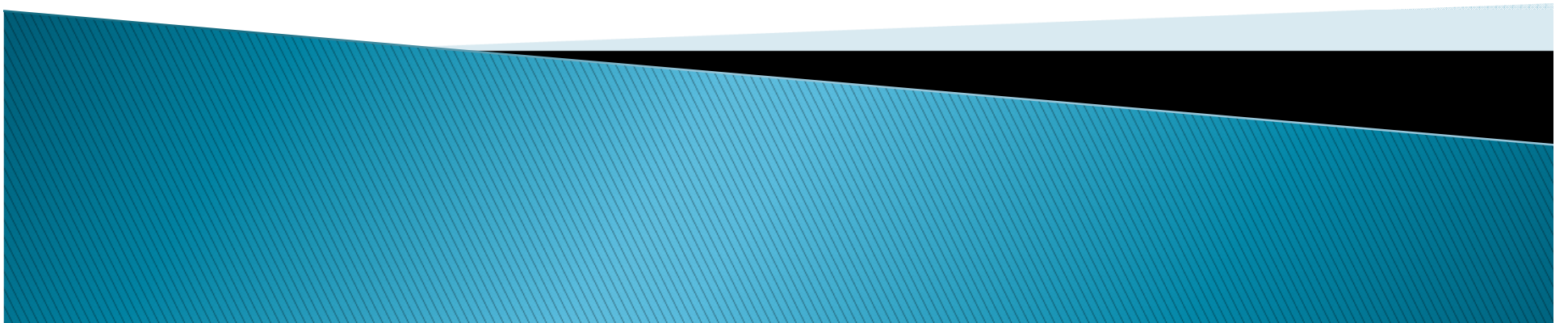


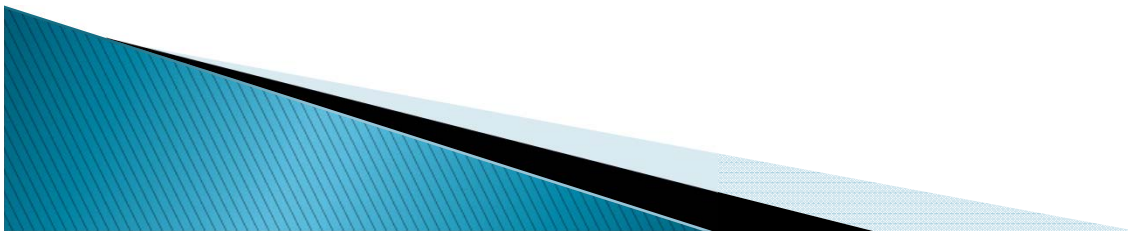
Heather Kuhaneck

LEND Project 2009
(still in progress)



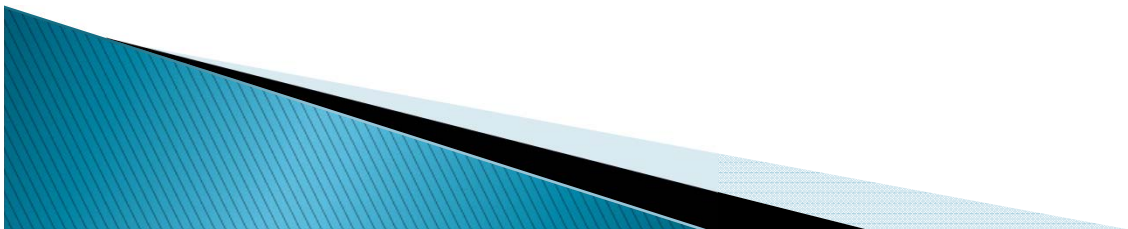
Background and Rationale

- ▶ Increases in prevalence of the ASDs
- ▶ My background as an occupational therapist interested in play and family functioning
- ▶ My curiosity regarding sibling play in families where one sibling has an ASD.
- ▶ Most literature on sibling relationships is about psychological impact and behaviors—not play interactions.



Objectives of the Project

- ▶ Learn more about the play of sibling dyads when one of the siblings has an ASD
- ▶ Since there is minimal literature in this area – decided to begin with a small qualitative project.
- ▶ Primary questions regarding sibling play and the family's needs in terms of interventions and/or programs to assist sibling play.
- ▶ Wanted to speak with both mothers and children to get both perspectives.



Project Methods

- ▶ Recruited families via local support groups, local occupational therapy outpatient clinics, and occupational therapy clinicians known to me.
- ▶ After initial content and consent procedures, met with mother and sibling to complete interviews in a location of their choosing (majority were completed in their home).
- ▶ Interviews lasted 45 minutes to 90 minutes with the mothers and generally 30 minutes with the siblings.



Project Methods (cont.)

- ▶ All interviews were transcribed verbatim using MS word.
- ▶ Coding was completed using the methods described by Corbin & Strauss, 2008



Project Results– Subjects

- ▶ The subjects included 7 mothers and 7 siblings. The siblings were ____males and ___females. All siblings were older than the child with an ASD. They ranged in age from ____ to _____.
- ▶ Families lived in a variety of locations across the state from Bridgeport CT to outside of Storrs. However, all families that contacted the researcher and agreed to be interviewed were white and appeared at least middle class based upon their homes and their neighborhoods.



Project Results – Themes

- ▶ Play between siblings was universally affected.
- ▶ However, sibling relationships were reported to be strong and supportive by the majority nonetheless.
- ▶ Siblings used favored objects and activities to create shared play (music, computer, characters).
- ▶ There does not appear to be a consistent desire for programs specifically geared towards sibling play although some families would have liked this.
- ▶ For those families who would have liked a program, they would have preferred it to occur in the home rather than a clinic setting.



Project results– a surprise

- ▶ One consistent finding from all mothers was the desire for more help navigating the system when they had first learned about the ASD diagnosis. The amount of information available was overwhelming and everyone they spoke with had a financial interest in their decisions for intervention services. Mothers wanted an impartial person to serve as a “coach” of sorts– to help them make decisions– without having any financial benefit to the coach– so that the person could be impartial.



Implications and Recommendations

- ▶ Future possibility for LEND– coaching function for families newly diagnosed.
- ▶ Families universally wanted more assistance finding programs and interventions, and navigating the choices when they first learned of the diagnosis.
- ▶ The LEND– as a group that does not provide direct service intervention – could provide that coaching function without financial implication.



Implications and recommendations

- ▶ Some mothers expressed a desire for a sibling support group as there were few available across the state.
- ▶ Siblings did not often express this same desire and they generally felt comfortable with their sibling and their relationships.
- ▶ However, mothers suggested that having time to talk with other siblings going through similar things could be beneficial.
- ▶ Perhaps the LEND could run a sibling support group at the Exchange which is a location fairly central in the state– with easy highway access as well.



Summary

- ▶ Although the project was small and certainly non-representative, it was helpful in expanding my thinking in regards to the needs of families in CT,
- ▶ Good ideas for future programs and services were generated even after having spoken with only ___ people.

