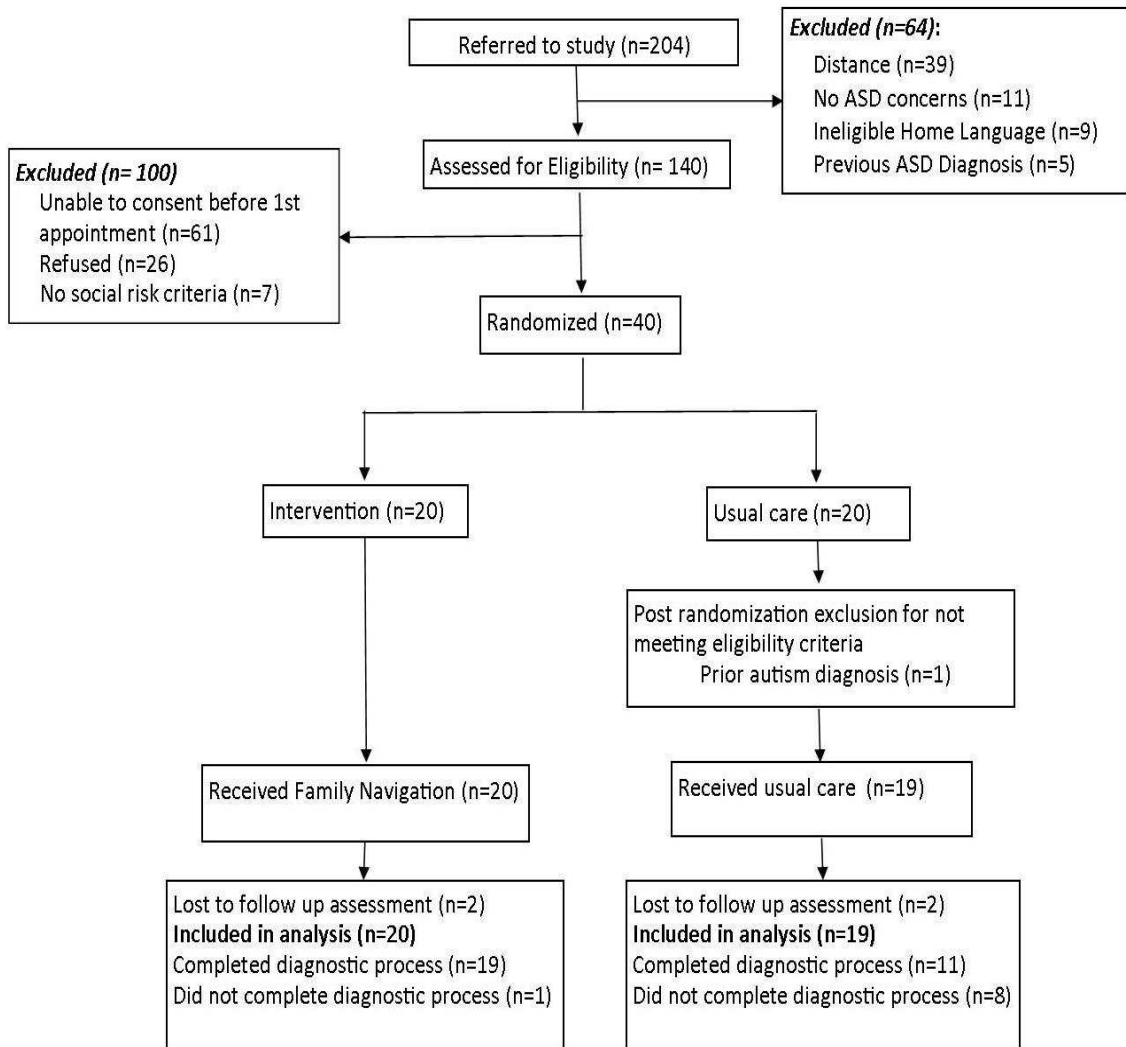


**Online Supplement**

**CONSORT Flowchart of Randomized Trial**



### **Families Focused Outcomes: Additional Information**

Three secondary, family-focused outcomes – perceived stress, patient activation, and social support – were assessed through in-person interviews by research assistants masked to study allocation. These interviews were conducted two weeks after completion of the diagnostic assessment or, for families who did not complete the diagnostic process, 90 days after the child's first scheduled clinic visit.

