ECIDC Early Childhood Intervention Doctoral Consortium

Creating Leaders in Intensive Interventions for Infants, Young Children and Their Families

Case Study: Intellectual Disability

Part 1: Getting to Know Eli

Eli and His Family

Eli (age 4) lives in a small rural town in Vermont with his mother, Rachel (29), father, Marcus (31), and younger brother, Noah (18 months). The Thompson family identifies as White and values outdoor activities, community involvement, and a simple lifestyle. They frequently spend time hiking, gardening, and attending local library events. English is the primary language spoken at home.

Rachel is a part-time librarian who adjusted her work schedule to accommodate Eli's therapy appointments. Marcus works full-time as a carpenter and often takes seasonal jobs to supplement the family's income. The Thompsons have limited access to specialized services due to geographic isolation and transportation challenges. They rely on telehealth consultations and occasional visits to a regional developmental clinic which was two hours away.

Eli is a gentle and curious child who enjoys water play, stacking blocks, and watching birds. He struggles with transitions and becomes distressed by loud noises or crowded environments. Rachel has noticed that Eli prefers predictable routines and often repeats actions, such as lining up toys or humming the same tune. He communicates primarily through gestures and a few vocalizations, and he uses a picture board to express basic needs.

Family routines are structured around meals, outdoor time, and quiet evenings. Rachel incorporates sensory-friendly activities and uses visual schedules to support Eli's understanding of daily events. Despite her efforts, Eli's expressive language remains significantly delayed, and he often becomes frustrated when he cannot communicate effectively. Rachel has expressed feelings of guilt and isolation, especially when comparing Eli's development to his peers or explaining his needs to extended family.

Medical and Developmental History

Rachel's pregnancy with Eli was complicated by gestational diabetes and mild preeclampsia. Eli was born at 38 weeks via emergency cesarean section due to fetal distress. His Apgar scores were low, and he required oxygen support for the first 24 hours. Early signs of hypotonia and feeding difficulties prompted a referral to a neonatologist.

Eli struggled with sucking and swallowing, leading to poor weight gain and frequent hospital visits during his first year. He was diagnosed with global developmental delay at 18 months and began receiving early intervention services shortly thereafter.

Motor milestones were significantly delayed: Eli sat independently at 14 months, crawled at 20 months, and began walking at 30 months with an unsteady gait. He continues to receive physical therapy to improve balance and coordination. His fine motor skills are emerging, but he struggles with tasks like using utensils or manipulating small objects.

Eli's expressive language is limited to a few sounds and gestures. His receptive language is stronger; he responds to his name, follows simple directions, and shows interest in familiar routines. Behavioral observations include repetitive movements (e.g., hand flapping), sensory-seeking behaviors, and occasional self-injurious actions when overwhelmed.

At age 3, Eli underwent genetic testing due to persistent delays and distinctive facial features, including a broad forehead, low-set ears, and a flattened nasal bridge. Results confirmed a diagnosis of Smith-Magenis Syndrome, a rare chromosomal disorder associated with intellectual disability, sleep disturbances, and behavioral challenges.

Discussion Prompts:

- What systemic barriers might the Thompson family face in accessing specialized care for Eli's Smith-Magenis Syndrome?
- How can professionals support families in rural areas with limited access to developmental services?
- What questions might the early intervention team ask to better understand the Thompson family's routines, values, and priorities? Considering Eli's sensory sensitivities and rural environment, what strategies could help him engage more comfortably in community settings?

Part 2: Screening and Assessment

Following the genetic diagnosis, Eli's pediatrician referred the family to a multidisciplinary team for a comprehensive developmental evaluation. The team included a speech-language pathologist (SLP), occupational therapist (OT), and developmental psychologist. Assessments included the Vineland-3 Adaptive Behavior Scales and the WPPSI-IV, which confirmed significant delays in communication, motor skills, and social-emotional development.

The team observed Eli in his home environment and noted his reliance on visual supports, difficulty with transitions, and sensory-seeking behaviors. Rachel shared her strategies for calming Eli, including weighted blankets, quiet music, and nature walks. The professionals praised her intuitive parenting and emphasized the importance of embedding interventions into daily routines.

