Background

Research has consistently demonstrated that caregiver education of early milestones is associated with feelings of competence and skill building in their children (Schafer, 1991). Gaps in knowledge regarding child development often act as barriers to seeking developmental evaluations and early intervention (EI) services to address delays in early childhood (Reyes et al., 2018).

Autism Spectrum Disorder (ASD) is the fastest growing neuro-developmental diagnosis in the United States (Maenner et al., 2020). Per the most recent estimates, the median age of diagnosis is 31 months; however, ASD can be reliably diagnosed early in toddlerhood by trained professionals (Maenner et al., 2020). Earlier diagnosis and participation in EI services during the period of birth to three years old have been associated with developmental skill building and reducing connection among families (Fuller & Kaiser, 2018).

Project Aims

- To examine the impact of parent education on: 
  - Parent understanding of child development, skills, and perceived concerns
  - Caregiver effectiveness between parent and clinician
  - Examine the association of: 
    - Parent knowledge with parent reported stress and parent confidence in supporting their child

Hypotheses

- Parent education regarding concerns specific to their own child (through use of the CADE tool) will increase parent knowledge over time.
- Parent and clinician views on a child’s skills and challenges will be in greater alignment over time (using the CADE tool symptom profile).
- As parents become more knowledgeable by using the CADE tool, parental stress will decrease over time.

Project Introduction

The CLEAR Autism Diagnostic Evaluation (CADE) is an assessment that measures 11 domains of child development as reported by primary caregivers and clinicians (Waller & Korley, 2019). Used with families regardless of a child’s diagnosis or delay, this is a 35-item rating scale designed to educate caregivers on these 11 domains and sub-domains that are often affected in ASD. The CADE is designed for use with individuals ages 24 months and older. Findings from the CADE have been highly correlated with the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), which is a highly reliable and valid tool to diagnose ASD (Crepeau-Hobson et al., 2021).

The 11 domains of development as measured by the CADE include: (1) Understanding, (2) Learning, (3) Communicating, (4) Socializing, (5) Daily Living, (6) Moving and Sensing, (7) Focusing, (8) Remembering, (9) Eating and Feeding, (10) Pacing. Through assessment of a child in each of these areas, the CADE seeks to provide a holistic understanding of a child’s strengths and challenges through graphical pictures [see figures 1 and 2], next steps, and intervention recommendations.

The present study sought to use the CADE with families participating in EI Colorado services.

Participants

Up to 25 clinicians will be recruited and enrolled from ENRICH and Rocky Mountain Human Services (RMHS). ENRICH is a grant-funded team of early intervention service providers for the University of Colorado Anschutz Medical Campus within 3JH Partners. RMHS is the Community Centered Board (CCB) that enrolls EI programming within Denver County.

Clinician Inclusion Criteria:

- ACP-CPC/CEM/CRC/CBCA contracted to provide EI services:
  - Licensed clinician holding accreditation
  - Providing in-person or telehealth services to children 2 years, 0 months to 3 years, 0 months for minimum of 2 months visits
  - Willing to ask caregivers on care teams to participate in study
- Between the age of 18 and 88 years

Caregiver Inclusion Criteria:

- Parents or caregivers (with or without ASD) of children receiving EI services from a clinician:
  - Care for a child age 2 years, 0 months to 3 years, 0 months
  - Will participate in EI services with the clinicians for services for at least 10.5 months over the course of 5-6 months
- Between the ages of 18 and 88 years

Methods

This study is currently in the pre-psychometric phase. Participating clinicians were randomized in two CADE trainings. The Parenting Stress Index, 4th Edition (PSI-4) is a standardized assessment that will be used to measure beliefs and behaviors that impact children’s development in the five domains: (1) Parental Distress, (2) Parent-Child Dysfunctional Interaction, and (3) Difficult Child. During pre-trainings, 1 and 2, clinicians and caregivers will complete the CADE separately and discuss perspectives, personal concerns, and the clinician’s results within at least three areas, including (4) Socializing, (5) Understanding, (6) Communication, (7) Learning, and (8) Socializing. For the study, this is an additional domain, and (9) one other domain to guide education and intervention (see figures 1 and 2) Clinician surveys, surveys, and data collection are managed through REDCap, and the PSI-4-5 will be completed online via the REDCap database.

Outcome Measures

- CADE Training Read Competency
- Communication of caregiver competency of CADE following self-paced training modality
- Caregiver demographic survey
- Caregiver knowledge survey
- CADE activity report documented on pre- and post-trainings
- Parenting Stress Index, 4th Edition, Short Form
- Clinician and caregiver dependency in CCB determined pre- and post-study
- CADE Clinician Survey, CCB

Data Analysis and Next Steps

This data is ongoing with rolling clinician and caregiver recruitment. Clinicians and caregivers will be surveyed to report perceptions of perceived knowledge of child development and reliability between clinicians and caregivers. Description and inferential statistics will be used to describe information presented in pre- and post-study measures.

References


Acknowledgements

Thank you to Jaya Bhakta, OTR/L, Jaya Bhakta, OTD, OTR/L 3JF Partners, University of Colorado School of Medicine.