



Increasing global access to early intervention for young children with ASD

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Comment on: Ramseur K, de Vries PJ, Guler J, *et al.* Caregiver descriptions of joint activity routines with young children with autism spectrum disorder in South Africa. *Pediatr Med* 2019;2. doi: 10.21037/pm.2019.03.04.

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In their recent paper, “Caregiver descriptions of joint activity routines with young children with autism spectrum disorder in South Africa”, Ramseur and colleagues examined the applicability of an early intervention model for children with autism spectrum disorder (ASD), which was developed and validated in more highly resourced settings, to the diverse cultural context of South Africa (1). They highlighted the importance of this work by noting the dearth of ASD research on the African continent; for example, Africa is yet to see an ASD prevalence study, and as of 2017, a scoping review identified only 53 peer-reviewed publications on ASD published in sub-Saharan Africa (2). Moreover, none of the publications focused on early intervention in Africa. Thus, Ramseur *et al.*'s study represents an important step forward in addressing the needs of children with ASD in South Africa.

Caregiver coaching methods of early intervention offer a promising approach to intervention delivery in South Africa. Caregiver-mediated interventions allow a single therapist (i.e., caregiver coach) to reach a wider range of families in a more cost-effective manner compared to interventions delivered directly to a child by the therapist, which is critical in a geographical area characterized by scarce services. When considering potential models of intervention, Naturalistic Developmental Behavioral Interventions (NDBIs) (3) stand out as strong contenders, given that caregivers are afforded the opportunity to embed teaching strategies in the context of typical daily routines. However, as the overwhelming majority of research on NDBIs has been conducted in settings that are well-resourced, the appropriateness of an NDBI such as the

Early Start Denver Model (ESDM) (4) in a South African setting remains to be evaluated. This study aimed to address this question.

The study was conducted in Cape Town, South Africa, which is a capital city characterized by a culturally and linguistically diverse population, with limited availability of diagnostic and intervention services for ASD (5). In order to better understand whether the type of daily routines that are emphasized in many NDBI interventions, such as ESDM, would map on to typical caregiver-child interactions in South Africa, focus groups were conducted with 22 caregivers of children with ASD between the ages of 24 and 59 months. Groups provided information on common caregiver-child play and daily routines, and transcripts were analyzed using content analysis. Predetermined initial themes were established based on ESDM joint activity routine categories of object-based play, sensory social routines, and family routines.

The authors found that caregivers of children with ASD in South Africa engage in similar joint activity routines with their children to those used in more highly resourced countries, suggesting a strong fit between current caregiver-child interactions in South Africa and a caregiver coaching intervention approach consistent with an NDBI framework. In particular, caregivers described object-based play (e.g., dyadic interactions, caregiver incorporating learning into play, caregiver joining in play), sensory social routines (e.g., awareness of affect and social cues, variety of play participants), and family routines (e.g., mealtime routines, bath time routines). Caregivers offered rich examples of daily interactions with their children including prayer time,

washing dishes, playing with cousins, chase games, and imaginative play. Having established the similarity between joint activity routines in ESDM and in diverse settings in South Africa, these findings support the validity and feasibility of local implementation of ESDM.

This study makes an important contribution to science in a region marked by gaps in understanding how cross-cultural variation may inform prevalence, treatment, and developmental trajectories related to ASD. Caregivers who participated in this study came from a variety of ethnic backgrounds, had no prior exposure to NDBIs, and ranged in their experience with other types of intervention. Findings revealed that common joint activity routines in a low resource setting such as South Africa appear similar to those in high resource settings in which much of the validation work has been conducted.

The study shed light on a fundamental aspect of how NDBIs are delivered in the home, namely, on the appropriateness of joint activity routines. Future research is needed to explore how other aspects of a low resource setting might affect the applicability of a caregiver coaching approach. As noted by Ramseur and colleagues, caregivers themselves indicated that culture and language can present barriers to successful early ASD intervention, emphasizing that some features of child rearing/kinship practices (e.g., interdependent nature of the culture, necessity of having a diverse set of caregivers in societies with high rates of communicable disease/early death) are important contextual factors that should be considered. It will be important to explore whether there exist specific challenges when actually implementing the intervention in a low resource setting. For example, does availability of access to materials (e.g., toys, children's books) determine whether an NDBI might be an appropriate intervention to consider? Similarly, it will be important to understand how a caregiver's level of literacy/education might impact the likelihood of their ability to engage in a caregiver coaching intervention. These are among a number of considerations or adaptations that remain to be evaluated in a setting where resources are limited relative to those where empirical validation was conducted, many of which are outside the scope of Ramseur and colleagues' paper. This work nevertheless represents a significant advance in understanding the suitability and feasibility of implementing interventions developed in highly resourced countries in areas such as Africa. Similar research is needed in other low resource regions to better understand the

generalizability of Ramseur *et al.*'s findings.

In recent years, there has been an increased focus on identifying challenges and opportunities to build research services across the globe, especially in low resource settings. Durkin and colleagues highlighted disparities in access to autism screening, diagnosis, and treatment worldwide, and identified the high cost of proprietary tools for diagnosis and for delivering therapies, and high costs of training as barriers contributing to the imbalance (6). Similarly, in a 2016 review paper, de Vries emphasized the great need for increased capacity for high-quality research in low resource settings such as South Africa (7). Ramseur *et al.*'s study underscores the importance of assessing the applicability of interventions to diverse populations and cultures, rather than assuming all features and active ingredients are relevant. In terms of clinical implications, this line of research seeks to increase access to services for individuals affected by ASD in Africa; the study advances work toward improving access. Policy implications, similarly, continue to indicate a need for greater ASD research in low- and middle-income countries, as has been suggested for several years (8). Various initiatives to expand research infrastructure are underway, including Autism Speaks' Global Autism Public Health Initiative (GAPH) (9), as are initiatives to expand evidence-based guidelines aimed at non-specialists for managing developmental disorders (10). Yet more work remains to be done. Policymakers are strongly encouraged to consider locally relevant ASD research when establishing priorities, in an effort to ensure that individuals on the spectrum are able to access appropriate supports and maximize their potential.

In conclusion, Ramseur and colleagues demonstrated that low resource environments may be able to make use of interventions and other tools developed in high resource settings, given that their cross-setting applicability is assessed. Modifications may be necessary to accommodate cultural or linguistic needs, should this be identified as a potential barrier to implementation. Further, devoting greater attention to conducting research in geographic areas where previous ASD research has been inadequate to date will serve to enhance our understanding of what it means to be affected by ASD in settings with scarce resources, and how disparities and barriers to diagnosis and treatment may be reduced. We are reminded of the importance of viewing ASD from a cultural lens, and bearing in mind the biopsychosocial factors that contribute to an individual's ability to access and benefit from appropriate services.

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