



## INSAR 2016 Summer Institute

### Session III: Parent and Family-Led Interventions

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1:00 pm EDT

#### Course Materials

The purpose of these materials is to help provide an introduction to the Summer Institute session on parent and family-led interventions. The materials were designed to prepare trainees who are unfamiliar with research using parent and family-led interventions with the general background to get the most educational benefit from Dr. Kasari's presentation. Toward this objective, we have prepared the following: (1) learning objectives for this session; (2) some key terms and concepts to become familiar with parent and family-led intervention research; (3) some broad review articles that are recommended reading. These materials could be considered "prerequisites" in preparing for Dr. Kasari's presentation.

In collaboration with Dr. Kasari, these materials were developed by the trainee group for this session: **Kyle Sterrett** (Doctoral student at UCLA; [ktsterrett@ucla.edu](mailto:ktsterrett@ucla.edu)), **Stephanie Shire** (Postdoc at UCLA; [spatterson@mednet@ucla.edu](mailto:spatterson@mednet@ucla.edu)), **Alan Gerber** (Doctoral student at Stony Brook University; [Alan.Gerber@stonybrook.edu](mailto:Alan.Gerber@stonybrook.edu)) and **Debra Prykanowski** (Doctoral student at University of Florida; [dprykanowski@ufl.edu](mailto:dprykanowski@ufl.edu)). Feel free to contact us with questions/comments.

Register for this course and other sessions in this series at [www.autism-insar.org/research-opportunities/summer-institute2016](http://www.autism-insar.org/research-opportunities/summer-institute2016).

## Learning Objectives

The Summer Institute for Autism Research was established in direct response to requests from early career researchers (graduate students, postdocs, etc.), who asked INSAR for greater training opportunities in multidisciplinary topics. In designing the Summer Institute, the priorities were: (1) to provide a multidisciplinary training platform for young scientists from various backgrounds; (2) allow international participation; and (3) make it freely available. Thus, the Summer Institute covers broad topics (which are geared to researchers outside the respective topic areas), is offered over a free web platform, and allows researchers from around the world to connect with the presenter. The overarching goal of the Summer Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists could learn from each other to ultimately advance the understanding of autism spectrum disorders.

The current session, Parent and Family-Led Interventions, is led by Connie Kasari and a team of trainees who worked in tandem to prepare these materials and the web presentation. The learning objectives for attendees of this session include:

- To obtain a broad overview of the current research and evidence-base for parent mediated interventions for children with autism spectrum disorders.
- To gain an understanding of the intervention goals of parent-mediated interventions targeting social communication, and to appreciate the importance of selecting developmentally appropriate outcomes.
- To learn about the wide range of formats, settings, and active ingredients utilized in parent-mediated interventions through high quality randomized controlled trials.
- To discuss how success is measured in parent mediated interventions both in terms of parent and child outcomes.
- To receive a brief overview of JASPER, an intervention targeting core social communication deficits, in the context of a parent mediated intervention.
- To delve more deeply into areas of research such as the development of play skills and Naturalistic Developmental Behavioral Interventions that are the expertise of the presenter, Dr. Connie Kasari.

## Glossary of Terms

Below is a breakdown of some of the technical terminology used in this session.

- **Active Ingredients:** The specific strategies or components that make up an intervention approach.
- **Adherence:** The accurate completion of intervention protocol by the parent. Can be broken into two categories, adherence to treatment and adherence to dosage:
  - Treatment Adherence: Bleeding between conditions (accessing treatment they are not assigned), dropping out because of undesirable treatment allocation.
  - Dosage Adherence: Completion of the recommended amount and frequency of intervention hours by parents.
- **Parent Education Model:** Group and individual intervention in which the parent receives educational material that may include a range of content from basic psychoeducation (i.e. what is autism?) through specific strategies to learn a target intervention. Does not provide coaching to support the parent's delivery of the intervention directly with the child. This form of intervention can be less resource intensive.
- **Parent Mediated Model:** Intervention in which the parent receives in-vivo coaching sessions to learn how to carry out the target intervention directly with their child. Allows parent to practice and get feedback from interventionist but can be more resource intensive than parent education models.
- **Comprehensive Treatment Models:** A set of interventions and practices that are designed to influence children's development and learning across multiple dimensions (e.g., cognition, communication, adaptive behavior).
- **Dose:** The frequency and length of the intervention.
- **Joint Attention:** Discrete pre-linguistic (e.g., coordinated joint looks; points to share, gives to share, shows to share) or linguistic skills (e.g., spoken word to comment, augmented word to comment) for the purpose of socially sharing with others. A shared triadic interaction between two people and an object or event (e.g., child points to a bird to share it with their caregiver).
- **Joint Engagement:** Child and partner are actively involved with the same object or event. The child shows awareness of his partner (e.g., watches adult take a turn, imitates an action, imitates adult language model). Joint engagement can be divided into supported and coordinated joint engaged states:
  - **Supported Joint Engagement:** Child and partner are involved with same object and/or event. The child shows awareness of the partner and shared activity but does not direct or coordinate the activity.
  - **Coordinated Joint Engagement:** The child and partner are actively involved with the same object or event, and the child is actively and repeatedly acknowledging the partner's participation by coordinating his or her attention to both another person and an object or event they are sharing (e.g., child and adult are playing with blocks. The child gives the adult a block to stack for the purpose of sharing and inviting the adult to play.)
- **Maintenance:** Whether a skill taught as a part of an intervention protocol is still mastered after support from intervention staff is removed.
- **Naturalistic Developmental Behavioral Interventions (NDBI):** Interventions implemented in natural settings, that involve shared control between child and therapist, utilize natural contingencies, and that use a variety of behavioral strategies to teach developmentally appropriate and prerequisite skills

