

Differences in Extracurricular Activity Participation between Children and Youth with and without Barth Syndrome

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BACKGROUND

- Through participation in extracurricular activities which include voluntary play, sports, social connection, entertainment, learning, work, and religious expression children can learn societal, roles, norms, and values (King, et al., 2004).
- Because of the health conditions, children with disabilities have a higher need to participate and enjoy their capable activities, interests, and holidays outside of school than unaffected children (Stone, 2007).
- Understanding the differences of their extracurricular activity participation between children with and without Barth Syndrome is a foundation for developing treatment goal and rehabilitation intervention for clinicians.

PURPOSE

The objective of this poster: to investigate the involvement percentage, diversity, intensity, partnership, context, and enjoyment of extracurricular activity participation between children with and without Barth Syndrome

METHODS

Subjects

- N=37** (21 typical children and 16 children with Barth Syndrome)
- Age:** 6-15 years (mean age=9.5 3.2 years)

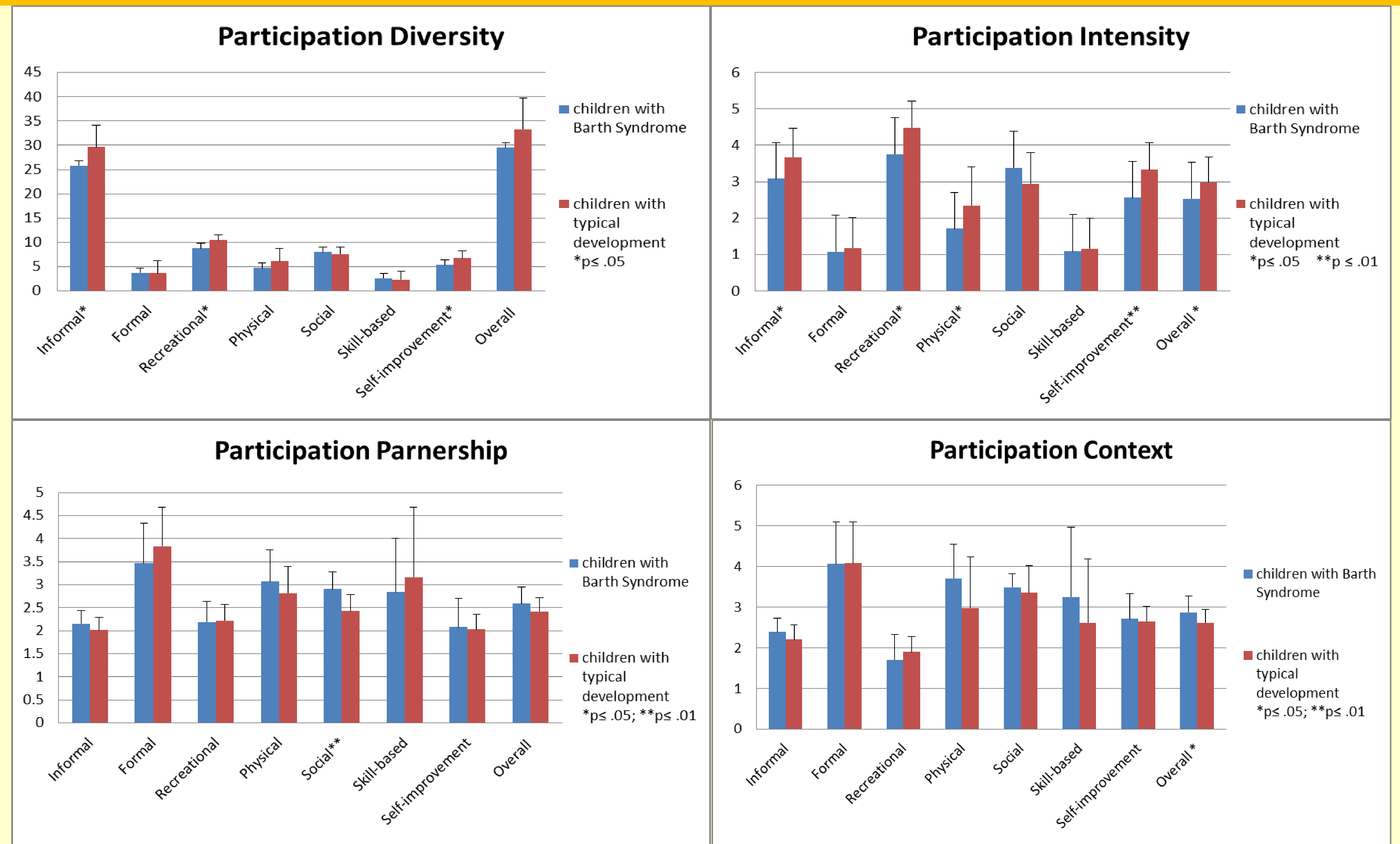
Measurement

The Children's Assessment of Participation and Enjoyment is a standardized questionnaire for 6-15 years children's participation diversity(0-1), intensity (1-7), partnership(1-5), context (1-6), and enjoyment (1-5). It includes 55 items (2 domains: formal (15 items), informal (40 items); 5 categories: recreational (12 items), physical (13 items), social (10 items), skill-based (10 items), and self-improvement (10 items).

Data Analysis

- 1) *Descriptive statistics* were conducted for participant demographic characteristics
- 2) *Independent Sample t Test* was used to compare the differences of participation diversity, intensity, partnership, and context between affected and unaffected groups.

RESULTS



CONCLUSIONS

1. Children and youths with Barth Syndrome experience decreased range and frequency of extracurricular activity participation.
2. Children and youths with Barth Syndrome engage in social activities with a broader range of partnership and involve in overall extracurricular activities in a broader range of places than their typically developing peers.

Clinical messages:

- This knowledge will enable clinicians to better understand participation needs of their young patients with Barth Syndrome and work more with families to develop strategies to improve participation.
- Furthermore, possible barriers to participation in children with Barth Syndrome (e.g., insufficient family or peer support; and lack of accessible information for in/off community resource) should be further evaluated by clinicians. Accordingly, clinical therapists can develop strategies for supporting families of children with Barth Syndrome to explore and access preferred activities with their level of participation.

References:

1. King G, Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., & Young, N. Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC). San Antonio, TX: Harcourt Assessment, nc; 2004.