Siblings' roles in social interactions of youth with disabilities: A social network and qualitative analysis

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Background

What we KNOW:

➢ Contexts of clients' lives are critical considerations when developing individualized client-centered interventions [6]

➢ Siblings are a source of friendship and aid for each other [1,2]

➢ Siblings can affect each other's cognitive and social skills [4]

➢ Sibling impact on social activity participation is life-long [7]

➢ Few studies have examined the influence siblings have on each other when one sibling has a disability and there needs to be studies that incorporate the youth with disability into data collection [5]

What we WANT TO KNOW:

➢ What are social interactions like between youth with disabilities, their siblings, and their peers?

➢ Is there a connection between where siblings are located on the youth's social network and the types of interactions described in interviews?

Methods

IRB approval and written consent and assent prior to any data collection (Project # 232-2012).

Participants: 12 youth with siblings, ages 11-16 years, with diagnoses of learning disability, attention deficit disorder and/or autism spectrum disorder. **Recruitment**: Flyers, referrals and word of mouth

Design: Mixed Methods Cross-sectional

Data Collection & Analysis:

➢ Egocentric Social Network Analysis

  ➢ Quantified measure of connectedness of siblings: highest degree centrality of all siblings living in household

  ➢ Visual map of youth's personal network: showed siblings' connections to groups and individuals, which aided the youth and researchers in making visual connections and discussing specific individuals during the interview.

  ➢ EgoNet (a free internet source)[3] to calculate network centrality and generate visual map

➢ Qualitative Analysis

  ➢ Semi-structured interview guide: dynamic tool - Question examples:

    ➢ Did you know your sister/brother is that connected? Is that a good thing?

    ➢ What is it like when you are with your friends and sibling(s)?

  ➢ Interviews were audio-recorded, transcribed verbatim, 2 researchers independently coded all interviews. Conceptual consensus achieved through weekly discussions.

  ➢ Codes grouped as to typical sibling interactions (some negative some positive) vs. primarily negative sibling interactions

➢ Quantitative Analysis: 2-tailed independent samples t-test performed using SPSS Version 20.

Results

Category	Participant Examples	Quote Re. Social Interactions with Sibling + Peer	Social Network Mapping	Results
Primarily TYPICAL Sibling Interactions (*n* = 6)	13 y.o. male with brother Brother connected to **9** people on youth's network.	*Interviewer:* What sort of things do you and your brother and [friend + friend's sibling] do or talk about? *Participant #17*: Well, at dinner we ya know, eat at the same table. And then we'll usually watch TV or play some computer games or something together. We talk about school and stuff like that.		➢ This group of participants described social interactions that were expected of sibling communication. ➢ Siblings were less connected to other people in the youth's network created during interviewing. ➢ Coded dialogue: • Youth asserts self socially with siblings • Sibling is the group leader • Youth as the group leader • Egalitarian relationship with sibling
	12 y.o. female with sister. Sister connected to **7** people on youth's network.	*Participant:* Sometimes when they [sister's friends] come over I say what's going on? Want to play the Wii or something? *Interviewer:* Do they join you? Participant: Not all of the time but most of the time. *Interviewer*: What if they're doing their stuff? Can you easily join them? Participant: Yes. It depends on what they are doing…. probably not if they are in sister's room.		
Primarily NEGATIVE Sibling Interactions (*n* = 6)	15 y.o. male with brother Brother connected to **14** people on youth's network.	*Participant*: "We [youth, brother, and friend] will be talking and [brother and friend] will get excited with each other and they'll even do like weird noises just messing with each other, like weird code names…"		➢ This group of participants described interactions where siblings excluded them from social activities. ➢ Siblings were very connected to other people in the youth's network created during interviewing. ➢ Siblings sometimes verbally and physically excluded youth. ➢ Some siblings directed play away from the youth in a subtle way that was not always noticed by the youth with disability. ➢ Coded dialogue: • Subtle & overt exclusions by siblings • Modifications to social interactions by the parent (i.e. social coaching for youth) • Youth distances self from social interactions
	16 y.o. female with sister Sister connected to **16** people on youth's network.	*Interviewer*: "So who decides what you do as a group in this group?" *Participant*: "Sister. She is kind of bossy. Whenever I hang out with my friends, I have to listen to her because she will correct me and make me be quiet so I can't talk to my friends with her."		

