

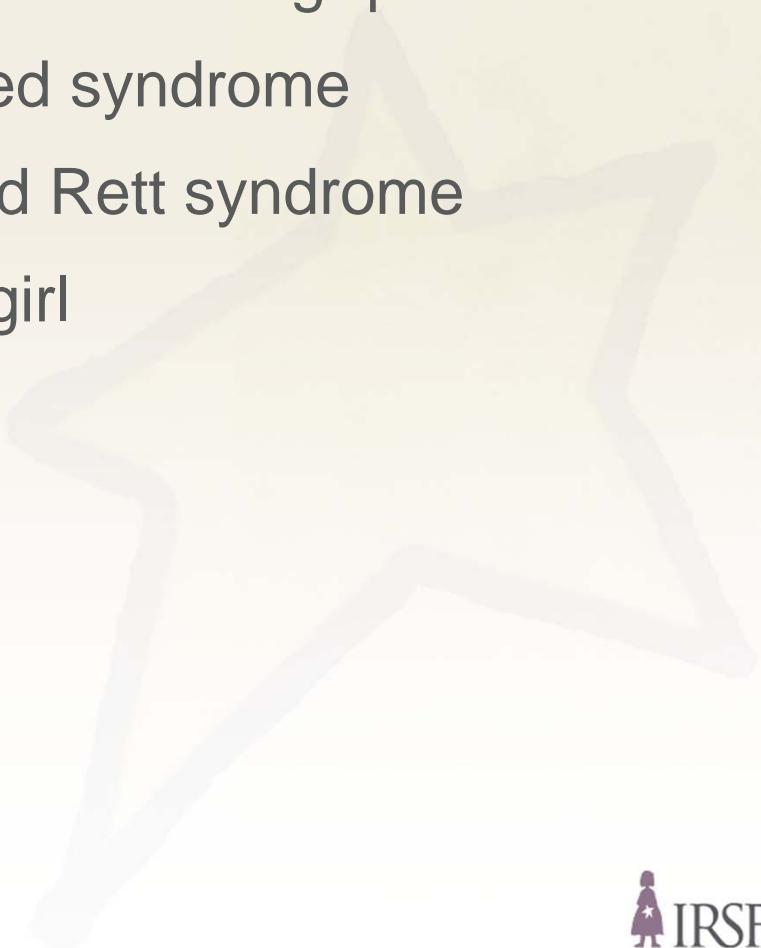
A Pathway to Learning and Literacy

- Elements of an Enriched Environment
 - Communication
 - Mobility
 - Attention to apraxia
 - Neurosensory regulation
 - Anxiety
 - Socialization
 - Good medical health



