Published in final edited form as:
Autism. 2020 February ; 24(2): 526–530. doi:10.1177/1362361319864079.

Short Report: Defining the Core Components of Family Navigation for Autism Spectrum Disorder

Sarabeth Broder-Fingert, MD, MPH[a], **Nicole Stadnick, PhD, MPH**[b,c], **Emily Hickey, PhD**[d], **Julia Goupil, BS**[d], **Yaminette Diaz Lindhart, MSW, MPH**[e], **Emily Feinberg, ScD, CPNP**[a,f]

[a]Division of General Pediatrics, Department of Pediatrics, Boston University School of Medicine, Boston, MA

[b]University of California, San Diego, San Diego, CA

[c]Child and Adolescent Services Research Center, San Diego, CA

[d]Department of Pediatrics, Boston Medical Center, Boston, MA

[e]The Heller School for Social Policy and Management, Brandeis University, Waltham, MA

[f]Boston University School of Public Health, Boston, MA

Abstract

This study aimed to define the core components of Family Navigation (FN) for autism spectrum disorder (ASD), a promising intervention to reduce disparities in care for this population. Teams from four trials of FN for ASD completed the Template for Intervention Description and Replication checklist (TIDieR) to outline intervention components. Through intervention component analysis and qualitative synthesis, we identified 11 core components across three domains: Training and Supervision; Navigator Tools; and Navigator Activities. We discuss the importance of identifying these core components and implications for future research and practice.

Keywords

Autism; Family Navigation; Care Coordination

Background

Family Navigation (FN) is a case management approach to increasing access to diagnostic and treatment services over a time-limited period. Our model of FN was originally developed to support families of children at risk for autism spectrum disorder (ASD) obtain a definitive diagnosis and access to treatment services.

Corresponding Author: Sarabeth Broder-Fingert, MD MPH, Boston Medical Center/Boston University School of Medicine, 88 East Newton St, Vose 3, Boston, MA 02118, Fax: 617-414-3679, Telephone: 617-414-5938, sarabeth.broder-fingert@bmc.org.

Declaration of conflicting interests: Sarabeth Broder-Fingert declares that she has no conflict of interest. Nicole Stadnick declares that she has no conflict of interest. Emily Hickey declares that she has no conflict of interest. Julia Goupil declares that she has no conflict of interest. Yaminette Diaz Lindhart declares that she has no conflicts of interest. Emily Feinberg declares that she has no conflict of interest.

A number of institutions have implemented and tested FN (“Bridging Hospital and Community,” 2013; Diaz-Linhart et al., 2016; Feinberg et al., 2016; Kubicek et al., 2016). While data from these projects on the effectiveness of FN are beginning to emerge (Feinberg, 2019a; Feinberg et al., 2016), no studies have delineated the core components of the FN for ASD.

Following the principles of implementation science and intervention development, defining core components of a multi-component intervention is important in precipitating rapid dissemination and scale-up- if and when effectiveness is determined (Curran, Bauer, Mittman, Pyne, & Stetler, 2012; Hoddinott, 2015). The template for intervention description and replication checklist (TIDieR) was developed to guide intervention component reporting practices (Hoffmann et al., 2014). To date, no studies have utilized TIDieR to describe FN. Therefore, the purpose of this paper is to report the core components of FN for ASD as identified from TIDieR checklists completed by teams from four trials of FN for ASD.

Methods

Completion of TIDieR

The principal investigator (PI), co-investigators (Co-I), and research staff (total n = 8) from four clinical trials of FN for ASD completed a TIDieR checklist about their studies. For each trial, first the study coordinator completed a TIDieR. After completion, the PI (trial one, two, and three) or site PI (trial four), along with a co-investigator, research staff, and a navigator from each clinical trial reviewed the checklist. Any differences identified during this review were discussed among the study team until consensus was achieved.

TIDieR Checklist

TIDieR is a 12 item checklist to describe an intervention with sufficient detail to permit replication in research or practice settings (Hoffmann et al., 2014). TIDieR was developed through literature review, a Delphi group consensus rating with experts in intervention design, and an in-person panel meeting. TIDieR is an extension of both the CONSORT for reporting results from randomized clinical trials and the Standard Protocol Items (SPIRIT) for study protocols of clinical trials (Pandis et al., 2017). Checklists represent four clinical trials of FN for ASD across five states (California, Connecticut, Florida, Massachusetts, Pennsylvania) and 620 families (NCT01340092; NCT02359084; NCT03575429). Checklists were completed between October 2017-October 2018.

