Case Study: Spina Bifida (Myelomeningocele)

Part 1: Getting to Know Liam

Liam and His Family

Liam is a 4.5-year-old boy who lives in a suburban neighborhood in Seattle with his mother, Erica (34), and father, Matt (36). The family identifies as Asian American, both parents are Japanese, and they are actively involved in their local community. Erica works as a nurse at a nearby clinic, and Matt is a middle school math teacher.

Medical and Developmental History

Liam was diagnosed prenatally at 20 weeks of gestation with Spina Bifida – Myelomeningocele. His parents opted against in-utero surgery due to the risk of premature birth. As a high-risk pregnancy, Erica was monitored weekly by her obstetrician. At 30 weeks of gestation, Erica was hospitalized to ensure immediate access to the neonatal surgical team if premature labor occurred. At 34 weeks, Liam was delivered via C-section to minimize birth trauma.

Immediately after birth, the neonatal surgical team wrapped the exposed spinal cord, removed the meningocele sac, repositioned his spinal cord into the vertebral canal, and closed the spinal defect. A ventriculoperitoneal (VP) shunt was placed to manage hydrocephalus, a common complication of myelomeningocele. Liam remained in the NICU for five weeks due to prematurity, low birth weight, and the need for close monitoring following both surgeries. Upon discharge, he received nursing services three times a week for wound care and attended monthly appointments at the NICU follow-up clinic. When Liam returned home from the hospital, Erica decided to resign from her job to become his full-time caregiver.

During the first six months after surgery, Liam developed several complications, including a VP shunt infection that required a seven-day hospitalization and a shunt replacement. Following the surgery, Liam's pediatrician recommended early intervention (EI) services to Erica and Matt, explaining that Liam was eligible for these services. Liam entered Washington State's IDEA Part C early intervention program at eight months of age.

He continued to attend monthly NICU follow-up clinic visits to monitor his surgeries and paralysis associated with his myelomeningocele. He was also receiving weekly physical therapy through the NICU follow-up clinic. Liam's EI team received updates from the NICU follow-up clinic, as Erica and Matt had signed a HIPAA waiver allowing the medical team to share information with the EI providers after each visit. Liam's EI team visited him and Erica weekly at their home. The initial authentic assessment confirmed significant gross motor delays due to complete lower-limb paralysis and limited trunk stability. His fine motor control was impaired due to reduced hand strength and difficulties with bimanual coordination. Liam's cognitive development was mildly delayed, while communication and social-emotional skills were age-

appropriate. His most urgent needs, however, remained medical care, given the complex nature of the surgeries and high risk of infections. Liam also had a neurogenic bladder resulting from the nerve damage caused by the myelomeningocele that affected his bladder control, requiring regular catheterization and monitoring for recurrent urinary tract infections.

Given his health condition, his Individualized Family Service Plan (IFSP) prioritized health maintenance and safe healing, with weekly home visits provided by an occupational therapist and an early childhood special educator. Erica and Matt requested that Liam continue receiving physical therapy through the NICU clinic, and this was included in the IFSP. The primary goals of these sessions focused on improving his functional and developmental outcomes:

- Improving proximal stability and postural control to support transitions from supine to prone, rolling, and supported sitting using upper extremities.
- Increasing fine-motor precision, grasp efficiency, and bilateral coordination to support purposeful toy engagement and emerging self-feeding skills.
- Providing assistive technology for safe, supported movement-based experiences to promote sensory-motor exploration and participation in activities of daily living (e.g., progressive scooter-board training, initially receiving passive movement and later developing the ability to self-propel using upper-extremity strength and endurance).

When Liam was two years old, the family introduced a small, motorized ride-on car. Over time, Liam learned to independently operate the controls, providing him with an age-appropriate form of early powered mobility. This access to self-directed movement allowed him to engage with his family members and supported the development of emerging executive-function skills.

Liam transitioned to preschool services under IDEA shortly after his third birthday.

Discussion Prompts:

- What prenatal surgical intervention is available for fetuses diagnosed with myelomeningocele?
- How might Liam's family background and culture influence his family's participation in EI?
- In what ways might Liam's cultural background, family structure, and community involvement shape his parents' engagement with early intervention services, communication preferences, and decision-making processes?
- What factors should be taken into consideration when planning transitions across home, medical settings, and early childhood programs, particularly for children with complex medical needs and mobility impairments?

Part 2: Transition to Preschool

At the age of three, Liam transitioned from Early Intervention (EI) services to preschool special education under the IDEA Part B. Given his complex medical and motor needs, the transition required careful coordination between the EI team, the medical team, and the school district's preschool special education staff.

