

ABSTRACT

BACKGROUND: The social environment serves as a crucial arena in which to advance competence necessary for participation, social engagement and overall development. While social network effects have been studied related to a number of health and social-developmental outcomes, few studies have investigated these effects in **disabled pediatric populations**.

OBJECTIVE: Exploratory examination of social networks as arenas of participation and integration for disabled youth.

METHODS: Personal Network Analysis, Case Series, & Pearson's Correlation

RESULTS: The children demonstrated a range of network structures with lived perceptions of network experiences included themes of isolation, peer hazing, social protection and naivety. Measures of network centrality and cohesion correlated with activity participation. Measures of network characteristics correlated with quality of life.

CONCLUSIONS: Findings from this preliminary investigation begin to shed light on the complexity of the disabled youth's contextual circumstances that envelope childhood activity and impacts quality of life.

BACKGROUND

The social environment serves as a crucial arena in which to advance competence necessary for participation, social engagement and overall development. While **social network** effects have been studied related to a number of health and social-developmental outcomes, few studies have investigated these effects in **disabled pediatric populations**.

➤ Still needing to be understood are the mechanisms by which a disabled child's social network impacts engagement in everyday life activities and overall wellbeing.

➤ Qualitative features of the context of disabled childhood participation, such as aspects of enjoyment and with whom, are only beginning to be investigated (King et al., 2004).



OBJECTIVE

This research is an exploration of **the relationship of social networks to participation and quality of life for youth with disability**, with the eventual goal of identifying and describing potential social network level targets of intervention.

Study aims include an exploration of the methods of **personal network analysis with children growing up with a disability**. As such, factors related to their disability such as **cognitive, emotional or developmental delays**, can hinder their ability to handle the level of cognitive respondent burden inherent in the design. While social network effects have been studied related to a number of health and social-developmental outcomes, *few studies have investigated these effects in children with disabilities*. Resultantly, there exists a dearth of empirically guided or tested social network-level interventions for youth with disabilities.

METHODS

Subjects

- Six children with chronic disability
- Hidden/cognitive or physical disability
- Ages 10-17 years (mean = 12.17 ± 2.64)
- 83% male
- 83% Caucasian

Methods & Materials

- **Personal (egocentric) network analysis**
 - **Name generator:** "All ... 'hang-out' or do things with"
 - **Alter attributes:** gender, age, kin, social-developmental roles
- **Children's Assessment of Participation & Enjoyment (CAPE)**
 - Self-report or proxy measure, ages 6-21 years old
 - 55 activities; 330 items
 - Activity Diversity, Intensity, Where, With Whom, and Enjoyment
 - Recreational, Physical, Social, Skill-based, & Self-Improvement activities
- **PedsQL™**
 - Self-report or proxy measure, ages 2-18 years old
 - 23 items; sum scoring
 - Physical, Social, Emotional & School functioning

Analysis

- Case Series
- Personal (egocentric) Network Analysis (UCInet 6 & NetDraw 4.14)
- Descriptive Statistics (SPSS 17.0)
- Exploratory Pearson's Correlation

RESULTS: Exploratory Correlations

Network Closeness Centrality & Participation Diversity

- Closeness Centrality (Mean = 34.43 ± 15.87) Social power measured as closeness to others (degree of network inequality of distances between network members)
- Activity diversity (Mean = 25.67 ± 10.52) 55 possible activities
- Pearson's correlation: **r=-0.823 p=0.043** (alpha level=.05, 2-sided test)

Network Factions & Participation Enjoyment

- Factions (Mean = 6.67 ± 2.58) Number of fully connected sub-groups in the network
- Activity enjoyment (Mean = 3.72 ± 0.33) 5 point scale; 5 = highest enjoyment)
- Pearson's correlation: **r=-0.825 p=0.043** (alpha level=.05, 2-sided test)

Network Closeness Centrality & Quality of Life: School Functioning

- Closeness Centrality (Mean = 34.43 ± 15.87) Social power measured as closeness to others
- Perceived School Functioning (Mean = 6.17 ± 3.87) 0-4 point scale; 0 = no problems; 20 = highest possible score/worst functioning
- Pearson's correlation: **r=0.860 p=0.028** (alpha level=.05, 2-sided test)

Percent Adults & Overall Quality of Life

- Percent of adult network members (Mean = 34.88 ± 16.81)
- Perceived Overall Functioning (Mean = 29.83 ± 19.22) 0-4 point scale; 0 = no problems; 92 = highest possible score/worst functioning
- Pearson's correlation: **r=0.832 p=0.040** (alpha level=.05, 2-sided test)

