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## Views of teenage children about the effects of a Parent's mobility disability

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## ABSTRACT

**Background:** Few U.S. studies have explored how children experience a parent's mobility disability and its effects on their daily lives.

**Objective:** We aimed to engage youth ages 13–17 who had at least one parent with mobility disability in describing their perceptions of their parent's disability and its consequences for their daily and family life.

**Methods:** Participants videoed and photographed their experiences following general guidelines from the researchers about topics of interest. Participants made their own choices about what they submitted. We used conventional content analysis to identify broad themes.

**Results:** The mean (standard deviation) age of the 10 participants was 15.2 (1.9) years; 5 were male; 9 participants were white. All 5 girls submitted multiple self-focused (selfie) videos made in their bedrooms; the 5 boys submitted more diverse data files. Several broad themes or topics emerged including: the effects of timing and trajectory of the parent's disability; perceptions of early maturity and responsibility; fears and frustrations relating to the parent's disability; support and emerging resilience; and sense of social justice. Participants generally felt their parents' disability made them become – compared to their peers – more mature, responsible, capable of performing household tasks, and aware of disability civil rights.

**Conclusions:** Participants raised many issues that health care providers should be aware of when youth have parents with mobility disability. A parent's mobility disability may be associated with resilience but also may pose challenges for youth. More research is needed to understand better adolescent's experiences and how clinicians might best assist these youth.

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## Introduction

Mobility disability – movement difficulties involving upper and/or lower extremities – is the most common disability type among all adult Americans. About 23.3% of noninstitutionalized, civilian U.S. residents ages ≥18 years old report chronic mobility difficulties affecting upper and/or lower extremity function.<sup>1</sup> Even

among persons 18–44 years old, 5.5% report difficulties with lower extremity function.<sup>2</sup> Nonetheless, these individuals generally have similar goals for their lives, including parenthood, as do others.<sup>3</sup> An estimated 164,000 American women with chronic mobility disability are pregnant each year,<sup>4</sup> and these numbers are growing. However, relatively little is known about the daily lives of U.S. children whose mother or father has mobility disability or how this disability affects family life.

According to the 2011 *World Report on Disability*, “When adults acquire a disability, children are often asked to help. ... These increased demands on children may impair their education and their health.”<sup>5</sup> Research, most extensively from the U.K.,<sup>6,7</sup>

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Scotland,<sup>8</sup> Wales,<sup>9</sup> Australia,<sup>10</sup> and Canada,<sup>11</sup> has explored caregiving by children of parents with disability. These studies generally suggest both positive and negative effects: children can feel closer to and more appreciated by their parents, but they may have worse physical and emotional health and educational performance than their peers. Children of parents with disability typically have more disadvantaged socioeconomic circumstances than their peers, complicating interpretation of these findings. The most comprehensive U.S. study of child caregivers found they lived in lower income households than other children, and 58% provided care for one or more activity of daily living.<sup>12</sup> Noting that their study provided an overview “but not the details,” the researchers urged qualitative studies to understand better child caregiver experiences.<sup>12</sup>

Despite questions specifically about child caregiving, a first step in understanding the experiences of having a parent with mobility disability is directly asking youth about their views. We therefore collected video, photographic, and audio data from youth ages 13–17 who had one or more parent with significant mobility disability. We aimed to hear from youth “in their own voices” about how their parent’s mobility disability affects them, their views of their parent, and their daily and family lives.

## Methods

The Massachusetts General Hospital (MGH)/Partners Health-Care Institutional Review Board (IRB) approved this research. To

further protect participants, we obtained a Certificate of Confidentiality from the National Institutes of Health.

