

# The WWW-roadmap:

## Parents' experiences with an online tool help them prepare a consultation with rehabilitation professionals

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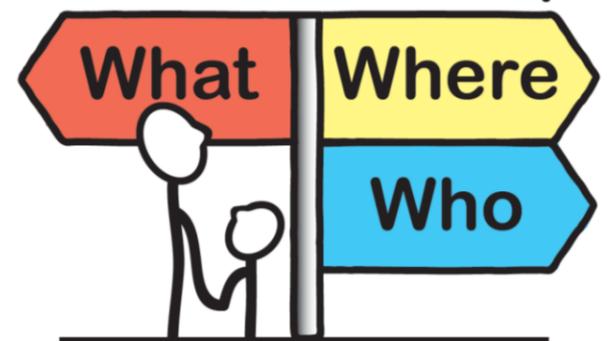
### Introduction

- Gathering information and preparing for the consultation with a rehabilitation professional are important requirements for the process of empowerment.
- Parents who are better informed are better able to support each other and become partners in negotiating care and supporting their child's participation.
- Previous research shows that parents have difficulties formulating questions and finding information.
- Together with parents we designed a digital tool, the WWW-roadmap that aims to enable parents to explore their needs, help in their search for information, and refer to appropriate professionals.
- **The objective of the current study is to describe experiences of parents with the tool.**

### Patients and Methods

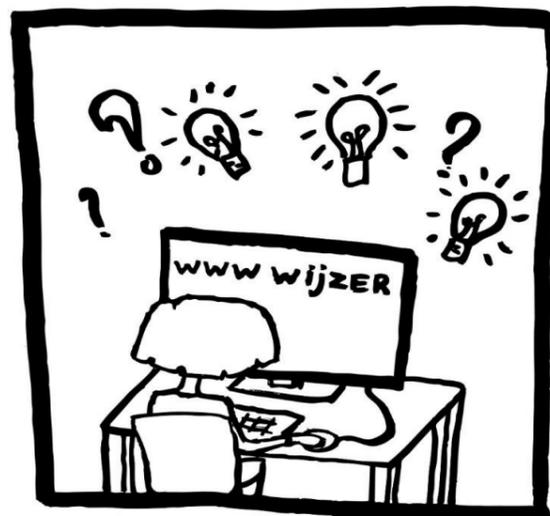
20 parents of children with physical disabilities aged 1–18 years used the WWW-roadmap and were interviewed about their experiences with the tool and with preparing consultation with the rehabilitation physician. We interviewed 1 couple, 1 father, the rest were mothers.

### www - roadmap



roadmap for parents of children with a disability

Browse through possible questions and topics



Find information in the tool and on the internet

Take a question prompt list to the consultation



### Results: themes

- **Using the tool** For most parents, the WWW-roadmap was easy to use. The information was considered reliable. However, some feedback was provided on design and interface issues.
- **Equal relationship** Parents appreciate having an equal role in the relationship with their doctors. The WWW-roadmap could serve as a tool to help parents and doctors, especially in the first stages of rehabilitation care.
- **Creating opportunities** Parents appreciated the provision of possible questions and themes. It supports and justifies their questions and the themes that play an important role in daily life.
- **Providing information** The information and links presented in the WWW-roadmap are well-appreciated. However, the desired amount of information and the demand for in-depth information and experience-based information differs between parents.
- **Prepare for the consultation** Preparing a consultation helps in equal partnership and self-direction. Not all parents prepare their consultation with the doctor. Although the WWW-roadmap could play a role in this, it seems that parents need more tools and opportunities to do so.
- **Question prompt list** The use of the question prompt list helps parents to tick off the subjects they want to discuss during the consultation.

### Limitations and room for improvement

- **Experience based information** Parents describe the need for information and tips based on (parental) experiences. Although the current version of the WWW-roadmap doesn't provide this kind of information, future versions will.
- **Step-by-step guidance** for practical procedures was mentioned often by parents. For instance, guidance in possible steps in applying for funding and reimbursements.
- **Keeping the WWW-roadmap up-to-date** In order to keep the WWW-roadmap and the information up-to-date and available for parents, regular management and funding should be available.

### Conclusion

- The WWW-roadmap seems a feasible tool for parents.
- Parents can use the WWW-roadmap to prepare the consultation with a doctor.
- Professionals should consider providing parents with the WWW-roadmap in order to help them thinking up questions and guide their search for information.
- Further effects on parental empowerment and on the consultation with rehabilitation professionals are under study.