Comparative Statistics

Group Statistics

		N	Mean # of Sibling Connections	Std. Deviation	Std. Error Mean
Sibling Centrality Score - highest for all siblings	Typical Interactions with Siblings	6	8.00	1.414	0.577
	Negative Interactions with Siblings	6	14.17	2.927	1.195

Independent Samples Test

				95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Lower	Upper
Sibling Centrality Score - highest for all siblings	-4.647	10	.001	-9.124	-3.210

Discussion

➢ This was an initial exploration into this topic using this methodology so conclusions cannot be generalized.

➢ Youth who described typical sorts of interactions had siblings who were not as connected to others in the network.

➢ Youth who described atypical and negative sorts of interactions had siblings who were more connected to others in the network.

➢ Cues were not always recognized by the youth as an act contributing to social exclusion.

➢ Understanding of sibling interactions can be useful to therapists addressing social participation.

➢ Siblings of youth with disabilities have the ability to influence the youth's social participation through inclusive and exclusive dialogue.

➢ Some siblings might feel a role burden due to their potential role in affecting their sibling's social participation that they may resent- further investigation needed.

Strengths

➢ Youth with disabilities were the primary source of information about their own social world.

➢ Mixed-methods design.

➢ Targeted participants were at an age where identity and roles are influenced by social status among peers and ability to participate in social interactions.