Liam's EI providers shared the IFSP, developmental data, progress monitoring reports, and his complete medical documentation with the preschool team. Erica and Matt were invited to visit the classroom, which was a part of the PreK program serving 18 children, one-third of whom had identified disabilities. During the visit, they met a team consisting of a physical therapist, an occupational therapist, a speech-language pathologist, a special education teacher, and a school social worker. The team explained that they will conduct a comprehensive developmental assessment both in the classroom and at home. The social worker would conduct a home observation to validate Liam's skills in a familiar and accessible environment. They requested collaboration with Liam's NICU physical therapist, who had continued to treat him weekly to plan for his motor, assistive equipment, positioning, and mobility needs.

Liam demonstrated age-appropriate cognitive and language skills. He showed an interest in stories, repeatedly revisiting his favorite story books, and was actively self-teaching himself sight words.

He continued to exhibit delays in fine motor control, primarily due to limited hand strength and coordination. Nevertheless, Liam showed persistence and used creative strategies to participate in activities he enjoyed, e.g., building blocks, pretend play, and learning about dinosaurs. He enjoyed socializing with other children and playing with them.

Given his interests, occupational therapy focused on introducing adaptive tools to facilitate participation in fine-motor activities using blocks, pegs, and dinosaur soft toys to facilitate goal-directed use of his upper extremities. Speech-language therapy supported his use of visual supports and social scripts to improve communication and social participation.

A comprehensive motor assessment was conducted by the school physical therapist using standardized tools, including the Gross Motor Function Measure (GMFM), Peabody Developmental Motor Scales (PDMS-2), and the Pediatric Evaluation of Disability Inventory (PEDI). These tests concluded that Liam has minimal to no voluntary movement in the lower limbs, significant difficulty maintaining upright posture without support, is dependent on adult assistance for transfers, has limited endurance for propelling a walker, and has difficulty navigating the classroom environment independently.

Although he was intrinsically motivated to ambulate, Liam's mobility was consistently restricted by physical barriers and fatigue. He could use a walker for short distances but was unable to keep pace with his peers during transitions or outdoor play.

The preschool PT consulted with Liam's NICU PT, who observed the classroom environment. She recommended a lightweight pediatric manual wheelchair with customized seating and positioning supports. This would allow Liam to participate in classroom routines and activities while ensuring safety and independence.

The PT collaborated with the school team to ensure the classroom layout accommodated Liam's mobility needs, including clear pathways, adjustable-height tables, and accessible storage so he would always be in a position for optimal access to materials and peers.

The NICU PT also provided training to Liam's teachers and paraprofessionals on safe transfer techniques, positioning strategies, and ways to incorporate movement into Liam's daily routine. Regular check-ins were scheduled to monitor Liam's progress and adjust his support as required.

Lastly, the school nurse met with Erica and Matt to assess Liam's toileting needs. Liam continued to require catheterization every two hours, and the school was required to provide this service under Liam's IEP.

Discussion Prompts:

- How can assessments be adapted to accommodate Liam's physical needs while still capturing his developmental profile?
- What role does the family play in shaping meaningful goals for children with complex medical conditions?
- How can assistive technology be evaluated and integrated into Liam's learning environment to support independence?
- Who is required to provide accommodation and technology for Liam to benefit from preschool?

Part 3: Peer Relationships in an Inclusive Preschool Setting

Liam attends a local inclusive preschool program, where he receives integrated physical therapy and occupational therapy. Liam's inclusive preschool classroom was designed to support diverse learners through universal design and individualized supports. His teachers were committed to fostering a sense of belonging and actively worked to promote peer interactions.

Initially, Liam was hesitant to engage with peers during free play. He often observed from a distance and preferred solitary activities, such as building with blocks or reading picture books. His teachers noticed that some children were unsure how to approach Liam or include him in their play, especially when activities involved movement or physical coordination.

To address this, the team implemented several strategies:

- **Cooperative Play Activities**: The classroom incorporated turn-taking games, building projects, and storytelling circles that allowed Liam to participate using his strengths in language and imagination.
- **Circle Time Inclusion**: Liam was given a leadership role during circle time, such as choosing songs or helping with calendar activities, which increased his visibility and peer recognition.
- **Buddy Program**: A peer buddy program was introduced, pairing Liam with a different classmate each day who would help him during the day, especially with transitions.
- **Teacher Facilitation**: Educators used gentle prompts, scaffolded conversations, and proximity to support Liam's engagement, helping him navigate social situations and respond to peers.

Over time, Liam began initiating interactions and participating in group activities. His peers became more comfortable and inclusive, often adapting games to ensure that Liam could join in. Erica shared that Liam talked about his friends at home and looked forward to school each day.

Discussion Prompts:

- What strategies can educators use to promote peer relationships for children with physical disabilities in inclusive settings?
- How can classroom routines and environments be adapted to support social participation for children with mobility challenges?
- What role do peers play in shaping inclusive classroom culture, and how can educators foster empathy and collaboration?