The assessment concluded that Eli would benefit from continued early intervention services, including speech therapy, occupational therapy, and behavioral support. The team recommended parent coaching and the use of augmentative and alternative communication (AAC) tools, such as PECS and visual schedules.

Discussion Prompts:

- How can professionals ensure that assessments are culturally and contextually sensitive for families in rural settings?
- What strategies can providers use to help families feel comfortable sharing concerns and participating in the evaluation process?
- How can interdisciplinary teams support families who may be unfamiliar with developmental milestones or hesitant to seek services?

Part 3: Transition Planning from IFSP to IEP

As Eli's developmental profile became more defined, the early childhood special education team shifted their focus toward strategies that could be naturally woven into the rhythms of daily life. Living in a remote part of Vermont, the Thompsons faced significant barriers to accessing in-person services and the family preferred to have Eli stay home with them and receive his services there. Long drives to regional clinics were exhausting and infrequent, and local resources were limited. In response, the team embraced telehealth consultations as a lifeline, one that not only brought expertise into the home but also empowered Rachel to take the lead in Eli's developmental journey.

Rachel quickly emerged as the primary interventionist, a role she embraced with both determination and vulnerability. During their first virtual planning session, she shared her hopes for Eli with quiet clarity. She wanted him to be able to express his needs and preferences, especially during moments of frustration. She hoped he could participate more fully in family routines, like mealtimes and outdoor play, and she longed for ways to help him navigate transitions without distress.

"I just want him to feel understood," she said, "and to enjoy the things we love as a family."

The team listened closely and helped Rachel shape these hopes into three primary goals:

1. Increase Eli's ability to communicate using visual supports and gestures.
2. Support Eli's participation in daily routines, especially those that bring the family together.

3. Reduce frustration and promote emotional regulation during transitions and unexpected changes.

Rachel emphasized her desire for naturalistic, play-based interventions specifically ones that honored Eli's love of nature, music, and sensory exploration. She also acknowledged the emotional toll of managing challenging behaviors, especially during moments when Noah needed attention or when the family ventured into public spaces.

Telehealth sessions were scheduled every two weeks, connecting Rachel with a developmental specialist and a speech-language pathologist. These virtual visits became a space for learning, reflection, and collaboration. The team modeled strategies for using PECS and visual schedules during meals and play, and coached Rachel on embedding communication prompts into everyday moments such as offering choices during snack time, narrating actions during gardening, and using simple signs during bath time.

Together, they tackled behavioral challenges like head banging and resistance to transitions. Using ABC logs, the team helped Rachel identify triggers and develop calming routines. They celebrated small victories like Eli pointing to a preferred toy, initiating a hug, or following a visual cue and reminded Rachel that progress often comes in quiet, powerful steps.

Rachel appreciated the flexibility of telehealth. Marcus occasionally joined sessions when his work schedule allowed, and the team used screen sharing to review Eli's progress and demonstrate new tools. They also offered asynchronous video feedback, inviting Rachel to record short clips of Eli's routines and receive personalized suggestions.

"I feel like I'm not alone in this," Rachel shared during one session. "Even when it's hard, I know what to try next."

The team helped Rachel embed interventions into Eli's natural environment:

- Visual Supports: Laminated picture cards and a portable choice board were used during meals, play, and transitions.
- Sensory Breaks: A cozy "calm corner" with soft textures, weighted items, and nature sounds gave Eli a safe space to self-regulate.
- Parent-Implemented Interventions (PII): Rachel used rhythmic songs, imitation games, and simple signs to encourage communication and engagement.
- Routine-Based Teaching: Therapy goals were integrated into gardening, birdwatching, and bath time, making learning meaningful and consistent.

Throughout the process, the team emphasized culturally responsive practices, validating Rachel's strengths and adapting strategies to fit the family's lifestyle. They connected the

Thompsons with a regional parent support network and provided printed resources on Smith-Magenis Syndrome, helping Rachel feel more equipped to explain Eli's diagnosis to others.

Discussion Prompts:

- How can teams effectively coach parents to become primary interventionists, especially in rural or underserved communities?
- What are the benefits and limitations of embedding interventions into daily routines versus using structured therapy sessions?
- What strategies can be used to build trust and empower families to actively participate in decision-making?
- What tools and techniques can be used to monitor progress and adjust interventions in a telehealth model?