- **Parental Synchrony:** Responsiveness of parents to children's attention and actions during play. It has been shown to be predictive of language growth and engagement but has been operationalized differently across studies:
  - Synchronous communication acts: Verbal or non-verbal, non-directive communication acts, comments, statements or acknowledgement, which maintain the flow and follow the child's focus of attention. (Pickles et al., 2015)
  - Parental responsivity: A parent-child interaction style characterized by warmth, nurturance, and stability as well as specific behaviors, such as contingent positive responses to child initiations (Brady et al., 2014).
  - Behavior synchrony: The proportion of undemanding caregiver shows, points, and verbal labels towards an object of interest to the child to the amount of time the child's attention was directed towards a toy (Siller et al., 2002).
  - Responsive Teaching: Parents who are highly responsive to their children's verbal and nonverbal attempts to communicate. Treating all attempts at communication as legitimate communication, even if the intentions were unclear (Mahoney et al., 2006).
- **Randomized Controlled Trial:** A study in which participants are allocated by chance into different conditions (e.g. treatment and control groups). This allows treatment effects to be attributed to the intervention with a higher degree of confidence. It is the gold standard for clinical trials.
- **PRT:** Pivotal Response Treatment. (Refer to Minjarez et al., 2011 for more information).
- **ESI:** Early Social interactions. (Refer to Wetherby et al., 2014 for more information)
- **PACT:** Parent Mediated communication-focused treatment. (Refer to Green et al., 2010 for more information).

### **Background Readings:**

- Gulsrud, A. C., Helleman, G., Shire, S., & Kasari, C. (2015). Isolating active ingredients in a parent-mediated social communication intervention for toddlers with autism spectrum disorder. *J Child Psychol Psychiatr Journal of Child Psychology and Psychiatry*, 57(5), 606-613. doi:10.1111/jcpp.12481
- Kasari, C., Lawton, K., Shih, W., Barker, T. V., Landa, R., Lord, C., . . . Senturk, D. (2014). Caregiver-Mediated Intervention for Low-Resourced Preschoolers With Autism: An RCT. *Pediatrics*, 134(1). doi:10.1542/peds.2013-3229
- Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Evid.-Based Child Health Evidence-Based Child Health: A Cochrane Review Journal*, 8(6), 2380-2479. doi:10.1002/ebch.1952

### **Further Readings**

- Dunst, C. J., Trivette, C. M., & Raab, M. (2013). An Implementation Science Framework for Conceptualizing and Operationalizing Fidelity in Early Childhood Intervention Studies. *Journal of Early Intervention*, 35(2), 85-101. doi:10.1177/1053815113502235
- Green J, Charman T, McConachie H, Aldred C, Slonims V, Howlin P, et al. Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *Lancet* 2010;**375**(9732):2152-60.
- Hardan, A. Y., Gengoux, G. W., Berquist, K. L., Libove, R. A., Ardel, C. M., Phillips, J., . . . Minjarez, M. B. (2014). A randomized controlled trial of Pivotal Response Treatment Group for parents of children

with autism. *J Child Psychol Psychiatr Journal of Child Psychology and Psychiatry*, 56(8), 884-892. doi:10.1111/jcpp.12354

- Minjarez, M. B., Williams, S. E., Mercier, E. M., & Hardan, A. Y. (2011). Pivotal Response Group Treatment Program for Parents of Children with Autism. *J Autism Dev Disord Journal of Autism and Developmental Disorders*, 41(1), 92-101. doi:10.1007/s10803-010-1027-6
- Nix, R. L., Bierman, K. L., & McMahon, R. J. (2009). How attendance and quality of participation affect treatment response to parent management training. *Journal of Consulting and Clinical Psychology*, 77(3), 429-438. doi:10.1037/a0015028
- Stadnick, N. A., Stahmer, A., & Brookman-Frazee, L. (2015). Preliminary Effectiveness of Project ImPACT: A Parent-Mediated Intervention for Children with Autism Spectrum Disorder Delivered in a Community Program. *J Autism Dev Disord Journal of Autism and Developmental Disorders*, 45(7), 2092-2104. doi:10.1007/s10803-015-2376-y
- Wetherby, A. M., Guthrie, W., Woods, J., Schatschneider, C., Holland, R. D., Morgan, L., & Lord, C. (2014). Parent-Implemented Social Intervention for Toddlers With Autism: An RCT. *Pediatrics*, 134(6), 1084-1093. doi:10.1542/peds.2014-0757
- <http://www.kasari.org/>