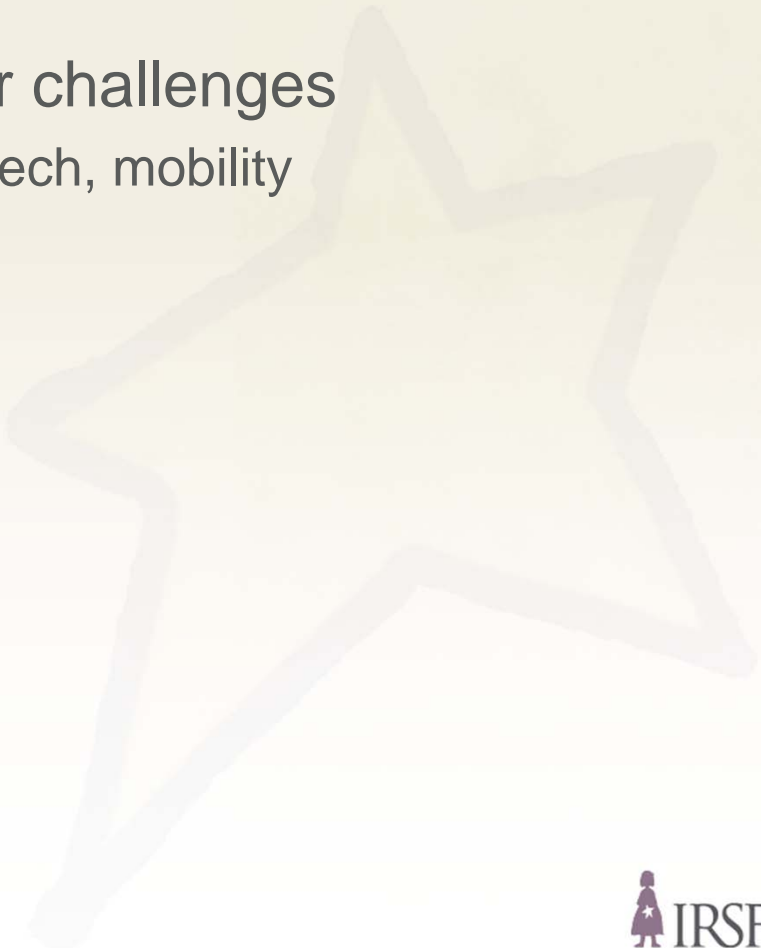


Why is planning an IEP so difficult?

- We visited schools asking and answering questions
 - Rett syndrome is a complicated syndrome
 - Everyone needs to understand Rett syndrome
 - Everyone needs to know the girl
- 



Why is planning an IEP so difficult?

- An individual, not a diagnosis
 - Yet the diagnosis explains her challenges
 - Loss of hand use, expressive speech, mobility
 - Apraxia, apraxia, apraxia!
- 



Why is planning an IEP so difficult?

- We were surprised to find that even after explaining the child's challenges, a teacher asked, "What would you have me do?"



What to do?

- Don't expect to understand Rett syndrome right away
- Keep in mind the vision of education
- Get to know the girl and learn her strengths
- It is easy to get preoccupied with mastery, but inconsistency is part of Rett syndrome
- The special education teacher needs to discover what is interesting to the non-verbal, non-signing student, and then be able to access age-appropriate curriculum coordination with the regular education teacher (is part of the work)



What to do?

- Remember
 - Girls are inconsistent
 - They don't show mastery
 - They get bored with drilling





What to do?

- Goals: What do we want to achieve and what do to make it happen?
- Allow for inconsistency
- Small short-term goals with long-term vision for education and literacy



What to do?

- Usual evaluation tools not appropriate
- Know and believe in our girls
- The enriched environment exists in the smallest, less advantaged schools when “believe” is present



What to do?

- The hard work will not go unrewarded
- It may seem like a long time, but with appropriate therapies in place, progress will be made
- The reason is that **neuroplasticity** is supported by an enriched environment, which fosters the connection between neurons