Analysis

Analysis was guided by Intervention Component Analysis (ICA) (Sutcliffe et al., 2015). ICA was developed to assist investigators in systematically describing interventions. It involves two primary principles: 1) using an inductive approach to describe an intervention and 2) making use of investigators’ informally reported experiences. This method is designed to combine data from multiple studies on a specific intervention to compare components across each study and identify the core components that are consistent across studies. ICA involves investigative teams working together in two stages. Stage one involves identifying intervention similarities and differences; stage two involves identifying which of these similarities and differences are important.

Stage 1: Identifying similarities and differences.—Checklist items were identified as either overlapping or non-overlapping across studies. The first author (S.B.F.) and a trained research assistant (J.G.) reviewed each checklist, along with descriptions of each item. Disagreements were discussed and resolved through consensus. Although frequently in content analysis 'memos' are generated to document initial impressions and define parameters for specific codes, this was deemed unnecessary due to the brevity of the checklist (each was two pages in length), and the similarity across checklists. Therefore, the TIDieR checklists were used in place of memos, with the data from each item on the checklist being used as an analyzable unit. Because of the iterative nature of the analysis, Intraclass Correlation Coefficient (ICC) was not calculated. We did have >90% agreement across checklists for initial ratings, and reached 100% agreement in the final codes. The final checklists were presented to the study team, and any final disagreements were resolved by consensus until one final version of codes was agreed upon.

Stage 2: Determining and Defining the Intervention Components.—Once consensus was reached on the final TIDieR checklist, the first and second author independently coded all TIDieR checklists using qualitative content analysis (Elo & Kyngas, 2008). First, each coder reviewed each TIDieR checklist. Each item was labelled with codes based on emergent themes. These were continually refined and compared to each other, and disagreements were discussed and resolved through consensus. Categories (termed "components") were aggregated into broader themes (called "domains") using the same consensus methodology. Finally, formal definitions for each component were developed based on TIDieR codes using consensus approach. The components, domains, and definitions were then presented to the study team to ensure respondent validation, also known as "member checking". After discussion, the list of components and domains were refined, and then re-presented to the research teams. This process continued until consensus was reached on the core intervention components and their domains.

Results

Eleven core components were identified and shared by all FN models tested across the four clinical trials. These core components fell into three distinct domains: Training and Supervision; Navigator Activities; and Navigator Tools (Table 1). Each domain contained a number of components, with one component spanning two domains. Specifically, Training and Supervision encompasses three components, Navigator Activities includes six components, Navigator Tools includes two components and one component (Navigator Checklist) spans both Training and Supervision and Navigator Tools.

TIDieR Checklist.

The eleven core components included: (1) initial training; (2) ongoing supervision; (3) linguistic and cultural brokering; (4) individual (Navigator to family) face-to-face, phone, and email encounters; (5) identification of barriers to appropriate care (e.g., language, cultural beliefs, transportation); (6) Navigator Workbook; (7) care coordination and linkage to community-based resources; (8) emotional support; (9) Navigator checklist; (10) Navigator Workbook; (11) ongoing, systematic fidelity monitoring. The operationalization of each core component is detailed in Table 1.

Discussion

Family navigation is a service delivery intervention to promote timely and coordinated access to diagnostic and treatment services, particularly for underserved families. There is significant interest in FN, with both policy and funding initiatives aimed at expanding the implementation of FN models for ASD, as well as other areas of child health (e.g., NIMH) ("Bridging Hospital and Community," 2013; "PAR-17-265: Initiation of a Mental Health Family Navigator Model to Promote Early Access, Engagement and Coordination of Needed Mental Health Services for Children and Adolescents [R01]," 2017; Diaz-Linhart et al., 2016; Feinberg et al., 2016; Kubicek et al., 2016). However, limited information exists regarding the core components of FN. This description of the core components of FN for ASD is meant to address the urgent need for precise operationalization of the intervention and to be used as a generalizable blueprint for others in research and practice pursuing FN implementation.

