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Overcoming tensions between family centered care and fidelity within Early Intervention implementation research

The past decade has brought heightened awareness of the need to efficiently translate evidence-based practices (EBPs) into community systems that serve autistic individuals and their families (Boyd et al., 2021). Indeed, access to EBPs before age three has been shown to produce quantifiable gains and cost saving for autistic children and their families (Cidav, Munson, Estes, Dawson, Rogers & Mandell, 2017, Zwaigenbaum et al., 2015). The Public Early Intervention (EI) system has been a focus of translational efforts, as it is federally mandated to provide therapeutic services to children 0-3 years with developmental delays under Part C of the Individuals with Disabilities Education Act. In 2020, 427,234 children were served within EI systems (ECTAC, 2022) and upwards of 10% of children served in this setting have an increased likelihood of being autistic (Eisenhower et al., 2020). Thus, the EI system serves as an entry point to services and a delivery context for first line interventions during a critical window of early development and often prior to children receiving a medical diagnosis of autism spectrum disorder (Maenner et al., 2021).

Part C, Early Intervention systems are perceived as a promising setting in which to implement EBPs for autism, yet implementation efforts seldom account for the unique service delivery model of EI systems. That is, in addition to funding constraints and workforce-related issues (Aranbarri et al., 2021; Noyes-Grosser, Benham, & Osbahr, 2018), EI systems embody family-centered care, an emphasis which may at times pose tradeoffs to the implementation of manualized EBPs. Family-centered care is “an approach to working with families that honors and respects their values and choices and which includes the provision of supports necessary to strengthen family functioning” (Dunst, 2007). This family-centered approach stems from parent

advocacy movements in the 1970s, which contributed to legislative changes, like the Individuals with Disabilities Education Act (IDEA). Passed in 1990 to support the free and appropriate education of children with developmental disabilities (Yell, Rogers, & Rogers, 1998), Part C of IDEA specifies minimum standards that must be implemented by each state's EI system, including timely and comprehensive multidisciplinary evaluation, family-directed identification of goals and needs, and a family service plan and service coordination [IDEA, 2004; 20 U.S.C. §1435(a)]. Over time, the integration of family-centered care within EI systems has been interpreted as delivering services in a manner that is individualized, flexible, and responsive to each family's unique circumstances, that provides family members complete and unbiased information to make informed decisions about intervention, and that involves family members in acting on their choices to strengthen child, parent, and family functioning (Division of Early Childhood, 2014; Tomasello et al., 2010). Specific family-centered strategies may include allowing family members to voice what is important to them, asking caregivers for their advice and opinions, allowing families to guide the selection of treatment goals, and suggesting intervention activities that fit within a family's lifestyle (Cunningham & Rosenbaum, 2014). The delivery of family-centered care is associated with important family outcomes, including satisfaction with services, access to care, and overall family wellbeing (Kuhlthau et al., 2011; Ngui & Flores, 2006)

The principles of family-centered care are central to EI systems and, thus, are pertinent to consider within intervention research being conducted within these systems. This commentary highlights family centered care as an important factor of service delivery in EI systems that deserves greater attention and study. We lay out how family-centered care provides a framework for evaluating EBP adaptation in EI systems, how it may impact the adoption and

implementation of EBPs, and directions for future research to evaluate the impact of family centered care alongside EBP delivery. Although other autism and mental health interventions are implemented within EI systems (Aranbarri et al., 2021; McNeil et al., 2016), we specifically focus on parent-mediated naturalistic developmental behavioral interventions (NDBIs; Schreibman et al., 2015) given the evidence base for NDBIs in improving outcomes of autistic children (Sandbank et al., 2020), and growing interest in transporting these models into EI systems.

To date, efforts to transport NDBIs into EI systems have largely focused on training EI providers to coach parents to deliver NDBIs at fidelity, with an emphasis on evaluating the associated caregiver and child outcomes (Rogers et al., 2022; Stahmer et al., 2020). Findings have demonstrated that EI providers significantly improve their fidelity to parent coaching in NDBIs, particularly when they receive intensive training and ongoing consultation (Rogers et al., 2022; Stahmer et al., 2020). Further, implementation efforts in EI systems have resulted in good reach, with 6 times the number of children receiving NDBIs four years following implementation efforts (Rieth et al., 2022). However, EI providers' fidelity to coaching parents in NDBIs has not consistently predicted caregivers' learning and use of specific intervention strategies (Stahmer et al., 2020), or ratings of intervention acceptability (Rogers et al., 2022). Further, the primary emphasis on intervention fidelity appears misaligned with EI providers' perception that it is essential to adapt manualized EBPs in response to the values, goals, and priorities of families served in EI systems (Pickard et al., 2021).

Evaluating family-centered care may address this misalignment by providing a framework to understand and evaluate the balance between fidelity and flexibility, which has been a longstanding area of discourse within evidence-based medicine (Sackett et al., 1996).