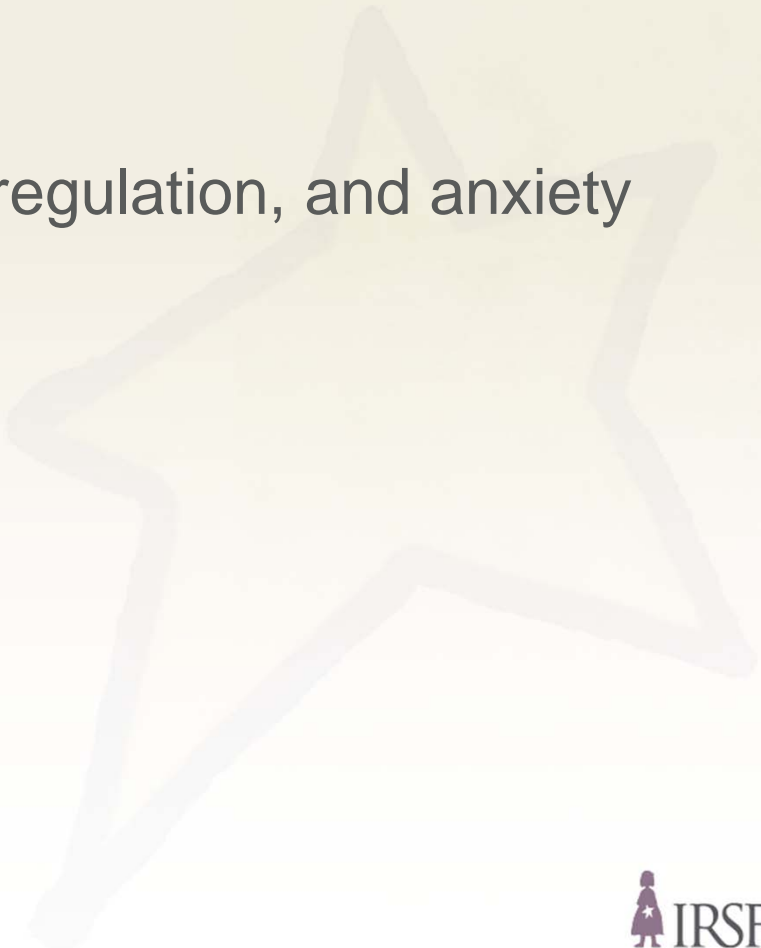


An Enriched Environment

- Works in mice with MECP2 mutations to improve motor coordination, motivation to try new tasks, and improve neuroplasticity (Kondo et. al)
- The Berger-Sweeney lab (Boston) showed that the MRIs of such mice placed in an enriched environment indicated brain growth
- An Italian study and yet another group in Boston independently supported the concept of neuroplasticity
- Good to help early, but the enriched environment also works in older mice!



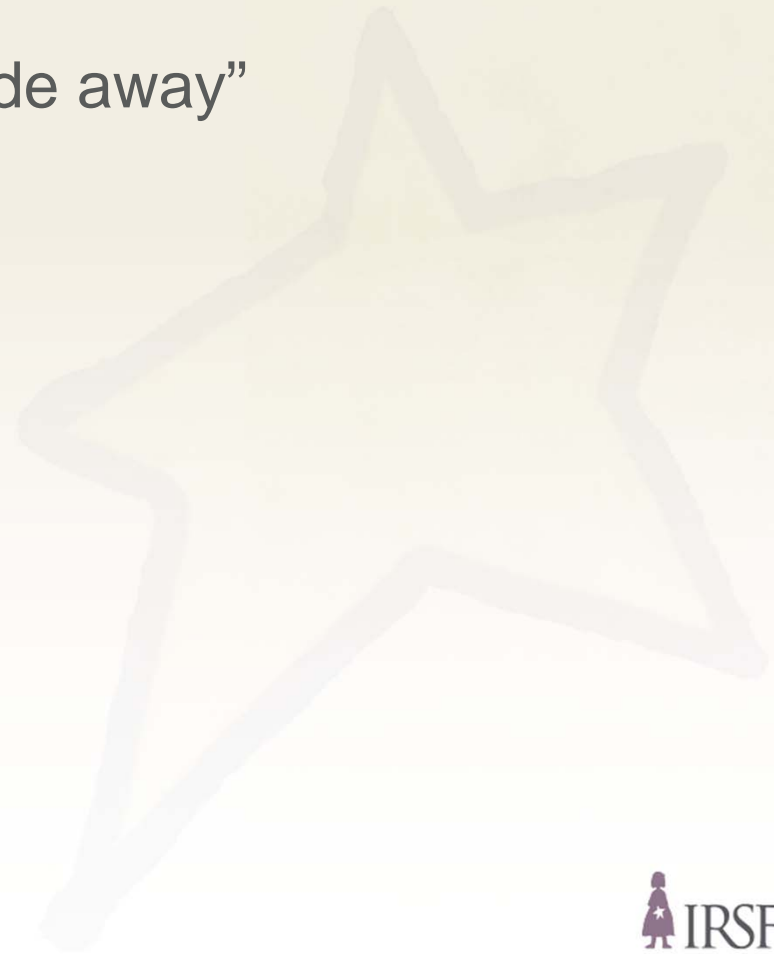
What is the Enriched Environment for girls?