Parental stress was assessed using the Perceived Stress Scale (PSS),<sup>11</sup> which is a 14 item scale with response categories “never,” “almost never,” “sometimes,” “fairly often,” and “very often.” Stress domains include unpredictability, lack of control, burden overload, and stressful circumstances. Reliability studies have demonstrated Cronbach alphas between .78 and .86 in a variety of populations. Evidence of concurrent validity includes positive correlations with inventories of burnout, somatic symptoms, healthcare utilization, and cortisol levels.

Patient activation was examined using the Patient Activation Measure (PAM).<sup>12</sup> This 13 item scale is a valid and reliable (Cronbach alpha .85) self-report scale that reflects four stages of patient activation: belief in self-management, confidence/knowledge, action, and persistence under stress. It has been used in a wide variety of patient populations for adults managing their own conditions; we adapted it for parents managing their children's conditions.<sup>3-4</sup>

Social support was measured using the Medical Outcomes Social Support Scale (MOS-SS);<sup>13</sup> and the psychological stability scale from the Coping Health Inventory for Parents (CHIP).<sup>14</sup> The MOS-SS is a 19 item scale with response categories “none of the time,” “a little of the time,”

“some of the time,” “most of the time,” “all of the time.” This tool comprises 4 functional support scales: emotional/informational, tangible, affectionate, and positive interaction and an overall social support index. All subscales are reliable ( $\alpha$ 's > .91). The measure was validated in a sample of patients from three different types of health care practices (health maintenance organizations, large multispecialty groups, and solo fee-for-service practices).<sup>5</sup> The Coping Health Inventory for Parents is 45 item scale with response categories “extremely helpful,” “moderately helpful,” “minimally helpful,” “not helpful,” “chose not to,” “not possible.” The CHIP is a valid and reliable instrument designed to measure parents' response to managing family life when they have a child with an acute or chronic illness. It comprises three subscales (maintaining family integration,  $\alpha=0.79$ ; maintaining social support and psychological stability,  $\alpha=0.79$ ; and understanding the child's medical situation,  $\alpha=0.71$ ) within which total mean scores are calculated.<sup>6</sup> Only maintaining social support and psychological stability subscale was used to assess social support.

To assess secondary outcomes across intervention groups, we calculated the mean difference between FN and Usual Care participants, controlling for baseline values; we used Cohen's *d* to estimate effect size. Effect sizes were moderate for social support (.59 for the MOS-SS scale; .46 for social support scale of CHIP), small for perceived stress (.20, PSS), and showed no signal of effect for patient activation (.02, PAM). (Online Supplement Table 1)

Of the family-focused outcomes examined, only measures of social support demonstrated potential differences by treatment arm. The study was not designed to detect statistically significant group differences. Rather, we were interested in the magnitude of the between group differences assessed by the effect size. The moderate effect size for between group differences in

measures of social support suggests its potential as a measure to assess FN's effect. Its sensitivity to change using two independent measures supports this hypothesis. Further assessment of family-focused outcomes in a fully powered study is necessary to adequately evaluate how FN may affect these outcomes.

**Mean difference in family-focused outcomes for families of children referred for ASD diagnostic assessment who did and did not receive the Family Navigation (FN) intervention**

	Usual care		Family Navigation		Mean difference*	95% CI	Cohen's d
	Mean	SD	Mean	SD			
<b>Social Support (MOS SSS)</b>	3.25	.99	3.77	.79	-.53	-1.17, 4.33	.59
<b>Social Support (CHIP)</b>	30.0	6.68	33.94	9.95	-3.94	-10.38, 2.5	.46
<b>Perceived Stress (PSS)</b>	23.41	9.47	25.06	7.12	-1.65	-7.63, 4.33	.20
<b>Patient Activation (PAM)</b>	72.22	12.98	71.98	16.25	.24	-10.17,10.65	.02
* Adjusted for baseline values Abbreviations: MOS, Medical Outcomes Study Social Support Scale; CHIP, Coping Health Inventory for Parents; PSS, Perceived Stress Scale; PAM, Patient Activation Measure.							

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