We identified 11 core components in three conceptual domains: Training and Supervision; Navigator Tools; and Navigator Activities. The Navigator Activities domain included the greatest number of components and included linguistic and cultural brokering, completing encounters with families, identifying barriers to access services, and providing emotional support. These components represent the primary and unique activities of the Navigator that they perform through use of the intervention materials that are categorized as the Navigator Tools. It is notable that three components were related to training and supervision. This is important for two reasons. First, there is debate in the field of intervention development and implementation science as to whether training and supervision is an intervention component or an implementation strategy. While one could argue that training is a mechanism to implement FN, stakeholders in the current study viewed training and supervision as an integral part of the intervention. This finding is also important in light of a recent mixed methods study of FN implementation that found that Training and Supervision was one of the key aspects of FN implementation that was prone to failure (Broder-Fingert et al., 2018). Therefore, it is important for the field to clarify if training and supervision is, in fact, a core component of FN, or an implementation strategy that can be utilized to implement FN. Such a debate is outside the scope of this paper, but one that warrants further investigation.

A second important fining is the differentiation between Navigator tools and Navigator activities. In planning to implement any intervention, it is critical to know what tools the interventionists need to carry out the intervention in a given setting. We recommend teams looking to use FN for ASD adapt these core components for their particular context. This is in line with the widely supported tenet in implementation science regarding the importance of adaptable innovations to maximize "fit" with the service context, service providers and end-users of the intervention (Moullin, Dickson, Stadnick, Rabin, & Aarons, 2019).

Finally, our findings hold significance for implementation in research (e.g., study design, implementation strategies to test) and practice (e.g., adaptations for other populations). This research demonstrates the utility of the TIDieR checklist in defining components of an intervention. These data can assist those working to integrate FN for ASD into existing service systems, particularly as a guide for adoption and implementation in community-based service systems. We anticipate that multiple adaptations to the intervention, as well as the selection and tailoring of specific implementation strategies, will be tested moving forward, particularly in settings with varying contextual needs and resources. An explicit definition of the core components will be valuable in developing and testing such adaptations and implementation. In this context, is important to note that one trial (four) had a single component (ASD Behavioral Treatment Administration) that was not reflected in the other studies. In this study the FNs provide ASD-specific treatment. Because this component only existed in one of the four studies, it was not included as a core component, but rather was considered an adaptation of the original model. This difference reflects the need for more data on the value of individual components, and other adaptations that may be made during implementation.

Limitations

This study was limited by our focus on FN specifically for young children with ASD, or concern for ASD, and their families. Children with ASD often present highly complex developmental and behavioral challenges; it is often difficult to identify generalizable interventions because of the heterogeneous abilities and related service needs of these children with ASD. Therefore, it may be that applications of FN for other health conditions may need fewer condition-specific adaptations than our example with ASD illustrates.

Future Directions

We have several new and planned studies to test family navigation implementation, including an ongoing trial using the multiphase optimization strategy [R01MH117123] to test the effectiveness of FN components within an urban Federally Qualified Community Health Center. The results from this ongoing trial and additional FN experiments will yield valuable findings to inform optimal matching of components to different health settings.

Acknowledgements:

Funding: Dr. Feinberg was supported by R01MH104355; Dr. Broder-Fingert was supported by K23 MH109673.

References

Bridging Hospital and Community: Family Navigator program expands. (2013, 7 22). Retrieved July 19, 2018, from Family Voices CO Home website: https://familyvoicesco.org/2013/07/22/family-navigator-program-expands/

Broder-Fingert S, Qin S, Goupil J, Rosenberg J, Augustyn M, Blum N, ... Feinberg E (2018). A mixed-methods process evaluation of Family Navigation implementation for autism spectrum disorder. Autism, 1362361318808460. 10.1177/1362361318808460

Curran GM, Bauer M, Mittman B, Pyne JM, & Stetler C (2012). Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. Medical Care, 50(3), 217–226. 10.1097/MLR.0b013e3182408812 [PubMed: 22310560]

Diaz-Linhart Y, Silverstein M, Grote N, Cadena L, Feinberg E, Ruth BJ, & Cabral H (2016). Patient Navigation for Mothers with Depression who Have Children in Head Start: A Pilot Study. Social Work in Public Health, 31(6), 504–510. 10.1080/19371918.2016.1160341 [PubMed: 27195704]

Elo S, & Kyngäs H (2008). The qualitative content analysis process. Journal of Advanced Nursing, 62(1), 107–115. 10.1111/j.1365-2648.2007.04569.x [PubMed: 18352969]

Feinberg E (2019a, 4). A Multi-Site Randomized Control Trial of Family Navigation's Effect on Diagnostic Ascertainment among Children at Risk for Autism: A DBPNet Study. Presented at the Pediatric Academic Societies (PAS), Baltimore, Maryland.