- Communication
 - Mobility
 - Attention to apraxia, sensory regulation, and anxiety
 - Socialization/motivation
 - Medical Health
- 



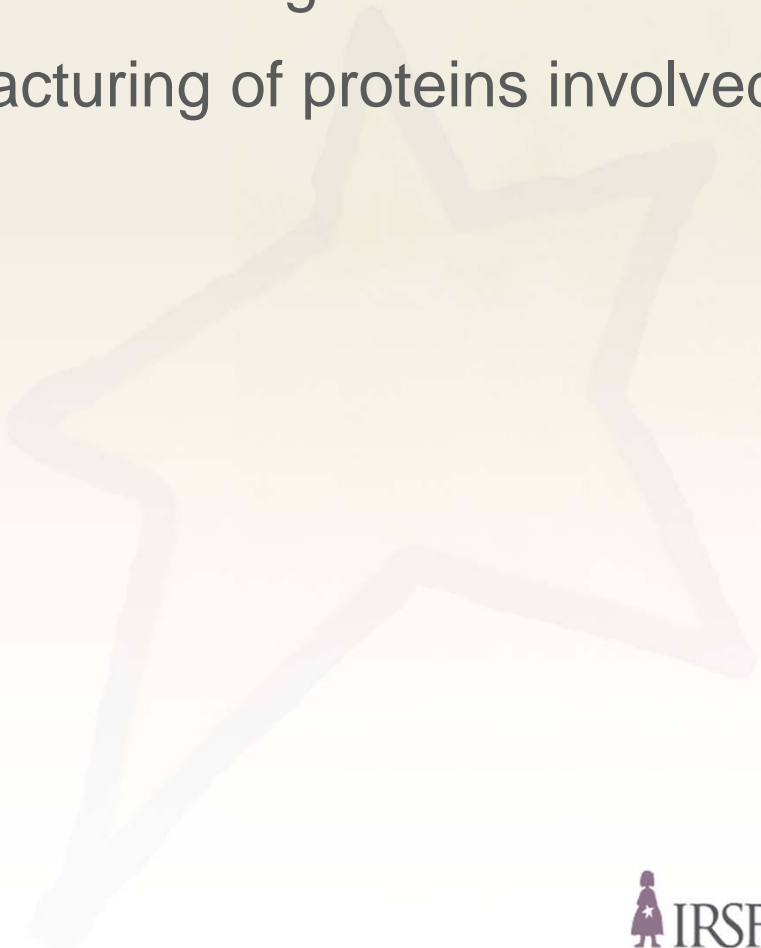
Rett Syndrome Basic Facts

- Not degenerative
- “All this work then to see it fade away”