RESULTS: Case Series

<p>17 year old Caucasian female 26 network members; 4 factions; 5 components, 4 isolates, 1 cut-point</p> <p>12% kin; 12% adult; 46% same gender 96% hang-out; 46% horse around; 58% do things-play; 42% share feelings; 42% takes care of you; 50% you take care of; 23% friemny</p> <p>Highest closeness centrality = friend 1 (2/7 roles) Closeness centralization network index = 29% Highest betweenness centrality = friend 1 Betweenness centralization network index = 28%</p>	<p>"I'd rather do things more by myself." "I guess it's like in the group... T and K would be the ones that come up with the ideas. And if I want to join them I join them and if I don't, I don't." "I have more ... acquaintances... I don't really hang out with them all that much."</p> <ul style="list-style-type: none"> ✓ themes of independence and purposeful separation from her groups ✓ themes of friction within sub-groups ✓ themes of actively working to keep groups separate 	<p>12 year old Caucasian male 29 network members; 4 factions; 1 component, 0 isolates, 0 cut-points</p> <p>45% kin; 45% adult; 45% same gender 14% hang-out; 3% horse around; 48% do things-play; 0% share feelings; 52% takes care of you; 3% you take care of; 7% friemny</p> <p>Highest close. centrality = adult assist (1/7 roles) Closeness centralization network index = 19% Highest betwn. centrality = adult sister (1/7 roles) Betweenness centralization network index = 6%</p>	<p>"...[network member] hits me and...splits on me"</p> <p>"She (mom) wants to try to keep me away from everybody..."</p> <ul style="list-style-type: none"> ✓ themes of physical aggression & name-calling from peers ✓ themes of desire to be part of social groups despite mother's protectiveness and peer hazing
<p>11 year old Caucasian male 22 network members; 7 factions; 2 components, 0 isolates, 1 cut-point</p> <p>77% kin; 55% adult; 46% same gender 73% hang-out; 46% horse around; 73% do things-play; 14% share feelings; 18% takes care of you; 14% you take care of; 14% friemny</p> <p>Highest closeness centrality = mom (7/7 roles) Closeness centralization network index = 54% Highest betweenness centrality = mom Betweenness centralization network index = 35%</p>	<p>"...To tell you the truth, I've been lonely..." "...My friendliness [sets me apart from other kids] 'cause everyone else is just plain mean."</p> <ul style="list-style-type: none"> ✓ themes of physical aggression from peers ✓ themes of isolation, loneliness, & solitary play; no peer socialization outside of school ✓ themes of friction and lack of social support from friends 	<p>13 year old Caucasian male 25 network members; 7 factions; 4 components, 1 isolate, 3 cut-point</p> <p>45% kin; 24% adult; 72% same gender 100% hang-out; 80% horse around; 84% do things-play; 4% share feelings; 20% takes care of you; 20% you take care of; 4% friemny</p> <p>Highest close. centrality = adult sister (3/7 roles) Closeness centralization network index = 7% Highest between. centrality = brother (5/7 roles) Betweenness centralization network index = 42%</p>	<p>"I don't get to see everybody that much"</p> <ul style="list-style-type: none"> ✓ themes of solitary or family-based play ✓ unsure of his own level of group acceptance ✓ identifies self as having only one social group
<p>10 year old Caucasian male 34 network members; 11 factions; 1 component, 0 isolates, 4 cut-points</p> <p>24% kin; 26% adult; 65% same gender 56% hang-out; 32% horse around; 65% do things-play; 27% share feelings; 52% takes care of you; 3% you take care of; 7% friemny</p> <p>Highest close. centrality = teacher 1 (3/7 roles) Closeness centralization network index = 48% Highest between. centrality = teacher 1 (3/7 roles) Betweenness centralization network index = 44%</p>	<p>"...Everybody in my network is kind..." "They're all very nice and kind and jokeular and are all pretty very smart."</p> <ul style="list-style-type: none"> ✓ themes of social support from network ✓ perceives a large, well-connected, homogenous network ✓ perceives mother as central person in network ✓ identifies classmates & teachers who are "important" or "valuable" to know based on social connections 	<p>13 year old mixed-race male 33 network members; 7 factions; 1 component, 0 isolates, 0 cut-points</p> <p>70% kin; 49% adult; 70% same gender 85% hang-out; 42% horse around; 27% do things-play; 0% share feelings; 55% takes care of you; 27% you take care of; 9% friemny</p> <p>Highest closeness centrality = brother (5/7 roles) Closeness centralization network index = 15% Highest between. centrality = brother (5/7 roles) Betweenness centralization network index = 15%</p>	<p>"...I feel like they (classmates) want me to go to another school...They'll usually ... laugh at me...yell at me."</p> <p>"...[friend] used to, to intimidate me...he would like bully me or like pick on me..." This friend perceived as central in network.</p> <ul style="list-style-type: none"> ✓ themes of peer rejection & kids picking on him ✓ themes of orchestrated "play-dates" outside of school ✓ perceives a small network

CONCLUSIONS

Findings from this preliminary investigation begin to shed light on the complexity of the disabled youth's contextual circumstances enveloping childhood activity and impacting quality of life.

- Children, even those with cognitive and emotional delays, can successfully handle the level of respondent burden needed for application of personal (egocentric) network analysis methods with varying levels of assistance from parent or other knowledgeable informant. The investigator must be prepared to accommodate for shortened attention and reduced endurance when using a personal network analysis approach.
 - Personal network analysis yielded unique information not obtained via in-depth qualitative interview alone.
- Preliminary empirical evidence that the structure of the relationships of the people surrounding youth with disability has an impact on the variety of types of activities engaged in and the level of perceived enjoyment during the activities.
 - As network cohesion increased (decline in number of factions), so did activity enjoyment
 - As social power inequality decreased (decline in closeness centrality) within the network, activity diversity increased.
- Preliminary empirical evidence indicating that both the attributes of the network members and the relationships between the network members influences perceived quality of life and overall and school functioning for youth growing up with a disability.
 - As the proportion of adults in the network increased, so did overall functioning and quality of life.
 - As social power inequality increased (increase in closeness centrality) within the network, so did the child's school functioning.

REFERENCES

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