Feinberg E, Abufhele M, Sandler J, Augustyn M, Cabral H, Chen N, ... Silverstein M (2016). Reducing Disparities in Timely Autism Diagnosis Through Family Navigation: Results From a Randomized Pilot Trial. Psychiatric Services (Washington, D.C.), 67(8), 912–915. 10.1176/appi.ps.201500162

Hoddinott P (2015). A new era for intervention development studies. Pilot and Feasibility Studies, 1 10.1186/s40814-015-0032-0

Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, ... Michie S (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ, 348, gl687 10.1136/bmj.gl687

Kubicek K, Murray D, Coury DL, Kuhlthau K, Zand D, Kipke MD, ... Kipke MD (2016). A Mixed Methods Approach to Describing Family Navigation as a Service Model within the Autism Speaks Autism Treatment Network.

Mind the Gap: Increasing access to care through parent engagement. (2013). Retrieved December 11, 2018, from AIR-B Autism Intervention Research Network on Behavioral Health website: http://www.airbnetwork.org/mind_gap.asp

Moullin J, Dickson K, Stadnick NA, Rabin B, & Aarons GA (In Press). Systematic review of the Exploration, Preparation, Implementation, Sustainment Framework. Implementation Science.

Pandis N, Chung B, Scherer RW, Elbourne D, & Altman DG (2017). CONSORT 2010 statement: extension checklist for reporting within person randomised trials. BMJ (Clinical Research Ed.), 357, j2835 10.1136/bmj.j2835

PAR-17-265: Initiation of a Mental Health Family Navigator Model to Promote Early Access, Engagement and Coordination of Needed Mental Health Services for Children and Adolescents (R01). (2017, 5). Retrieved July 19, 2018, from NIH website: https://grants.nih.gov/grants/guide/pa-files/PAR-17-265.html

Sutcliffe K, Thomas J, Stokes G, Hinds K, & Bangpan M (2015). Intervention Component Analysis (ICA): a pragmatic approach for identifying the critical features of complex interventions. Systematic Reviews, 4, 140 10.1186/s13643-015-0126-z [PubMed: 26514644]

Table 1:

Core Components of Family Navigation for Autism Spectrum Disorder

Domain	Component	Description
Training & Supervision	1. Training	Intensive initial training to navigators on MI, navigation, problem solving approaches, and ASD diagnostic and treatment services
	2. Ongoing Supervision and Case Review	Regular check-ins with navigators to ensure that navigation is proceeding smoothly and conversations to strategize how to handle challenging cases (e.g., family is not engaged).
	3. Fidelity Monitoring	Ongoing, systematic fidelity monitoring (e.g., Family Navigators audiotape one randomly selected session for each client; audiotapes are reviewed by a supervisor and used to provide feedback on FN delivery).
Navigator Activities	4. Referral to Navigation	Navigators proactively educate clinical teams on referral processes
	5. Linguistic and Cultural Brokering	Understanding a community’s values, traditional health beliefs, and language and using this to communicate in a cross-cultural context, interpret information, and mediate conflict.
	6. Complete Encounters	Individual (navigator to family) face-to-face, phone, and email encounters, occurring in family’s homes, clinic, or other community settings where the family requests support (e.g., in the Supplemental Security Income office);
	7. Barrier Identification	Identification of barriers to appropriate care (e.g., language, cultural beliefs, transportation, distrust/emotional barriers, medical system barriers, financial barriers)
	8. Emotional Support	Serve as a trusted confidant; listen to family’s concerns, frustrations, and fears and offer coping strategies to reduce stress and anxiety
	9. Care Coordination	Care coordination for the entire family and the provision of a necessary link to community-based resources
Navigator Tools	10. Navigator Workbook	The Navigator Workbook contains: a template for creation of a family-specific action plan to improve access to care; MI training manual; psychoeducational materials related to ASD and early intervention (e.g. Center for Disease Control Act Early campaign materials) and family resources (e.g., housing, social security applications).
Training & Supervision; Navigator Tools	11. Navigator Checklist	Checklist of family-specific navigator tasks (e.g., helping to schedule appointments)