Rett Syndrome Basic Facts

- Rett syndrome is a new mutation in the gene MECP2
 - This gene controls the manufacturing of proteins involved in development
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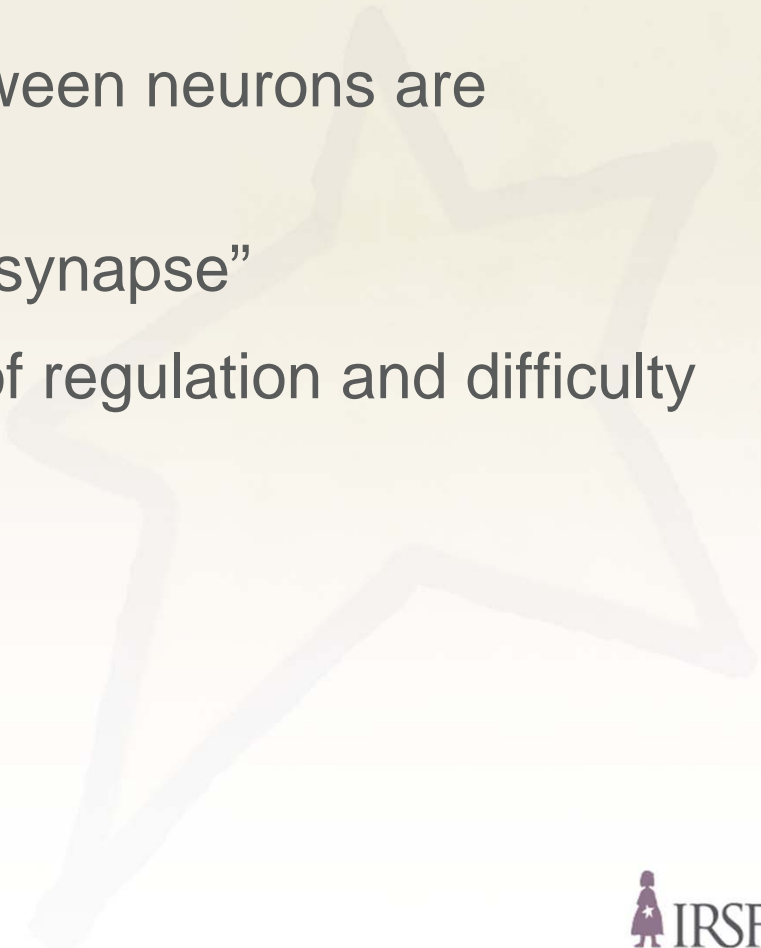


The Collateral

- MECP2 is not present in significant amounts in the embryo
- Neurons or brain cells are formed in the proper places in the brain
- Abnormal MRIs are not a diagnostic criteria of Rett syndrome



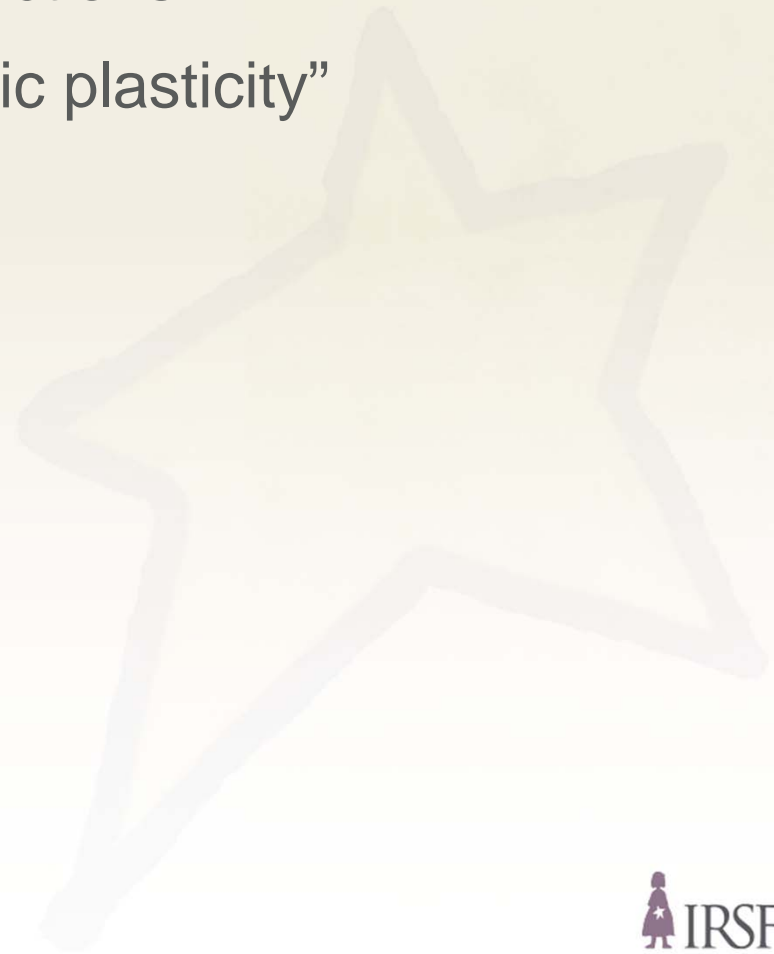
The Collateral

- Neurons or brain cell bodies are intact
 - Dendrites or connections between neurons are underdeveloped
 - The connection is called the “synapse”
 - Difficulty here results in loss of regulation and difficulty with motor planning
- 