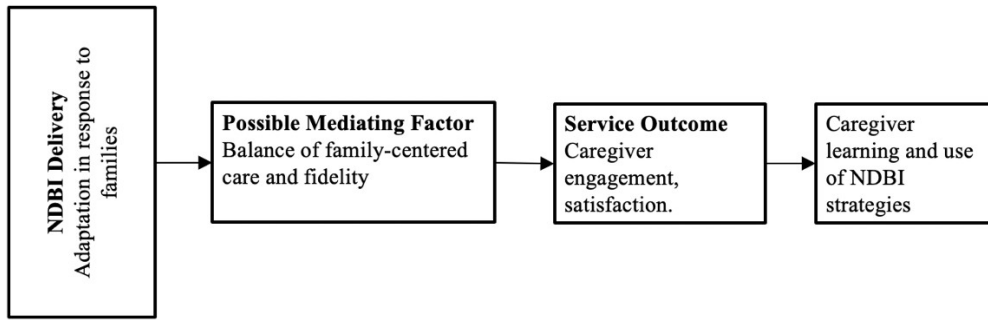
Although there is increasing interest within implementation science to document intervention adaptations and their impact on both the form and function of the intervention (i.e., fidelity; Chambers & Norton, 2016; Kirk et al., 2020), the extent to which adaptations are made in response to or in collaboration with individual patients or families is not fully integrated as an implementation process. Family-centered care, and in particular adaptation in response to the needs, values, or priorities of a family can provide a frame for evaluating the dynamic process of service delivery between families and providers that is at the heart of the system itself.

Measuring family-centered care may also provide important information regarding the adoption and delivery of NDBIs within EI systems. This is particularly important given the relatively narrow scope of these intervention models, with many exclusively emphasizing the development of social communication skills (Schreibman et al., 2015). Given that social communication skill development may not be a top priority for every family, family-centered care may impact the extent to which manualized NDBIs are adopted by EI providers (Pickard et al., 2021). Once adopted, the integration of family-centered care may also shape the delivery of NDBIs in ways that both enhance and attenuate family outcomes. For example, within NDBI delivery, the provision of family-centered care may include responding to caregivers' questions and goals not related to the content of NDBIs (e.g., feeding, toileting, navigating a diagnostic evaluation), to emergent events that disrupt NDBIs (e.g., challenging behaviors, caregiver mental health, housing insecurity), and to caregivers' cultural preferences within the NDBI itself (e.g., emphasizing intervention strategies that support following directions; Pickard et al., 2022). In these instances, it is possible that addressing a family's needs and priorities (i.e., using other clinical tools to deliver family-centered care) may enhance caregiver engagement and empowerment within NDBIs, leading to more effective intervention, even if these collaborations

may result in pauses of NDBI delivery or the integration of content unrelated to the intervention itself (Pickard et al., 2022).

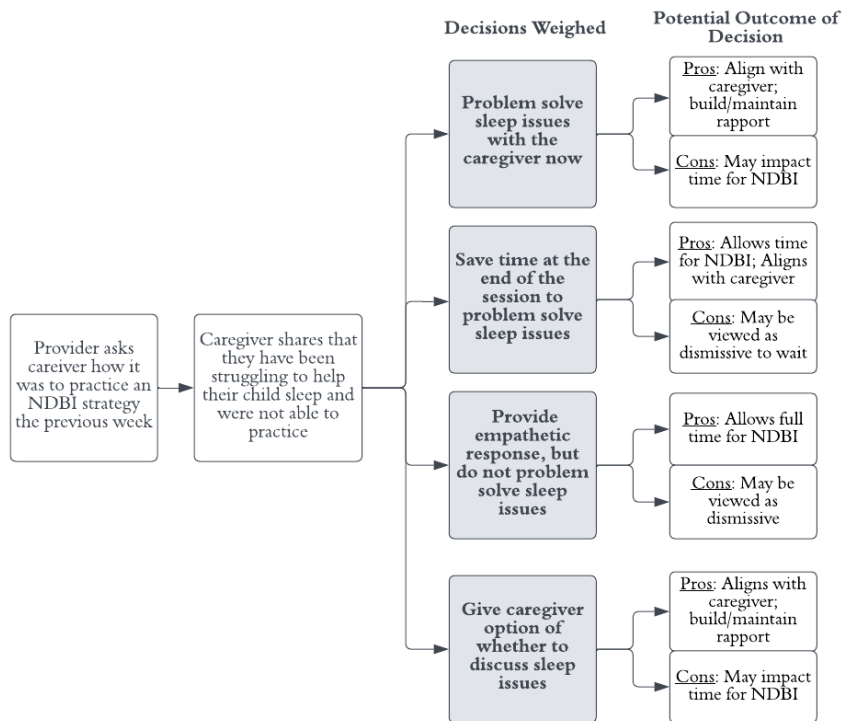
On the other hand, an overemphasis on family-centered care may result in more significant departures from NDBIs in a way that is perceived to follow a family's lead but that does not support child development and/or intervention fidelity. For example, providers may not adopt or deliver NDBIs operating under the bias that families may not desire or benefit from a family coaching model (Tomczuk et al., 2021). This gatekeeping under the pretense of family-centered care may also result in failure to deliver certain intervention strategies under the assumption that a family already knows or would not benefit from learning them (Pickard et al., 2022), or that the specific strategy may not fit the family's culture or beliefs. Thus, effective partnership between families and clinicians is critical to balance family-centered care with EBPs. As Figure 1 displays, this balance of family-centered care and NDBI fidelity may mediate the relationship between NDBI delivery and service outcomes, including caregiver engagement and satisfaction. The representation in this figure is consistent with and expands upon existing adaptation models, such as the Model of Adaptation Design and Impact, that specifies factors that may mediate and moderate the relationship between intervention adaptation and service outcomes (Kirk et al., 2020).

