

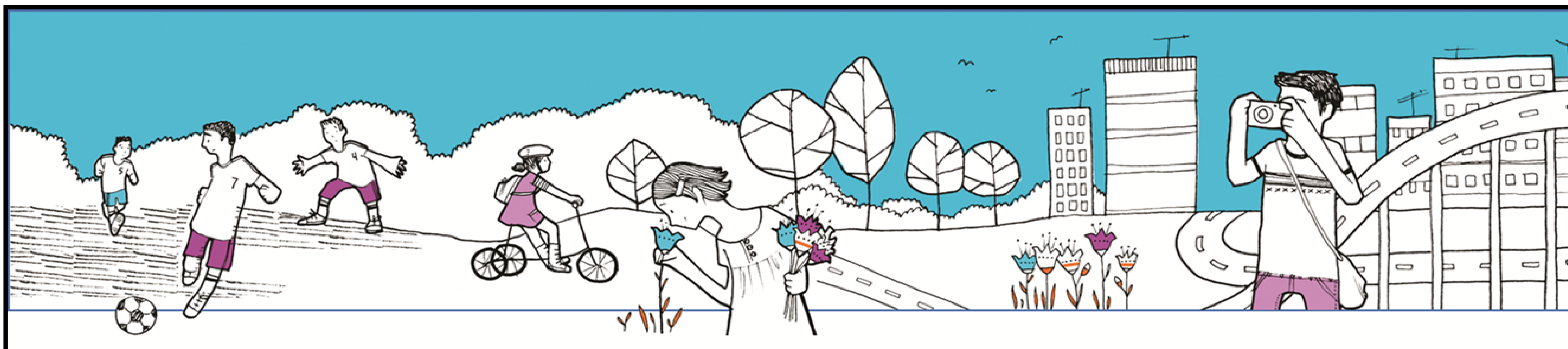
# Activity Setting Experiences of Disabled Youth: A Photo-Elicitation Study

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## BACKGROUND

Little is known about how youth with 'severe' disabilities experience and evaluate their everyday activity settings (i.e., places in which they "do things"). Even when youth are physically included in an activity setting, many are not engaged in activities in a meaningful way.



## AIMS

- To conduct a pilot study investigating:
- 1) Disabled youths' perspectives of their activity experiences
  - 2) Social and material mediators of participation

## METHODS

**Design:** Qualitative photo-elicitation pilot study

**Methods:**

- Participant-generated **photographs** of two home or community-based activities using adapted cameras
- **Electronic open-ended questions**
- **Qualitative interviews** using the photographs to elicit discussion

## PARTICIPANTS

Eight youth ages 14 to 20 years with:

- speech impairments/AAC users (n= 6)
- and/or complex physical impairments (n=8)



## RESULTS

**Primary Theme = Optimal activity settings are about WHO not WHAT**

Positive experiences were associated with social connections more than type of activity:

*It's just fun to be around somebody as opposed to being in your room by yourself on a computer*  
(Brenda, 17)

**Subthemes:**

- 1) **Assemblages:** Specialized networks of people, technologies, and places were needed for engagement

*She likes to drive the boat with her Dad. We looked at every model of a pontoon boat imaginable so she could reach over and grab the wheel with her Dad.*  
(Jessica[18]'s mother)

- 2) **Demonstrating Competency:** Preference for activities where youth could demonstrate prowess, successfully compete, or inform others

*I couldn't even push the ball down the ramp with my hands. I was frustrated. [Bowling] just sucks!*  
(Andrew, 17)

- 3) **Limited Accessibility:** Activities were limited by physical barriers and the need for personal and/or communication assistance.

*I don't really go out that much...It's easier to just leave me at home.*  
(Mimi, 14)

## SIGNIFICANCE

**Facilitating Connections:**

Much of the focus in rehab is on enhancing independence. While youth desire some independence, the results suggest that it is just as important to facilitate connections through targeted assemblages.

- Participants wanted opportunities to socialize and be in the world but many settings (like friends' homes) were inaccessible. This limited opportunities to interact and sustained their social exclusion.
- Focusing on identifying the right assemblages of technologies, personal assistance, and accessible places may be more fruitful in enhancing engagement than promoting 'independence' through hi-tech solutions or maximizing physical function.
- Further research is needed. We are currently conducting a mixed methods multi-site study to address the study aims and develop a measure of activity setting experiences.

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