Therapies

- Therapies help to build connections
- The process is called “synaptic plasticity”





Motivation

- Because there is so much difficulty making her muscles work, expressing cognitive intent requires a lot of motivation
- Typical peers and activities can be good motivators



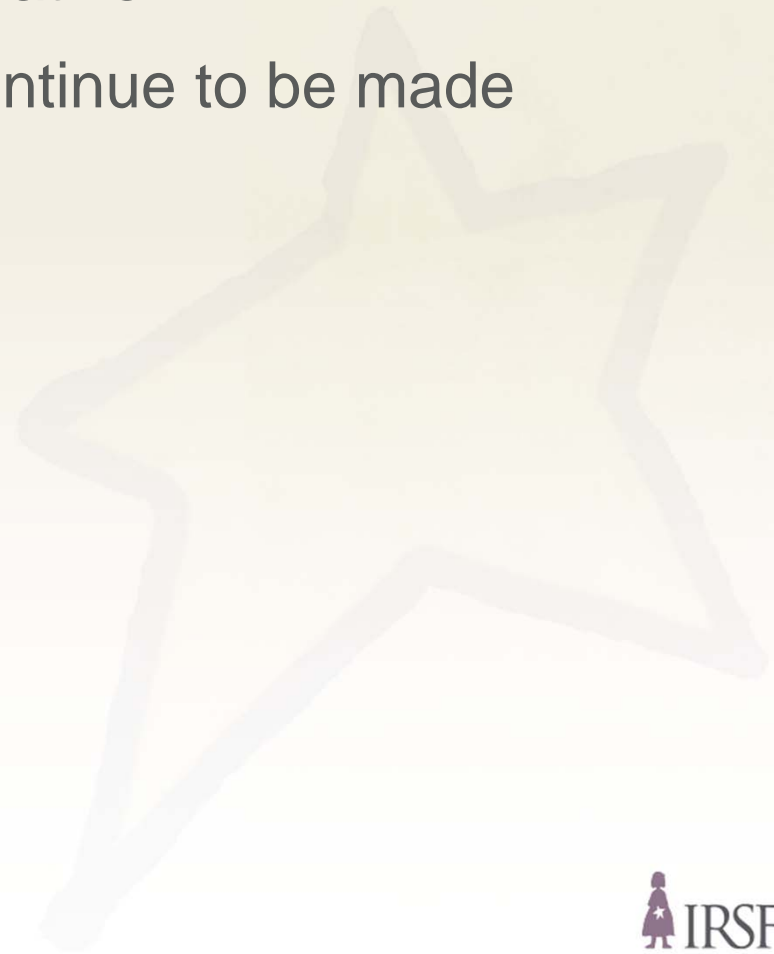
Motivation

- What is the hardest thing you had to do?
- How long did it take to train?
- Girl with Rett syndrome must work this hard to accomplish even the smallest motor task



Motivation

- Rett syndrome is not degenerative
- Progress is slow, but it will continue to be made





Wish List

- A respectful team working with an academic vision of literacy and learning, remembering balance and happiness



The Team

- Parent
- Developmentalist (psych, early specialist)
- AAC specialist
- Occupational therapist and physical therapist
- Educators (special and general)
- Aide
- ABA
- Music
- Medical Personnel (MD/RN/PNP)




The Team

- Each member of her team should be able to
 - List the ways in which she communicates and discuss her levels of regulation
 - Describe signs of interest/signs of tuning out



Communication Passport

- Team members may list ways she communicates
 - Interest in a topic
 - Staying awake, smiles, stares intently
 - Says “yes”
 - Leans into cheek switch
 - Stares, smiles
 - Says “no”
 - Looks away, goes to sleep
 - Expresses pain or fear
 - Screams or wrings hands
- 