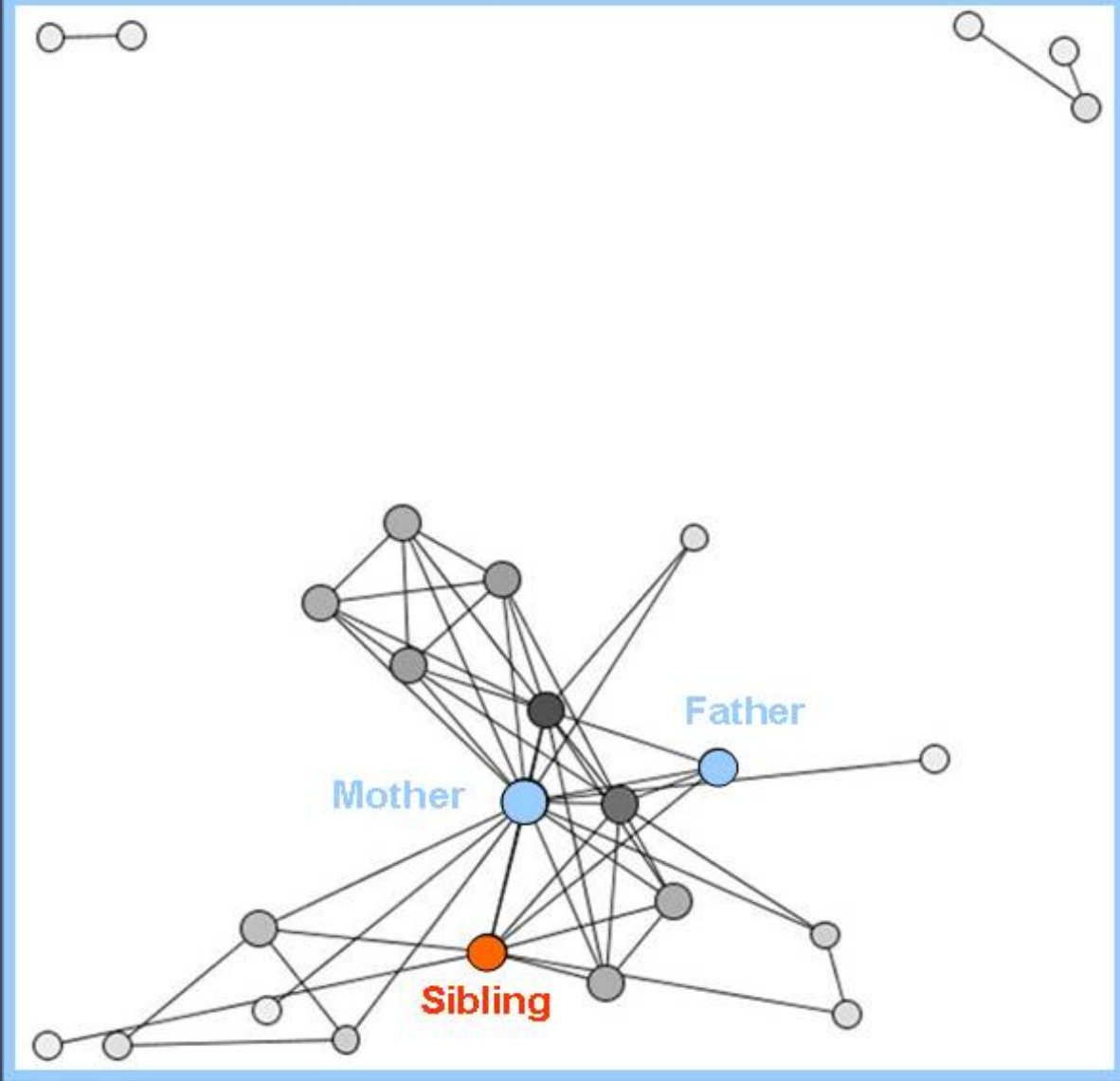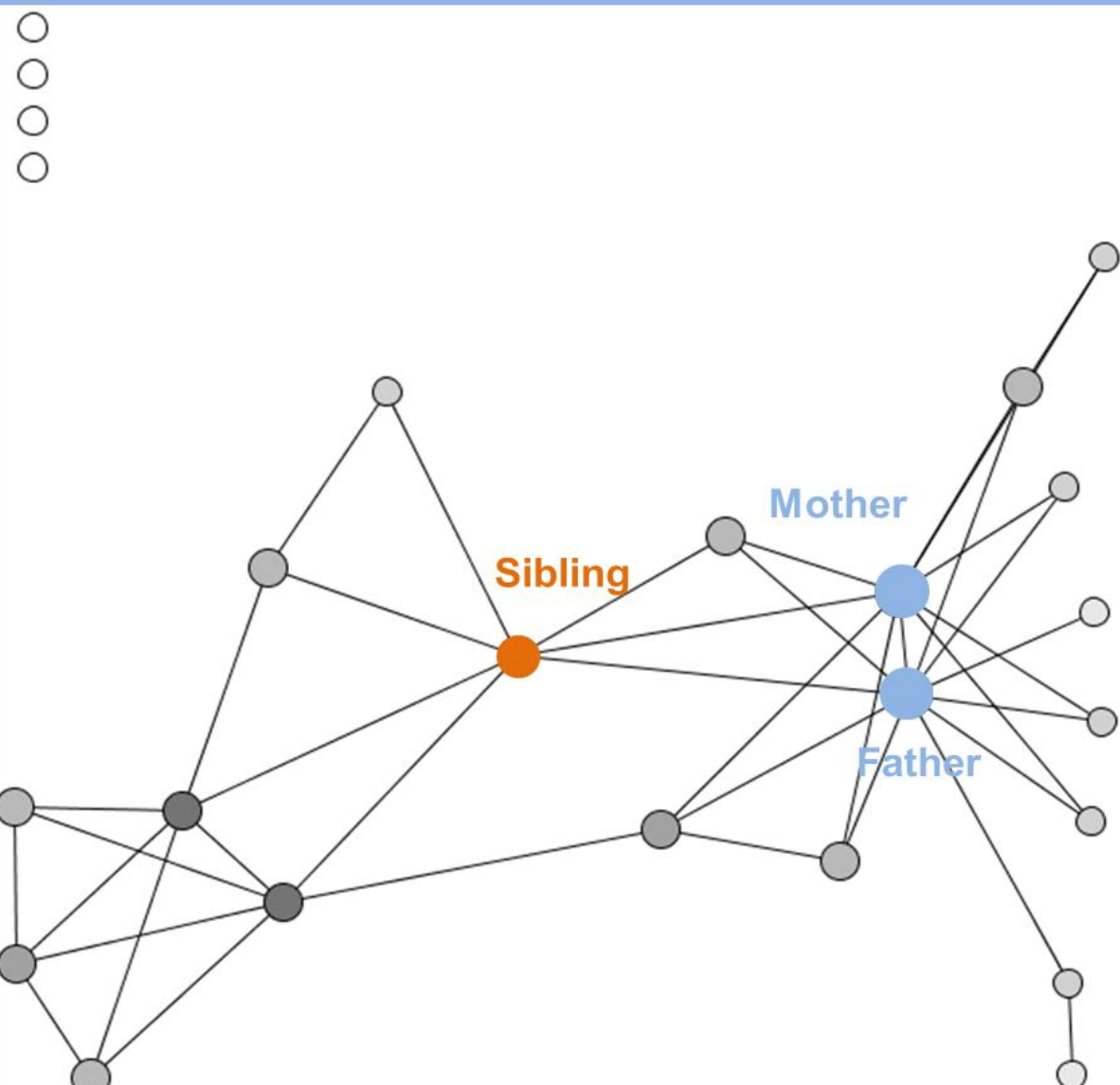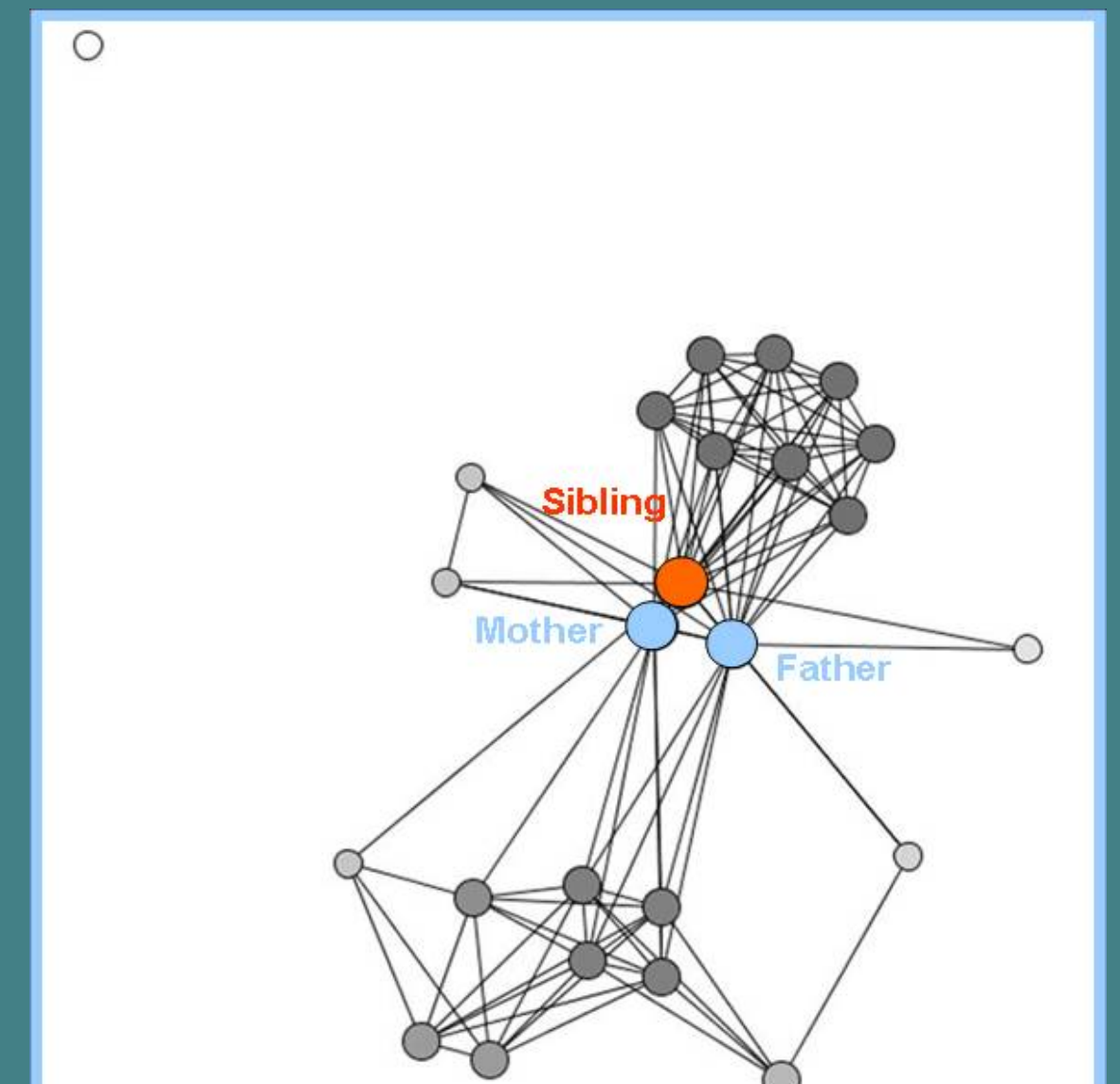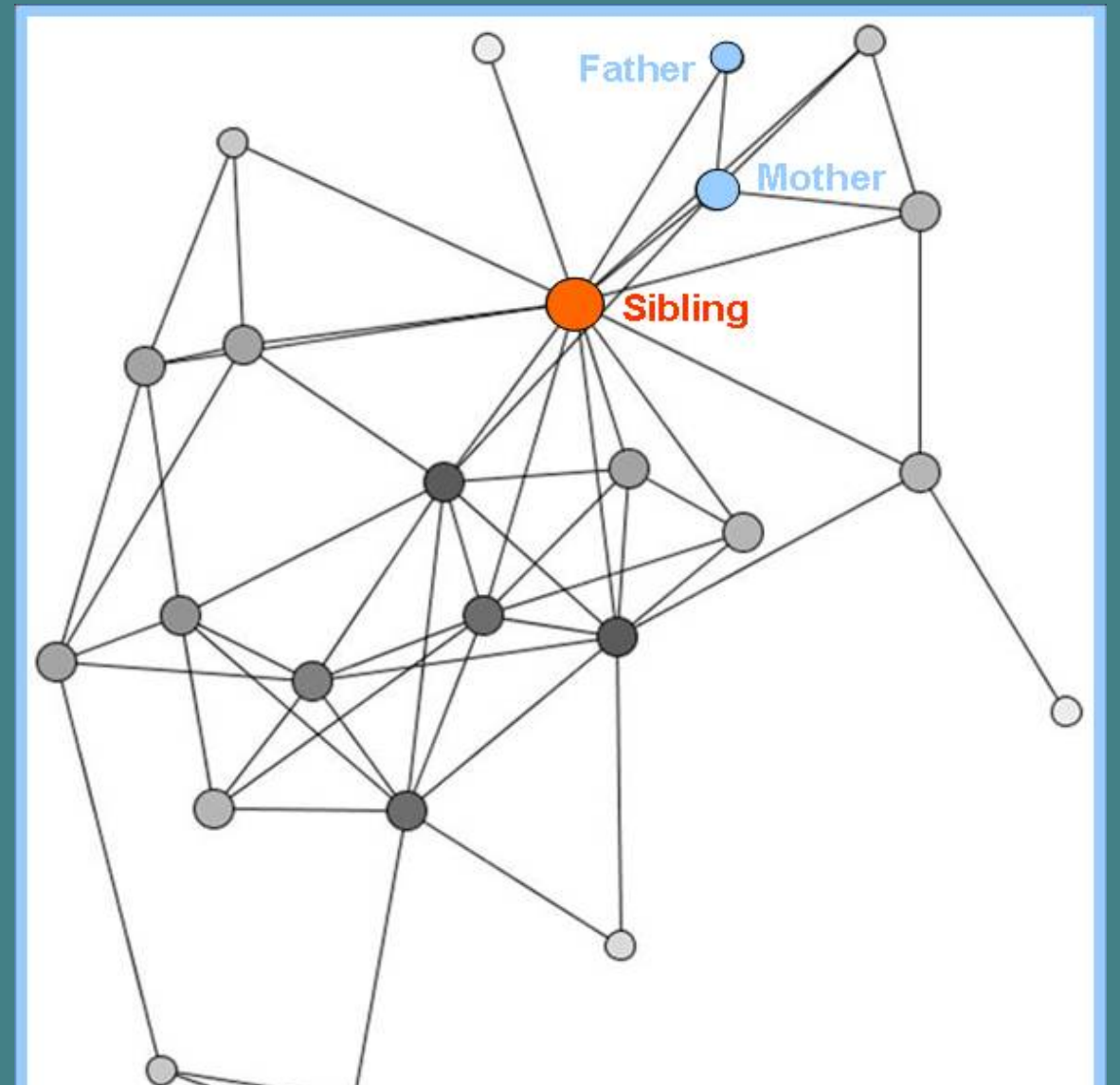
Limitations

➢ Siblings were not included in the data collection process.

➢ Sample size and methodology used means that generalizations cannot be made. Larger sample size needed for more refined analysis which could include categorization of data by gender, disability, etc.

➢ Additional informants or going back to the original participants for additional follow-up interview would have strengthened the findings.

References

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