### Designing data collection guide

To inform our approach toward youth, we conducted 20 interviews with persons  $\geq 21$  years old who as children had a parent with significant mobility disability. As detailed elsewhere,<sup>13</sup> one major finding from these interviews was the wide diversity of experiences. Gender concordance (discordance) between the child and parent with disability had important effects on both experiences and perceptions of the child, as did the timing of the parent’s disability (earlier or later in the child’s life).<sup>13</sup> Based on these results we developed a brief open-ended guide, to focus youth participants on observations about general issues relating to their parent’s mobility disability. We produced 3 versions of this guide (mother has disability, father has disability, both parents have disability). Table 1 shows the guide’s content when the mother has mobility disability.

### Participant recruitment

We sought interviewees who: were ages 13 to 17 at the time they participated; had at least one parent with mobility disability involving either upper or lower extremities; and, to facilitate in-person consent procedures, lived within easy driving distance of Boston. We aimed initially to recruit 30 English-speaking child

**Table 1**  
Video guide: Mother has mobility disability.

Slide Title	Content
Introduction	<ul style="list-style-type: none"> <li>• Thank you for doing this project.</li> <li>• We are trying to learn about what it is like for you – from your point of view – to grow up with parents with a disability.</li> <li>• Below you will find ideas for the kinds of things you might video or tell us about. This project is not about making the perfect video. It’s about telling <b>your</b> story and about how <b>you</b> feel</li> </ul>
Remember	<ul style="list-style-type: none"> <li>• Please remember that you are making a video for a research project</li> <li>• Ask permission to film people before you start.</li> <li>• You might be filming some sensitive situations. Please stop filming if anyone asks you to do so.</li> <li>• Do not share your videos with anyone other than the research team.</li> </ul>
<b>List of Possible Topics</b>	
1.	<ul style="list-style-type: none"> <li>• <b>Introduce us to your family.</b></li> <li>• Tell us about who you live with.</li> <li>• Tell us what your family does together, even something simple like eating together or just hanging out.</li> </ul>
2.	<ul style="list-style-type: none"> <li>• <b>Tell us about your mom.</b></li> <li>• Do you live with her? <ul style="list-style-type: none"> <li>◦ If not, please tell us about where she lives and how often you see her.</li> </ul> </li> <li>• Tell us about mom’s disability. <ul style="list-style-type: none"> <li>◦ What causes her disability?</li> <li>◦ What is hard or impossible for her to do because of disability?</li> <li>◦ Is her disability changing over time, such as getting better or getting worse?</li> </ul> </li> </ul>
3.	<ul style="list-style-type: none"> <li>• <b>Tell us about how your mom helps you.</b></li> <li>• If you want, you can video times when she is helping you.</li> <li>• Or you can talk directly to the camera and tell us about how she helps you.</li> </ul>
4.	<ul style="list-style-type: none"> <li>• <b>Tell us how you help your mom because of her disability.</b></li> <li>• If you want, you can video times when you are helping her.</li> <li>• Or you can talk directly to the camera and tell us about how you help her.</li> </ul>
5.	<ul style="list-style-type: none"> <li>• <b>Tell us how you feel about how your mom’s disability affects you.</b></li> <li>• If you want, you can talk directly to the camera about these feelings.</li> <li>• You probably have many different sorts of feelings. Some might seem good while others seem bad. Please share as many of these feelings as you can.</li> <li>• Remember, this is about you and how you feel – there is no right way of feeling.</li> </ul>
6.	<ul style="list-style-type: none"> <li>• <b>Tell us about whether her disability affects how you feel about your mom.</b></li> <li>• If you want, you can talk directly to the camera about how her disability affects your feelings about your mom.</li> <li>• As for #5, you probably have many different sorts of feelings. Please share as many of these feelings as you can</li> </ul>
7.	<ul style="list-style-type: none"> <li>• <b>What else is important for us to know about you and your family?</b></li> <li>• Are there any other things that affect your family that are important?</li> <li>• How do these other things affect you?</li> <li>• How do these other things affect your mom because of her disability?</li> </ul>
Thank you	<p><b>Thank you for participating in this study!</b> If you have any questions or need to talk to anyone at anytime, please call ...</p>

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