Communication Passport

- Communication goals overlap with academic goals
- The other elements support the process
- Build in time for the teachers to plan a curriculum
- Include the regular education teachers for ideas



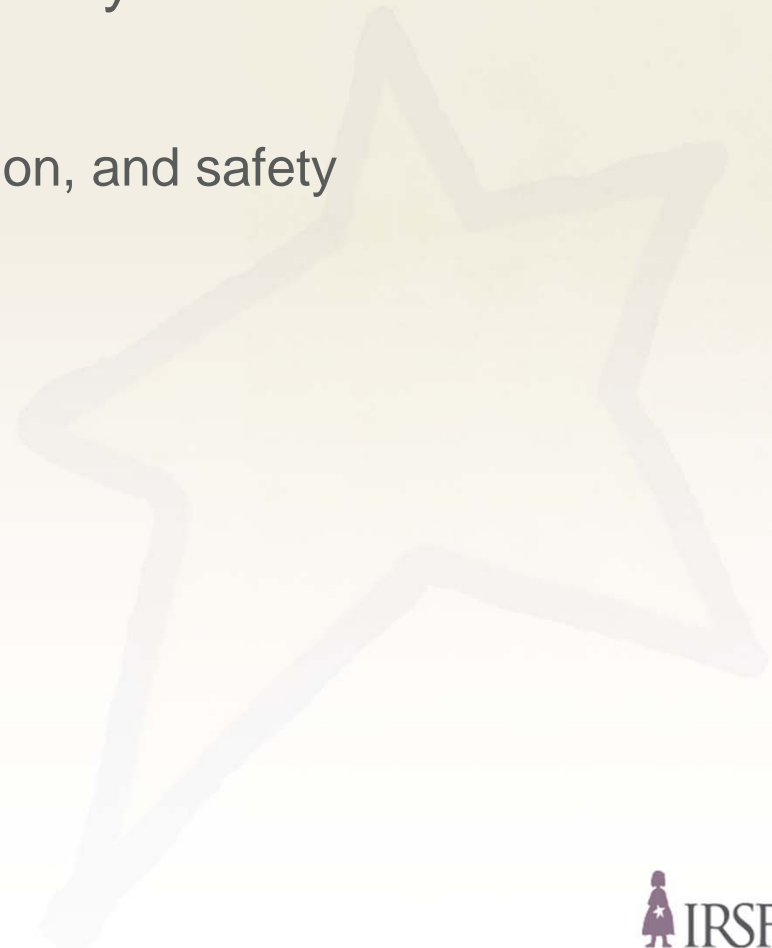
Neurosensory Difficulties

- Be able to define her “sensory rescue kit”
- Review by listing things about the girl
 - Problems such as apraxia, response time, proprioception, regulated state, need for a break
 - Ask every staff member to share discoveries



Neurosensory Difficulties

- Prepare a regulated state/sensory rescue kit
- What makes her anxious?
 - Don't forget balance, proprioception, and safety





Goals for goals

- Keep the vision for learning and literacy
- IEPs are only as good as the understanding of those who implement them
- Provide time for education of the team
- Provide time for their continuing review
- Request their input on a regular basis
- Use the elements of an enriched environment as a guide



Goals for goals

- An inadequate goal
 - What words are missing?
 - “Katie will use her hand to point to her choice from a field of 3 items on $\frac{3}{4}$ trials on 3 consecutive days”
- A revised goal
 - “When in a regulated state and position for access of communication device, Katie will use eye gaze to jointly communicate with the examiner making 3 statements about a subject of study”



Goals for goals

- Evaluations are needed, however, the type of testing is not mandated
 - Explain, describe, compare





Goals for goals

- Re-evaluate and take responsibility if not improving
 - Is the goal appropriate?
- What should the team change to make it happen?
 - Change the approach
- Not loss of services because progress is not made