Figure 1. The mediating role of family-centered care in NDBI outcomes within EI systems



Moving forward, it is critical to better conceptualize and measure the extent to which family-centered care impacts the adoption of NDBIs in EI systems and, once adopted, the extent to which the core content of NDBIs is balanced with the needs and priorities of families, and particularly those which may not be captured within the relatively narrow scope of NDBIs. For example, if an EI provider responds to a family’s questions about their child’s poor sleep or their acute stress related to housing eviction, it is necessary to understand the decisions that providers weigh in these moments and their relationship to NDBI fidelity. Some decisions may result in departures or pauses in NDBIs to support parent concerns, whereas others may result in the adaptation of NDBI content without departing from the intervention itself (e.g., repeating content based on caregiver questions or preferences). Figure 2 displays just one example of the decisions a provider might weigh in response to a family’s question, and the perceived impact of these decisions on NDBI delivery. Similar examples could be generated in response to a caregivers’ mental health/behavior, to a disclosed stressor, and to a family’s cultural values.

Figure 2. Possible decisions that are weighed to balance NDBI fidelity with family-centered care



Although autism research has advocated for the delivery of family-centered care (Gabovitch & Curtin, 2009) and has examined provider and caregiver perspectives of NDBI packages (Haine-Schlagel et al., 2020; Pickard et al., 2016; Stahmer et al., 2011), it has yet to examine family-centered care and clinical decision-making within NDBI and its impact on

intervention delivery. Measuring the integration of family-centered care within NDBIs can occur in several ways. First, caregiver perceptions of therapeutic responsiveness within the context of NDBIs can be assessed to understand the extent to which the intervention is delivered and adapted such that it aligns with their goals and priorities. There are several validated measures of family-centered care that could serve this purpose by assessing the extent to which caregivers perceive that an EI provider has partnered with their family to deliver responsive care (Cunningham & Rosenbaum, 2014), and cognitive interviewing to understand how caregivers complete these measures. Including measures like this within NDBI intervention and implementation research, particularly within EI systems, may help to determine the integration of family-centered care mediates the relationship between NDBI delivery and caregiver outcomes.

In addition to caregiver-report measures, the integration of family-centered care might be measured qualitatively by asking caregivers their goals for an EI session (e.g., patient defined outcomes) and the extent to which those goals are achieved at the conclusion of both the NDBI session and program participation. Data regarding what the provider hoped to accomplish within an NDBI session, how the session played out, and the decisions they weighed within intervention delivery could be collected as well. These qualitative data could highlight adaptations made in response to the needs and values of families and, importantly, the decision that providers weigh within their delivery of NDBIs. Decisional data may be particularly useful to generate hypotheses aimed at refining NDBI fidelity measures. For example, if EI providers ultimately pause NDBI delivery to respond to a family's questions and concerns, and the rationale for doing so is to support caregiver engagement and satisfaction, this understanding may justify empirical examination of whether these responsive pauses do indeed support caregiver engagement and how best to optimize these responses within the delivery of NDBIs. It is important to note that

some research groups have used behavioral coding systems to examine similar questions regarding how providers respond to emergent stressors within intervention sessions (Lind et al., 2020). A similar but expanded coding system may be useful to capture how EI providers respond to a variety of situations.

Finally, chart review may be a naturalistic method to examine the extent to which family-centered care is delivered alongside evidence-based practice. Chart review might include comparing the outcomes reported within an NDBI to those written into an Individualized Family Services Plan (IFSP) created with families at the start of their participation in EI. This type of review may provide insight into the alignment of NDBI with a family's priorities for their child.

In sum, the delivery of family-centered care is central to EI systems, which encourages the delivery of services that are individualized, flexible, and responsive to each family's unique circumstances. Measuring family-centered care as part of research within these systems will provide a more accurate representation of how NDBIs are delivered and the impact of family-centered care on EBP adoption and delivery. Such an approach can shift the autism field to a more balanced view of fidelity as both delivering core EBP components in a manner that closely aligns with fundamental tenants of EI systems. It will also advance the development of adaptive interventions that are user-centered and, thus, able to be focused on the most common needs expressed by families receiving services within EI systems.

Stakeholder Involvement:

This manuscript was written with the support of autistic adults, caregivers, providers, EI administrators, and researchers who are members of Emory's Early Intervention Community Advisory Board. This board provided input on the ideas presented in this commentary and

reviewed its content. Specific contributors include Patrick Thorbourne, Cidjah Rodney-Somersall, Michael Morrier, Patricia Moran, and Nicole Hendrix.

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