

Opening Doors for Children with Disabilities and Special Health Care Needs

Project Adventure: Lessons Learned

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Overview

- Introduction to *Opening Doors Project Adventure*
- Results to date
- Lessons Learned

Opening Doors Project Adventure

Goal: To improve health and well-being through inclusive community-based recreation.

Health

Inclusion

Community

Project Adventure: Concept

- Randomized controlled trial
- 120 school-age children with special health care needs and disability
- Inclusive recreation with mentored support
- 6 months recreation (9 months enrollment)
- Assess outcomes: fitness and QOL
- Work towards sustainability and implementation

Project Adventure Kids

- Ages 6-15
- Have special health care need & disability
- Targeted recruitment through CBOs and CHB
- Cleared by primary physician to participate



Project Adventure Coaches

- Community members
- College and graduate students
- Mentors are:

screened

trained

supervised

In collaboration with
Partners for Youth
with Disabilities



Matching

Matches are based on:


- Personalities/fit of child, coach, and family
- Preferences indicated by both mentors and children/families
- Schedule (site/family/coach)
- Language
- Physical requirements


Inclusive Recreation

- Children meet mentors (“coaches”) for recreational and fitness opportunities weekly for 6 months at the YMCA
- Activities based on child interest
- Review by physical therapist

Project Adventure Randomized Controlled Trial

| Group | 3 mo | 3 mo | 3 mo |
|-------|--------------------|-------------------|--------------------|
| 1 | Weekly recreation | | Observation period |
| 2 | Observation period | Weekly recreation | |

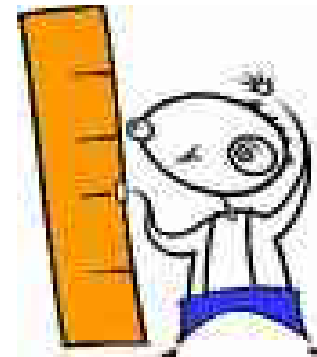
Weekly recreation = 

Observation period = 

Outcomes

- Satisfaction of children and families
- Activity
- Impact on staff and mentors

- *Fitness*
- *Quality of life*



Project Adventure: reality

Quick?

Easy?

Possible?

A learning experience. . .

Where we are now

- Pilot of procedure
 - 4 mentors
 - 1 child/mentor pair
- Currently enrolled
 - 9 child/mentor pairs
- Pending matching
 - 16 children
 - 26 mentors (9 trained; 17 to be trained)

Lessons Learned

- Issues specific to recreation and children with special healthcare needs and disabilities
 - Recreation
 - Research methodology
- Issues relevant to community-based research in general
 - Collaboration
 - Cultural considerations

Child safety

- Cleared by primary physician to participate
- Contact with school or therapist
- PT involved in goal-setting, training mentor
- Mentor screening and training
- YMCA training
- Family member presence



Coach/Staff safety

- Training mentors
- Vineland maladaptive behavior screen for children who may exhibit behavioral challenges
- Psychology consultation as needed
- Recognizing safety limits for inclusion
- Liability

Training mentors

- Group training
 - Panel discussion, disability awareness
 - Becoming a mentor
 - Behavioral management
- Online training
 - Required: adaptive recreation
 - Optional: specific disability education
- 1:1 teaching for specific child concerns
- Adult and Child First Aid/CPR

Measurement challenges: fitness

- Challenge: how to measure fitness improvement?
 - Medical and developmental diversity
 - Lack of standardized tools
- Resolution
 - Achievement of set goals

Measurement challenges: QOL

- Quality of life measure challenges:
 - Some items not likely to change
 - Other tools were disability specific
- Resolution:
 - Measure self-efficacy

Timeline

- Challenges:
 - Outcome measures in diverse population
 - Safety for children with more significant motor disabilities
 - Mentor attrition

Lessons Learned: community based research

- Collaboration with community organizations
- Recruitment from traditionally underserved groups

Collaboration

- Collaboration takes time
- Importance of sustained and repeated contact
- Need for champions



Community Based Organizations



Building Connections to Build Better Care



INSTITUTE FOR COMMUNITY INCLUSION
promoting inclusion of people with disabilities

Recruitment from underserved groups

- Cultural factors
 - Concept of disability
 - Relationships with healthcare providers and public agencies
 - Language
- Creating trust

Conclusion and next steps

- Assessment of measures of fitness and
- Streamlining staffing/training
- Sustainability

- Community based inclusive recreation can be achieved!

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- Partners for Youth with Disabilities
- Greater Boston YMCA
- Massachusetts Consortium for CSHCN/ New England SERVE
- Parent Advocacy Coalition for Educational Rights (PACER)

Opening Doors Community Partners

- Boston Chinatown Neighborhood Center
- Eritrean Community Center
- Ethiopian Community Mutual Assistance Association
- Haitian American Public Health Initiatives, Inc.
- Massachusetts Alliance of Portuguese Speakers
- Massachusetts Asian & Pacific Islanders for Health
- Somali Development Center
- Soul Touchin' Experience
- Sudanese-American Integration and Development Center

Opening Doors

Research and Rehabilitation Training Center

Goal: To reduce barriers and improve services and outcomes for children and youth with special health care needs and disabilities, including children and youth from traditionally underserved communities.