ratio (95% CI)[2,3]		P-value	Unstable housing Odds Ratio (95% CI)[2,3]		P-value
Parent characteristics									
Single	0.57	(0.24 – 1.36)	0.21	2.68	(0.90 – 8.01)	0.08	1.62	(0.54 – 4.84)	0.39
Works outside the home	0.52	(0.24 – 1.16)	0.11	0.15	(0.04 – 0.53)	<0.01 **	2.34	(0.74 – 7.42)	0.15
Characteristics at baseline									
Clinically significant stress	4.95	(2.34 – 10.47)	<0.01 **	–	–	–	–	–	–
Clinically significant depressive symptoms	–	–	–	23.04	(7.18 – 73.89)	<0.01 **	–	–	–
Unstable housing	–	–	–	–	–	–	8.48	(2.93 – 24.58)	<0.01 **
Child characteristics									
Age (months)	0.98	(0.94 – 1.03)	0.49	1.08	(1.00 – 1.16)	0.04 *	0.96	(0.88 – 1.05)	0.40
Mother has private insurance	0.63	(0.25 – 1.58)	0.33	1.57	(0.38 – 6.48)	0.54	0.25	(0.05 – 1.42)	0.12
English primarily spoken in the home	0.47	(0.21 – 1.06)	0.07	0.19	(0.06 – 0.60)	<0.01 **	0.41	(0.14 – 1.19)	0.10
Access to a patient navigator[4]	1.03	(0.49 – 2.16)	0.93	0.56	(0.19 – 1.60)	0.27	0.63	(0.22 – 1.83)	0.40

* P-value < 0.05, ** P-value < 0.01
Note:
1. Covariates in the logistic regression models were selected using manual backward selection methods.
2. Odds ratios were derived from logistic regressions with parent outcomes measured at the study exit.
3. Confidence intervals for odds ratios were derived using Wald 95% confidence intervals.
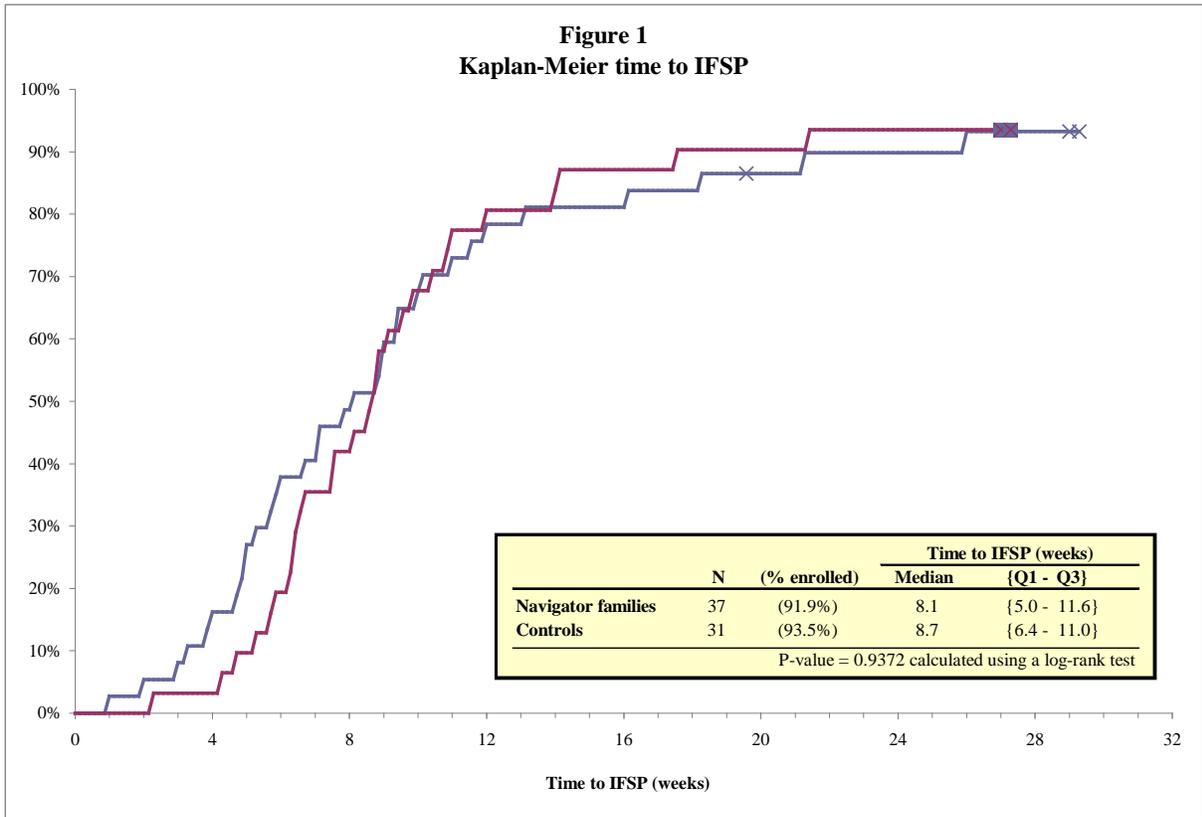4. Access to a patient navigator was included as a dummy variable in the logistic regression model.

Figure 1

Figure 1
Kaplan-Meier time to IFSP

	N	(% enrolled)	Time to IFSP (weeks) Median	{Q1 - Q3}
Navigator families	37	(91.9%)	8.1	{5.0 - 11.6}
Controls	31	(93.5%)	8.7	{6.4 - 11.0}
			P-value = 0.9372 calculated using a log-rank test	

Figure 2

Figure 2
Kaplan-Meier time to IEP

	N	(% enrolled)	Time to IEP (weeks) Median	{Q1 - Q3}
Navigator families	33	(72.7%)	13.9	{7.0 - NR}
Controls	29	(72.4%)	17.7	{8.6 - NR}
			P-value = 0.7250 calculated using a log-rank test	