

## Learning Activities: Rett Syndrome

### In-Class Activity: Role Play

**Name:** Lily

**Age:** 4 years

**Diagnosis:** Rett Syndrome

**Strengths:** Enjoys music, responds to visual cues, smiles and vocalizes when engaged

**Challenges:** Limited verbal communication, hand stereotypies, occasional seizures, difficulty with motor planning

Assign students to play the following team members:

- **Early Intervention Provider (EI)**
- **Preschool Teacher**
- **Speech-Language Pathologist (SLP)**
- **Occupational Therapist (OT)**
- **Family Member (Parent or Guardian)**
- **Program Administrator or Inclusion Specialist**

The team is meeting for Lily's **Individualized Family Service Plan (IFSP) transition meeting** as she prepares to enter a preschool classroom. The goal is to:

- Review Lily's current needs and strengths
  - Discuss seizure management and communication strategies
  - Plan inclusive classroom supports
  - Ensure family voice is central in decision-making
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- Identify the members of an EI team
  - Brief presentation of roles and responsibilities of team members

### Group Activity: New Diagnosis:

Understand the family perspectives of navigating emotions, finances, medical concerns, school decisions, etc. following a new diagnosis of Rett syndrome.

Directions:

1. Work with your group to find resources describing how to support families through a new medical diagnosis.
2. Practice active listening and motivational interviewing, role playing a provider and a family member in the context of giving/receiving a new diagnosis.
3. Identify 3 resources that exist in the local area to provide a family member regarding services or supports for their child.
4. Turn in a 1-2 page individual reflection based on your group discussion (due at the beginning of the next class period).